

# Healthcare Mobilities & National Health Systems

## Working Papers Collection

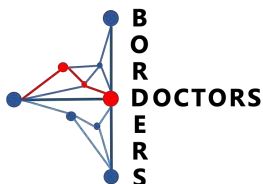
**Doctors within Borders** workshop  
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### About this collection

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The working papers in this collection were first presented at the Doctors within Borders [workshop](#) held at Lancaster University on Friday 10 January 2020. The event brought together an international group of social scientists, healthcare practitioners and activists to explore shared interests in migration, borders, healthcare and mobility.

[Doctors within Borders](#) is a Wellcome Trust-funded networking initiative that focuses on the status of mobile populations in contemporary health systems. To find out more about the project, the workshop and the authors in this collection, please visit: [www.lancaster.ac.uk/doctors-within-borders](http://www.lancaster.ac.uk/doctors-within-borders)

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## INTRODUCTION: HEALTHCARE MOBILITIES AND NATIONAL HEALTH SYSTEMS

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Health is a human right and as such is enshrined in various international frameworks (UN 1948; UN 1966). Broadly conceived, the right to health encapsulates the individual's physical and mental state and the resources which support health: food, shelter, social security and healthcare (UN, Article 25, 1948). However, in recent years the legitimacy of certain groups to access healthcare has been called into question in the UK and beyond. While health as a human right is for everyone, as with so many human rights, individuals and groups are denied these rights by dint of nationality, immigration status, race, gender, disability, age or sexuality. This has found expression in the exclusion of groups from access to health (for example undocumented migrants); increased charging for access to health systems (UK Immigration Acts of 2014 and 2016) and the mobilisation of healthcare organisational systems and professionals to deliver care based on the verification of immigration status (Yuval Davis et al. 2018). Health inequities, avoidable differences in health experienced by particular groups have been recognised within health systems (WHO 2008; Marmot 2020), but the strategies to address such inequities have had varied reach and success. Healthcare, that is the medical care offered to people to preserve or restore health, is a resource, and like all resources it is unequally distributed. Health inequalities are complex and raise fundamental questions about the structures of society: who has access to healthcare, who does not, and on what basis access is granted. Once within a healthcare system, who enjoys its full benefits?

*Doctors within Borders* (DwB) is a research-networking project, which grows out of our research interests in the causes and consequences of health inequalities particularly as they relate to mobility and migration. But it is also driven by our commitment to the idea of health as a human right. We recognize it as the political issue that it is, and we are concerned about the efforts of governments to limit healthcare, to obstruct access to it or to withdraw it altogether from certain categories of people. The DwB project focuses on groups that experience exclusions from healthcare as a result of their spatially unsettled status. We count among them migrants, asylum seekers, refugees, undocumented migrants, homeless people and members of the Travelling communities (see for example Abubakar et al. 2018,

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O'Donnell 2018, Drakakis-Smith 2007). We conceptualize them as mobile populations. All of them face health inequalities throughout the world, usually as a result of a combination of social exclusion and politically motivated policies designed to uphold health systems defined as “national”, that is restricted to citizens and lawfully settled residents (see Cassidy, Lonergan, this volume).

**DwB Workshop One**, of which this Working Papers Collection is a record, offered a space for academics, healthcare professionals and activists to meet around shared interests in migration, borders, healthcare and mobility, bringing together our insights from our respective fields. In doing so we aimed to do two things. Firstly, to start work on a new research agenda in health and mobilities. This involves exploring people-centred and mobile methods to improve the understanding of healthcare services from the perspective of patients, who are migrants, refugees, asylum seekers or perhaps citizens who end up excluded from healthcare due to a lack of fixed address. It also means identifying areas, which at the moment are poorly understood and imagining ways of tackling them.

Secondly, our longer-term goal is consolidating the knowledge we gather as a basis for action and targeted intervention. This means sharing advocacy and care case studies based on experience and research across the globe, through publications and public engagement. Workshop One offered a starting point to think through the means and format of collaboration. Following from our initial call for participation, three themes emerged clearly from the submissions from scholars across the globe. These themes were underpinned by key concepts which we outline below: borders, mobilities and activism.

## **BORDERS**

Informed by the interdisciplinary critical border studies literature, we think of a national border not as a line on a map or a place where passports are checked, but as a complex and, as Balibar points out, ubiquitous regime, a technology of government that serves to reinforce not only national sovereignty but also racial and social hierarchies, which in turn underpin ideas of who is and who is not deserving of healthcare and other public services (Balibar 2002).

Our project is called *Doctors within Borders*. This title is intended to operate on two levels. Firstly, it is designed to reflect the reality that healthcare professionals, that is doctors, nurses and other essential healthcare workers, do not have to leave their home country to find themselves caring for patients affected by conflict and displacement. We are all familiar with the humanitarian powerhouse *Doctors without Borders* (Médecins Sans Frontières). Our project is interested in the reversal and transmutations of traditional humanitarian practice (Castañeda 2011). In the cases discussed in the papers that follow it is not the doctors who travel to deliver care abroad, but the patients who arrive, in the process experiencing borders

in a very different way than Western humanitarians. Deniz Mardin and Nuray Özgülner's paper complicates even further the picture of how borders operate in healthcare, showing how both refugee doctors and patients run up against nationally bounded systems (Mardin and Özgülner, this volume). But in typical conditions of modern states doctors and other healthcare professionals work in hospitals and surgeries, which are rooted in place. These facilities serve primarily settled populations, but also in ever greater numbers they encounter people on the move, whose legal, fiscal and social status is uncertain.

On another level, the *Doctors within Borders* heading references healthcare as operating within the increasingly expansive border regimes of modern states. The concept of a border regime encompasses the entire system of rules and regulations intended to demarcate political entities, police entry, inclusion and exclusion, senses of belonging and citizenship itself (Borneman 1998; Follis 2012). As part of this policing, many states expanded immigration status checks into national health systems, turning those systems into sites of what Kathryn Cassidy and others have called "everyday bordering" (Cassidy, this volume; Yuval Davis et al. 2018). But there is a profound contradiction here, as noted in the papers that follow. The healthcare system cannot just become another site of border control, because medical professionals' primary duty is to care for patients, regardless of nationality, immigration status, race, gender or any other characteristics. To be a healthcare practitioner, may mean having to grapple with this contradiction on an everyday basis (Potter and Meier, this volume), to resist it or move beyond established ways of doing things to serve populations in need. In this way borders are in constant tension with mobility on the one hand, and with the imperative of health as a human right on the other.

## **MOBILITIES AND HEALTH**

The exclusion of people through immigration policies and practices which render them 'immobile' can be understood as part of a wider 'spatial politics of mobility' and bordering practices which seek to contain, expel and detain particular bodies. Cresswell describes mobility as a 'fragile entanglement of physical movement, representations and practices' (Cresswell 2010: 18), the consideration of movement through physical time and space and the ways in which places and spaces are shaped and mediated by social relations.

Scholars emphasise two key aspects of the mobilities approach. First, it engages with the actual physical movement of people, objects and ideas. When people talked of movement in the past, they were actually talking about *places* (Cresswell 2010). People, objects and ideas move from A to B with little exploration of the ways in which that movement takes place. Second is the way in which the mobilities approach looks across *scales*, from the cellular level as Stephanie Sodero's paper suggests (Sodero, this volume) to the body

and up through to the local and global. In part, this has been possible through the collapsing of disciplinary boundaries. Sheller notes that mobilities research brings together the social concerns of sociology (inequality and power), spatial concerns of geography (territories, borders and scale) and cultural concerns of anthropology (discourses, representations and schemas) into a co-constitution of subject, spaces and meanings (Sheller 2014).

Mobility theorists have also been quick to underline the inherent politics of mobility, the relationship between mobilities and immobilities and the ways in which these relationships and the production of space produce inequalities. Mobility, like citizenship, has an exclusionary dimension. There are those who are free to move and those who are not. In the realm of migration, this is increasingly tied to citizenship status, and constructions of the 'productive' migrant and 'vulnerable' migrant. Indeed, Doreen Massey reminds us that movement is never simple: while some can move around easily and can initiate movement, others in society can be fixed, imprisoned or weakened by the necessity to move (Massey 1991). Cresswell (2010) describes the politics of mobility as the production and distribution of power, outlines six aspects to consider when we think about the politics of mobility:

- 1) Force: why does a person or thing move?
- 2) Speed: how fast do they move?
- 3) Rhythm: in what rhythm does a person or thing move?
- 4) Routing: what route does it take?
- 5) Experience: how does it feel?
- 6) Friction: when and how does it stop?

These six elements, he argues, are interlinked creating a world in which subject identities impact on mobile practices resulting in the differentiation of hierarchies of mobility (Cresswell 2010: 26). What does this mean in the context of health and healthcare? Tony Gatrell (2011) began to explore the ways mobilities affect health and healthcare, and how health and healthcare affect mobilities. Focusing on the politics of mobility chimes with many key concerns of medical practitioners, activists and academics. Inequalities are riven through healthcare systems, reflecting the societies which produce them through policy and practice. The sedentary focus of healthcare systems is one way in which inequalities are realized.

The papers collected in the volume provide several opportunities to consider the health and healthcare of mobile populations through a mobility lens. From a mobility framing, a number of questions arise: What are the temporal and spatial aspects of delivery of care for mobile groups? What resources can be mobilized within unequal power structures? How do ideas and values around health illness and disability move in healthcare systems? Finally,

can a mobilities approach help us to understand the flows of information and knowledge required by patients and practitioners to claim rights to healthcare?

## **ACTIVISM**

In the literature, activism is broadly described as a form of collective political action sometimes occurring within the context of a wider social movement (Tarrow 1998). Yet, unlike social movements which imply a large collective which maintains continuity over time, activism is multi-scalar. It spans individual acts of conscience and ad hoc single issue collective protests, as well as durable networks organized for collective action. So in this sense it is a tactic capable of targeting the interpersonal, institutional, societal and political spheres.

Activism should also be distinguished from advocacy—even if they are sometimes used interchangeably. The latter is often predicated on having an insider status and working within an existing system of expertise to educate or extend provision of some service. And in some institutional spaces advocacy is even formalized as a professional role. In contrast, activism carries, if not a confrontational, at least an oppositional inflection.

Within the area of health research and delivery, it clearly implies a challenge to existing relations of power and emergent structures of care that threaten or withdraw health provision or which otherwise negatively impact the promotion of health. In this sense, activism is as much about responding to social change and institutional ‘reforms’ as it is about widening democratic participation over the delivery of healthcare and the production of knowledge associated with it.

One of the distinctive attributes of activist work we attempt to underscore is its inherent mobility. It is a fluid method of engagement; a set of tactics which emerge in the context of the contingencies and opportunities generated by health institutions and other forms of authority through their **routine operation**. So one question here might be reflexive. How do we think about these disparate encounters and mobile tactics if we want to transform them into durable and transferable strategies?

The papers submitted to Workshop One and contained here, illustrate the multiple openings, opportunities and positions which characterize health activism for mobile populations. For example, as Potter and Meier note, activism might require moving beyond existing norms of political contestation by addressing the ensemble of institutional procedures and practices designed to generate an affective and emotional counterpart to exclusionary health regulations. Above all, as Pawel Lewicki reminds us, activist work must reckon with one’s position in an uneven grid of power relationships and the likelihood that different sites present different opportunities for recognition, entitlement and closure.

Thus, one way that we might think about activism in the context of these working papers and discussions emerging from the workshop is to regard it as a **mobile methodology of resistance** and to ask how the different sites and scales for effecting change at individual, institutional, and political levels **intersect**. Finally, we should also bear in mind that although health activism's mobility gives it flexibility and immanence, it remains part of a dialectic. The institutional spaces and procedures it seeks to resist are **not static** but also in **motion, shifting** and **adapting**. And here, I think it important to emphasize (following de Certeau 1984) that activist tactics are in a unique position. They can expose one of the most obvious **constraints of power: its visibility**.

In the working papers we have examples of the multiple frames through which mobile populations are rendered visible (as dangerous classes, as suspects in the institutional record, or as temporary migrants in policy) and invisible (as taxpayers or categories of persons with rights and entitlements) sometimes with same broad brush (Lonergan, this volume). Finally, in addition to thinking about how we might view and adopt health activism as a mobile methodology of resistance, we should also explore what tactics and strategies might be most fruitful in resisting and countering these very same narratives of occlusion—that are themselves shifting and reconfiguring under our very eyes.

## **INTRODUCING THE PAPERS**

The papers within this Working Papers Collection reflect the key themes within Workshop One: bordering, activism and delivering care. While we have grouped papers thematically, points of intersection and discussion between the papers highlights the complex nature of mobility, mobile populations and health care.

**Gwyneth Lonegran's** paper tracks the emergence of the category of temporary migrant in UK Government, its links with everyday bordering practices designed to limit access to healthcare through immigration practice, and its location at the centre of nationalist discourses seeking to reframe the NHS as a British institution.

**Kathryn Cassidy** considers the impact of the expansion of bordering practices within the UK health system identifying pressures but also spaces of resistance to such practices.

**Agnieszka Kosowicz** discusses the work of a voluntary organisation in supporting migrants and refugees in Poland. Highlighting efforts to support groups to access resources and the barriers both the organisation and their clients face, efforts to engage the Polish community in understanding the needs of migrants is viewed as a key aim in combatting rising intolerance in Poland.



**Pawel Lewicki's** work explores Polish migrants access to HIV treatment in Germany, reflecting on everyday bordering practices and notions of citizenship.

**Deniz Mardin and Nuray Özgülner** offer insights into refugee and asylum seekers access to health care in Turkey, highlighting the barriers at the system, provider and interpersonal levels.

**Jess Potter and Isabel Meier** consider the emotional borderwork involved in delivering healthcare within the UK hostile environment policy.

**Stephanie Sodero** considers the 'vital mobilities' involved in the supply of blood and the fragility of such systems in the context of climate change and its impacts. Focusing on three different scales, Sodero questions what environmental change means for the delivery of treatment across the globe.

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# WHO IS A 'TEMPORARY MIGRANT'? DESERVINGNESS, NATIONALISM AND MIGRANT ACCESS TO THE NHS

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## BACKGROUND

In 2003, the Blair government announced that, going forward, only individuals who were 'ordinarily resident' in the UK would be able to access secondary care on the NHS free of charge (Pollock et al., 2005, 34). 'Ordinarily resident' was very broadly defined, to include 'legal' residents of the UK, including asylum-seekers, and migrants on work, spousal, and student visas. Visitors and undocumented migrants, including 'failed' asylum-seekers, however, would be charged for accessing secondary care on the NHS. Several charities reported that this had a 'chilling' effect on access to secondary care for some migrants, even for those who were legally entitled to this care, for example, asylum-seekers (Bragg, 2008; JCHR, 2007). In practice, regulations governing access to care were unevenly enforced in hospitals, and there was widespread confusion around who was legally entitled to free secondary care at the point of delivery. Moreover, the 'health tourist' discourse, which posited that foreigners were coming to the UK for brief periods specifically to access the NHS, continued to be widespread in the media (c.f. BBC News, 2012; Beckford, 2011).

The 2014 Immigration Act, introduced by the Coalition government, restricted who had access to secondary care on the NHS free at the point of delivery, by narrowing the category of 'ordinarily resident.' A healthcare levy was added to work, spousal, and student visas, in order to recoup the supposed cost of these individuals to the NHS. Following the passage of the Act, the Coalition government, and later the Conservative government, used statutory instruments to incentivize hospitals to perform eligibility checks on all patients, and to sanction those who were failing to do so (Department of Health, 2014). These policy changes occurred within a wider backdrop characterised by two trends: an NHS funding crisis and the Conservative party's explicitly anti-migrant agenda.

With regard to the first issue, the Coalition and Conservative governments' austerity scheme resulted in a severe funding crisis for the NHS. By 2016, the NHS was facing a £22 billion funding shortfall (Gainsbury, 2016), a shortfall which was having a detrimental impact on the quality of care (Fisher, Cooke O'Dowd, Dorning, Keeble, & Kossarova, 2016). Migrants made a convenient scapegoat for this financial mismanagement, particularly in light

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of the Conservative party's broader anti-migrant policies and discourse. During the 2010 and 2015 elections, the Conservative party had frequently promised to reduce immigration to the 'tens of thousands', and had enacted various policy changes designed to make it more difficult for migrants to settle in the UK. Theresa May, the Home Secretary at the time, pledged to create a 'hostile environment' for undocumented migrants and through various statutory and legislative instruments, notably the 2014 and 2016 Immigration Acts, made it illegal to provide individuals who could not prove their legal residency in the UK with bank accounts, drivers' licenses and rental accommodation. The border had thus been expanded not only to hospitals but also to banks, letting agents, and the DVLA (Aliverti, 2015; Yuval-Davis, Wemyss, & Cassidy, 2017). The introduction of visa checks in hospitals fit in with this wider 'hostile environment' policy, while the overt construction of migrants as a 'problem' made them an obvious target of blame for the NHS funding crisis.

### **THE 'TEMPORARY MIGRANT'**

*Sustaining Services, Ensuring Fairness*, the government's response to consultations on its plans to 'recover costs' from migrants using the NHS, repeatedly claims that migrants are an economic burden on the NHS. The document opens with the argument that the NHS is "overly generous to those who have only a temporary relationship with the UK", and, "struggles to identify and recover the cost of care from those not entitled to free treatment" (Department of Health, 2013, 5). The Department of Health also commissioned both qualitative and quantitative research reports and argued in *Sustaining Services* that the former, in particular, demonstrated that "there really is an issue with visitors and temporary migrants accessing free NHS services<sup>2</sup>" (Department of Health, 2013, 8). The quantitative research, it is claimed, "estimates each day in England, there is the equivalent of 2.5m overseas visitors and migrants (averaged across the whole year)" and that, in total, these individuals cost the NHS between £1,820 and £2,050 million per year (2013, 12).

However, an interesting sleight of hand occurs when discussing *who*, exactly, is posing this economic burden on the NHS. In the mainstream media, much of the discussion around migrants' supposedly illicit use of the NHS focused on 'health tourists', that is, people coming to the UK with the main intention of using the NHS. When passport checks in hospitals became mandatory in 2017, for example, the BBC reported this as "[h]ealth tourism charges come into force in England" (Silver, 2017). However, *Sustaining Services* acknowledges that the cost of health tourism is actually relatively negligible—estimated at

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<sup>2</sup> There were multiple methodological problems with this qualitative research which it is beyond the scope of this paper to discuss

around £70m per year, going up to possibly £300m. Instead, the report focuses on ‘temporary migrants’, especially non-EEA ‘temporary migrants.’

In Annex D of *Sustaining Services* a ‘temporary migrant’ is defined as “a non-EEA national who is in the UK for a time-limited period (usually between 6 months and 5 years)” (2013, 60). The document also notes that “[n]on-EEA temporary migrants, including workers, students and family members, currently, in the majority of cases, have free access to the NHS” (2013, 22). There are two things worth noting here. First, *Sustaining Services*, and both the Qualitative and Quantitative research reports it cites, specifically construct ‘temporary migrants/residents’ as a group whose impact on the NHS is problematic and needs to be further investigated. The Department of Health thus presupposed the existence of a problem and then set out to prove it. Secondly, by this definition, ‘temporary migrant’ includes people who have the right to be in the UK for up to 5 years, and in the case of spousal migrants especially, can be argued to have made a decision to live in the UK for at least the foreseeable future. Setting aside the question of whether it is ever ethical to require individuals to pay for necessary hospital care, the media discourse on the expansion of charging and passport checks focused on ‘health tourists’, who would seem to be in a very different situation to a resident on a spousal or work visa.

Indeed, the probable long-term residence of many ‘temporary migrants’, and their purpose for being in the UK, significantly undermines the economic rationale for charging for secondary care, as acknowledged in *Sustaining Services*. In discussing the application of a visa levy to cover secondary healthcare costs, *Sustaining Services* stresses the importance of ensuring that the levy itself is “competitive” so as not to dissuade economically productive migrants and students from coming to the UK:

By keeping the immigration health surcharge at a competitive level, it also enables the Government to recognise the contribution that non-EEA temporary migrants make to the wider economy and keep the UK competitive (2013, 23).

It is also suggested that a levy is preferable to insurance, as individuals with pre-existing conditions might find it difficult to get affordable health insurance, and:

It would be inappropriate to limit the benefits to the wider economy by denying those with any pre-existing health conditions from coming to the UK, where their condition does not compromise their ability to undertake a skilled job or study (2013, 23).

## **A NATIONAL HEALTH SERVICE**

Supplementing the somewhat shaky economic rationale for introducing the visa levy is a nationalist argument around who the NHS should be *for*. Discussing responses to the original consultation, *Sustaining Services* notes:

It is important to note that across all responses, views differed on whether temporary migrants from outside the EEA should make additional contribution towards the costs of their healthcare at all. For those who do not support the proposal it was felt to be discriminatory as, once here, they are part of the community and contributing as the rest of the population either through their taxes, National Insurance contributions or indirect taxes such as VAT. Also, additional contributions were seen as contradictory to the principle of 'fairness'. For others there was a clear point of principle that *the NHS should be a national not an international health service, so temporary migrants should make a proper contribution* (2013, 15 emphasis added).

Later in the document, the NHS is described as a "social contract between taxpayers and the resident population,"

with taxpayers paying for a comprehensive health service that is free at the point of delivery to all those who live here on a lawful and settled basis. In principle, others should pay for most, if not all, services they receive (2013, 18).

The above language has also been echoed in the recent (2019) election, with the Health Secretary Matt Hancock tweeting on 17 November 2019, "It's the National Health Service not the International Health Service."<sup>3</sup>

In light of the above, we can read the exclusion of 'temporary' migrants from free secondary care on the NHS as resting on said 'temporariness.' Although it is conceded in the document that many of these migrants *are* making some kind of economic contribution<sup>4</sup> already - even those who may be out of paid work will be paying VAT on purchased items, for example. The issue, then, may be that they have yet to form a "permanent relationship" with the UK (2013, 5, 13, 38). But again, this is tenuous given that many so-called 'temporary migrants' will be living in the UK for the foreseeable future.

The insistence on the need for not only an 'economic contribution' through paying taxes, but also a 'permanent relationship,' must be explored within the context of the construction of the NHS as a particular source of national pride and belonging, different to other aspects of the UK welfare state. The *idea* of the NHS is a great source of national pride in the UK, which can take on a possessive tone. Politicians frequently speak of '*our* NHS,' in a way they do not about, for example, the Job Centre or other welfare state services. Furthermore, while significant cuts have been made to NHS funding as part of the austerity regime (see above), politicians across the political spectrum feel obliged to deny that such cuts have occurred. This stands in sharp contrast to much of the other welfare state

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<sup>3</sup> <https://twitter.com/matthancock/status/1195997609942560768?lang=en>

<sup>4</sup> Although beyond the scope of this paper, it is also worth considering how the idea of a social contract with the British taxpayer could be used to limit the NHS access of UK citizens on benefits

restructuring that has occurred as part of austerity, which is spoken of as either a necessary sacrifice, and/or justified with reference to a discourse of ‘scroungers vs strivers’ (Bhattacharyya, 2015). The NHS remains, to an extent, a sacred cow in UK politics, its status cemented in part by its construction as a peculiarly *British* institution.

In this light, the insistence that migrants must have a *permanent* relationship with the UK to access secondary care free at the point of delivery can be read as a fear of foreigners somehow despoiling a British institution. It does not matter if ‘temporary migrants’ are also taxpayers; they are not properly *British* taxpayers. In addition, these changes in policy governing access to healthcare occurred around the same time as significant changes to immigration policy that made it far harder for people on work, student, and spousal visas to qualify for Indefinite Leave to Remain. Excluding them from NHS secondary care furthers this overall policy agenda, constructing the *foreignness* of these migrants.

## CONCLUDING THOUGHTS

The 2014 Immigration Act significantly narrowed the categories of migrants able to access NHS care free at the point of delivery. In particular, those on student, spousal, and work visas were re-defined as ‘temporary migrants’ and a levy was added to the fees for these visas, in order to recoup the supposed cost to the NHS of these migrants. Interestingly, though, in public discourse around these changes, the emphasis was placed on the need to stop ‘health tourists’—people coming to the UK, for a brief period of time, primarily to use the NHS for free, and financially burdening the system. These newly ineligible ‘temporary residents’, by contrast, are people who have come to the UK for a range of reasons, and are likely to be living here for the foreseeable future. Moreover, even government documents acknowledge that these migrants are frequently making an ‘economic contribution’, through taxes, to the upkeep of the NHS.

The emphasis on the supposed ‘temporariness’ of these migrants, and the frequent insistence in documents and by government ministers that the NHS must be a *national* health service, suggests that the motive for these policy shifts is not entirely economic. Instead, we are left with the impression of migrants, regardless of their economic contribution, as too *foreign* to use the NHS free of charge, potentially despoiling a *British* institution.

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## **BORDERING AND DISORDERING IN THE NATIONAL HEALTH SERVICE**

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### **Abstract**

*Recent immigration legislation in the UK has extended the internal reach of the UK's border. The intensification of everyday bordering has introduced immigration checks into more and more everyday encounters and required more UK residents than ever before to check the immigration status of others (Yuval-Davis, Wemyss & Cassidy, 2019). In this paper, I begin by exploring what this shift has meant for the UK's National Health Service (NHS) and healthcare workers, arguing that it has disordered the delivery of healthcare services. I then move on to demonstrate that the advent of everyday bordering has also, however, opened up new spaces to resist and disorder processes and practices of bordering, as well as illustrating why health care has become a key site for the disordering of everyday bordering amongst a wide range of actors. In particular, I explore how the campaigning work of migrant support organisations and other groups intersects with mundane practices of everyday resistance by workers within the NHS itself.*

### **INTRODUCTION: BORDERING AND ORDERING CONTEMPORARY STATES**

Since the 1990s, there has been a shift in the multi-disciplinary literature on borders (Brambilla, 2015), which has moved away from territorial borders and their assumed fixity, to more complex understandings of the myriad of processes and practices, which 'construct, reproduce and contest' them, known as bordering(s) (Yuval-Davis et al, 2019, p.1). This de-territorialisation of border studies has been accompanied by an attendant de- and re-territorialisation of state bordering itself; as more and more bordering practices, such as the issuing of visas and checks on immigration status, have shifted to within and without nationalised territories (Balibar, 2004). These borderings contribute significantly to and have been re-shaping the governance of contemporary political entities (Walters, 2006; Yuval-Davis et al, 2019).

Researchers have been particularly concerned with the dual processes of de- and rebordering (cf. Cassidy Yuval-Davis & Wemyss, 2018), for which the European Union (EU), has provided a key contemporary site of analysis. Specifically, this dualism is concerned

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with the ways in which the debordering of space for particular groups is accompanied by its rebordering elsewhere for others. For example, as the EU supposedly debordered the territory of many of its member and associated states, particularly through the Schengen agreement, so we also saw rebordering at the edges of the EU through securitisation and the creation of Frontex, an EU border force (Vaughan-Williams, 2008). At the same time, this debordered space, has not been evenly experienced, with some minoritized communities continuing to be subjected to a range of bordering processes and practices that question their legitimacy and belonging within the debordered territory of the EU (Yuval-Davis, Wemyss & Cassidy, 2018; Cassidy et al, 2018). Whilst this dualism of de- and rebordering is analytically useful, I believe there is a much more fundamental dualism at the heart of debates on borderings: dis/order. Although there is a wealth of empirical work (cf. De Genova, 2017) that seemingly highlights the disorders created by borderings, the underlying theoretical assumption – driven by the work of van Houtum (van Houtum, Kramsch & Zierhofer, 2005; van Houtum & van Naersson, 2002) primarily – continues to focus on borderings as forms of ordering, i.e. b/ordering. For me, this underlying supposition presents a conceptual dilemma, in which we continue to underpin work on bordering with statist views of borders, even though such an approach has been widely critiqued (cf. Walters, 2006).

We need to understand borderings as an interplay of disorders and orders, i.e. as forms of dis/ordering. They not only disorder the everyday lives and wider structures of society, but they also disorder other state institutions and the delivery of state services. The introduction of new 'everyday bordering' policies which have encouraged a 'hostile environment' in the UK since 2012 (Yuval-Davis et al, 2018), has brought with it new intersections of dis/ordering. Unlike other theorisations of the (re)making of borders in everyday life, everyday bordering refers specifically to the introduction of immigration checks into more and more routine encounters, administered not by trained, paid border officials, but by other residents. These practices have been developing over a number of decades, but have intensified in recent years, and are paralleled in other countries in the Global North, such as the USA and Denmark (ibid). This intensification has shaped and disrupted the delivery of a range of services, which everyday bordering ostensibly seeks to secure for a majoritised population – including those delivered by the welfare state such as social security and healthcare (Guentner, Lukes, Stanton, Vollmer & Wilding, 2016), as well as services provided in the private sector, e.g. bank accounts and rental accommodation.

Everyday bordering in the UK has necessitated increasingly complex regulations to determine access for non-citizens to healthcare, education and state support. Decisions on eligibility for healthcare, social security and education are being made by other UK residents—citizens and non-citizens. These checks restrict access for those with uncertain immigration status, other non-citizens, as well as settled populations, who are unable to

prove their status (Yuval-Davis et al, 2019). However, everyday bordering and its dis/orders have been widely resisted, with healthcare and its delivery proving to be a particularly important focus for this resistance.

People have historically come together to challenge bordering in a range of different ways (Gill et al, 2014; Askins, 2015). The advent of everyday bordering and internalization of bordering regimes has opened up new spaces to resist the processes and practices of bordering and create alternative securities (Koopman, 2011). These spaces include both established existing migrant support organisations (e.g. the Joint Council for the Welfare of Immigrants) but also a range of new campaigning and advocacy groups like Docs not Cops (Potter, 2018). Some more visible and well-established initiatives have been or are the focus of ongoing research, e.g. open borders (Paasi, 2018; Bauder, 2018) and cities of sanctuary (Bagelman, 2016). However, research has primarily highlighted the dis/ordering of everyday bordering (Cassidy, 2018), with little analysis of how this is being resisted by more mundane practices of 'quiet politics' (Askins, 2014). As Sarah Hughes (2019) has been exploring in her recent paper on 'resistance' – our view of resistance in human geography has not kept pace with the more emergent and fractured understandings of the political and power.

[A] framing of resistance as emergent prevents a foreclosure of emergent forces into predetermined forms (e.g. of activist, intentional subject, protest, tactic or dispute), and thereby keeps open the category of resistance to other subjects, materials, spaces and temporalities which do not always cohere to an (expected) resistant form and yet condition the possibility for future claims to be made. (Hughes, 2019, p.3).

I argue that analyses of the disorders of bordering need to explore this resistance as a form of dis/b/ordering, incorporating a wide array of different approaches to challenging and disrupting everyday bordering processes and practices *in situ*. The question is not only of who should be bordered and who should not, but also where and by whom borderwork should be undertaken (Rumford, 2008, 2013; Vaughan-Williams, 2008). The analysis of dis/b/ordering involves capturing a range of different attempts to disrupt contemporary bordering, but it is particularly attendant to everyday mundane acts— the healthcare worker who treats a patient without first establishing their immigration status, the advocacy worker who helps an individual entitled to access a service to gain that access. In addition, it is concerned with how in everyday life different residents challenge the underlying b/orders that support bordering, for example through befriending schemes between local residents and newly-arrived asylum seekers and refugees (Askins, 2014; Askins, 2015).

The purpose of this paper is to present examples of how we might analyse the confluence of orders and disorders in relation to everyday bordering in the NHS. I begin with a very brief overview of everyday bordering in the NHS before moving to some examples of

the ways in which we might understand bordering as disordering the delivery of healthcare, and finally, I present some examples of resistance or efforts to dis/b/order the NHS.

### **EVERYDAY BORDERING IN THE NHS: AN OVERVIEW**

The organisation we refer to as the National Health Service is, in fact, a far cry from being national; it is geographically differentiated within the UK but remains dependent on resourcing from outside the UK (Cassidy, 2018). Therefore, Britain's NHS is more accurately understood as both transnational, in its dependence on labour, skills and other resources, as well as local, in its differentiated organization and commissioning of services.

Bordering within the NHS hinges on a term that was created in the 1949 NHS (Amendment) Act, which designated the power to charge people not 'ordinarily resident' in Great Britain for health services. However, this power was not meaningfully operationalised until 1982 when regulations on eligibility for NHS hospital treatment were created. Charges for care were initially only made in hospitals and primary care and community care remained free 'by default'. The key legislation that introduced everyday bordering into the UK was the 2014 Immigration Act. Prior to the 2014 Act's implementation, being 'ordinarily resident' in the UK was based upon whether an individual was living here lawfully, rather than upon any minimum time requirement.

A person is ordinarily resident if they are normally residing in the UK (apart from temporary or occasional absences), and their residence here has been adopted voluntarily and for settled purposes as part of the regular order of their life for the time being, whether for short or long duration (Department of Health, 2017).

The 2014 Act changed this definition, so that 'ordinarily resident' would require indefinite leave to remain, which is contingent on five years' residency in the UK (Grove-White, 2014). This move removed the right to freely access healthcare for certain sections of the population and further undermined migrants' right to life (Keith and van Ginneken, 2015) by increasing barriers to healthcare and failing to make adequate provision to protect the lives of all UK residents. Those who are not 'ordinarily resident' are expected to pay up-front for non-urgent care, whilst urgent care is provided but the costs are then recouped by hospitals' overseas visitor offices.

Prior to the new regulations, hospitals had discretion in charging 'overseas visitors'. However, after 2014 NHS employees were compelled to carry out ID checks and identify migrants from outside the EU who must pay for most non-emergency or primary care NHS treatments. In addition, a health surcharge for non-EEA citizens staying in the UK for over six months was introduced in April 2015. The initial cost was £200/year (£150/year for students and young people on Tier 4 and 5 visas), rising to £400/year (reduced rate of

£300/year) in January 2019, with plans to further extend the charge to £624/year (reduced rate of £470/year) in October 2020. The surcharge has to be paid upfront for all years of the visa, e.g. £1200 for a 3-year visa. Those who come to the UK on tourist visas are not required to pay the levy, but will be fully liable for the costs of any NHS treatment they receive.

## **THE DIS/ORDERS OF EVERYDAY BORDERING IN THE NHS**

In this section, I highlight examples of the ways in which everyday bordering might be understood as disordering the delivery of healthcare in the NHS (for more details see Cassidy, 2018). Firstly, the new legislation dis/orders relationships between healthcare professionals and patients, which disrupts the delivery of care. This was a concern for professional bodies, migrants' rights and support organisations, and other groups and individuals from when the plans for the everyday bordering in the NHS emerged in 2013.

We do not want to turn GPs [general practitioners] into border agents. That is absolutely clear ... We should not turn people away at the front door because of their inability to pay. (Clare Gerada<sup>1</sup>, HC Deb, 29 October 2013)

Yet in making the decision to demand upfront payment a clinical one (in other words whether requiring urgent or non-urgent care) doctors are now effectively having to make such decisions. Maternity Action's 2019 report 'Duty of Care' based upon data from interviews with midwives highlights exactly the type of impacts on professional practice and relationships with patients that were raised during debates on the new legislation. In particular, some NHS trusts have been asking midwives to check immigration status and provide information about the possibility of charging for ante-natal care in the first full appointment they have with an expectant mother— known as the booking appointment.

Overall, midwives' considered that charging had an adverse impact on their professional practice, increasing barriers to good relationships between midwives and women. (Maternity Action, 2019, p.2).

In an interview in the north-east of England in February 2020, one junior doctor, illustrated how the changes had impacted her relationship with and treatment of one patient.

I particularly remember a man who was from South East Asia or of South East Asian origin [...] I think he'd been in the UK for quite a long time actually, but didn't have clear status, and pretty much everything I proposed, investigation or treatment, he would sort of ask me whether he was going to have to pay for that. So, it sort of changes the nature of the conversation a little bit. It sort of makes your conversation a bit more stilted, and you're more aware of their anxiety, not just about their own

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<sup>1</sup> Chair of the Council of the Royal College of General Practitioners (2010–2013).

health but about their financial status as well. And it gave, it actually probably made me more aware, that he might be a sort of [a] vulnerable person in various senses, which I might have been less aware of otherwise.

The situation has also been exacerbated by a memorandum of understanding (MoU) between NHS Digital, the Home Office and the Department of Health (Doctors of the World, 2017). The MoU came into effect at the beginning of 2017 and set out the terms under which the Home Office could request information from NHS Digital<sup>2</sup>.

Confidentiality is the cornerstone of doctor–patient relationship ... With that broken, I don't think you can carry on to have such a good relationship ... I don't think [the government] has considered enough the damage to public trust that has been done. (Lucinda Hiam<sup>3</sup> cited in Hill, 2018)

Fear of the sharing of information with the Home Office not only disordered the professional-patient relationship that is central to the delivery of health care, but was also one of the reasons why some patients entitled to free care did not always seek or receive care in a timely manner. I consider this to be a second, further, way in which everyday bordering in the NHS has disrupted healthcare, by increasing the need for urgent care. Everyday bordering reduces opportunities for preventive care and early treatment and diagnosis, thus disordering key principles of effective healthcare systems by shifting resource needs to more acute and urgent care. Concerns over the impact on the health of individuals, but also on minority groups as a whole had been at the heart of the debates surrounding the new legislation in 2013 and 2014.

... having a two-tiered system will create confusion, and could delay and discourage people seeking the most appropriate help ... This clearly has implications regarding public health. (Baroness Manzoor, HL Deb, 10 February 2014)

There was already clear evidence from a Doctors of the World's clinic in East London prior to 2015 that some from migrant and minoritized backgrounds were failing to seek healthcare in a timely manner because of concerns about their entitlement to free care (Wemyss & Nava, 2015).

This is a concern not just for the patient who is going to not access care at that point then until they're much more acutely ill and often then will access care through A & E, which means they've got to a stage where their condition is much more serious so it's obviously more concerning for them. But also, that's a significantly greater cost to the health system. We're not saving resources if all we're doing is pushing people

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<sup>2</sup> The MoU was partially suspended in May 2018 and withdrawn at the end of January 2019 (Bowcott, 2018).

<sup>3</sup> General Practitioner, Doctors of the World.

towards using already over-stretched accident and emergency services. (Phil Murwill<sup>4</sup> in Wemyss & Nava, 2015)

This was apparent after the introduction of the new regulations in January 2017, when a female asylum seeker showed me a pre-attendance letter from an NHS Trust that sought to establish her eligibility for free treatment prior to even scheduling an appointment. The letter explained that failure to pay for treatment and data sharing with the Home Office could impact a future immigration application. The woman said that on this basis she had decided not to have the necessary medical procedure, even though she was entitled to free treatment, due to concerns that personal information could be shared with the Home Office and impact on her asylum application.

Finally, in addition to disordering healthcare delivery by increasing the need for acute care, everyday bordering in the NHS has also disordered the administration of the NHS itself by increasing resources dedicated to identifying and recovering costs from patients who are 'chargeable' (Department of Health and Social Care, 2019), and changing the ways in which healthcare staff record and administer patient care.

I've been actually asked to be involved in the paperwork for actually asking someone to pay. [...] I remember they had a sort of sheet on the front of their notes saying, you know, this patient is gonna be charged, so you know, make sure you document what you've done with them, or something to that effect. Which, again, [...] I found quite difficult, [...] and I therefore spent quite a bit of time with that person trying to understand whether they actually did fit the criteria for charging or not and see whether they could register with a GP. So, I guess it's quite a use of health professionals' time which, I feel could be better spent doing other things. (Junior Doctor, North-East England, February 2020)

The consequences of these practices are evident not only in the growth of routine administration relating to the recording of treatment, but also in concerns about whether patients really were chargeable that drove extra investigation tasks and bureaucratic work that took healthcare staff away from other duties. Midwives also reported having to support women and relay messages between Overseas Visitors Offices and their patients to try to and ensure they weren't charge for care they were entitled to, or to have erroneously issued invoices cancelled (Maternity Action, 2019). In some cases, like in mental health trusts and community-based services, no clear policies were in place.

So recently, we have had, like, lots of emails from management, asking us to, like, clarify, what I'm going to do with patients who have got, like say, no settled status. And what are we going to do? Are we going to give them a service? Which is actually

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<sup>4</sup> UK Programme Officer, Doctors of the World.

a question which we hadn't encountered, like, 3-4 years ago. [...]And it's all like, very opaque. And this is the thing, and this is becoming more and more common in the NHS, you know like, they want you to discharge people. They want to, but there's not clear cut guidance. But then there's pressure at the ground level to discharge. And I'm supervising a junior doctor at the moment, and I've just heard that the manager is going to sit in a clinic with the junior doctor, and watch him while [he] discharges the patient because the patient does not have a settled status. (Consultant, Community Mental Health Team, London, March 2020)

Rather than dealing with questions of chargeability, it is clear in these cases that healthcare staff were under pressure to discharge patients before they were clinically fit, and this interviewee also stated that tensions were emerging between administrative/managerial staff and clinicians as a result. In this section I have elucidated some of the ways in which everyday bordering is disordering healthcare delivery within the NHS. In the final section of this paper, I seek to balance such a top-down account of dis/ordering with insights drawn from efforts to disrupt everyday bordering within the NHS.

## **DIS/B/ORDERING HEALTH CARE**

There have been concerns about access to healthcare for mobilised peoples with different statuses for many years in the UK. Some of these include organisations such as Doctors of the World, who as well as operating emergency and long-term healthcare to displaced people around the world, also offer care to vulnerable people experiencing barriers to accessing healthcare in the Global North as well. Many of these organisations developed specific responses to the introduction of everyday bordering policies, some of which were policy-orientated, but others focused on supporting healthcare staff to understand the new legislation (Doctors of the World, 2015; Maternity Action, 2019). The latter were based upon existing concerns that those entitled to healthcare, such as asylum seekers, were already experiencing difficulties in accessing healthcare and that the introduction of the new policies would lead to more people being turned away because of uncertainties on the part of healthcare staff. Doctors of the World were, therefore, outspoken in their criticism of the hostile environment from the beginning.

However, in addition to the resistance of these existing organisations that support migrants and racialised minorities, resistance has also emerged within professional bodies for health care, such as the British Medical Association and the royal colleges of surgeons, general practitioners, nursing and midwives.

The BMA called on the government to publish the findings of its own review into the effects of migrant charging, which it launched back in 2017, but this request has been denied. We can only assume that this is because the results confirm what clinicians at the front line already know—that mistakes, injustice, and avoidable

suffering have been caused not for financial benefit, but merely to help the government look tough on immigration. As doctors, we must continue to speak out against this policy, which harms us all: vulnerable people are denied care, public health is compromised, and the founding ethos of the NHS is undermined. (Salisbury, 2019: n.p.).

As a midwife I entered my profession to care for all women and their babies, with compassion. It breaks my heart that women will not get the treatment that they need, that they can no longer trust me because a booking appointment ends up as an immigration check. [...] Britain's leading doctors, nurses and midwives all say that this is a risk to individual and public health. [...] Midwives become midwives to care for women, not to act as border guards as part of a 'hostile environment' immigration policy. (Rigby, 2019: n.p.).

Within these statements, we see the use of professional identities and their ethics as the basis of resistance. The question is not only of who should be bordered and who should not, but also where and by whom borderwork (Rumford, 2008) should be undertaken. As well as the development of resistance through and with professional bodies, one group of doctors also established a new campaign group, Docs not Cops, which used campaigning and direct action to challenge everyday bordering in the NHS.

Healthcare workers are trapped by these policies, forced to undermine their duty of care to patients and threatened with fraud if they do not uphold the regulations. Knowingly or unknowingly, we are now complicit in the detention and deportation of the people we are supposed to be caring for. This is distressing to say the least and as the NHS becomes increasingly linked with immigration control, many healthcare workers have nowhere else to turn for advice on how to support their patients. I have spent hours on the phone to doctors who want to advocate for their patients. One told me they were pressurised by hospital management and senior colleagues to discharge someone so unwell they would die without treatment, simply because they could not prove their legal entitlement to care. (Dr. Jess Potter, Docs not Cops, 5<sup>th</sup> July, 2019)

In Potter's account, we also see the emphasis of healthcare professionals as being differentially positioned in relation to hospital management, who are seen as enacting everyday bordering on behalf of the state. Elements of these tensions are also present in the accounts given by the consultant with the community mental health team in London discussed earlier in this paper. Whereas s/he and the junior doctor from the North-East of England sought to disorder everyday bordering through mundane actions within their workplaces, members of Docs not Cops were spurred on by a sense that the scale of the problem required a collective response.

[S]o right from the offset I sort of found myself in a way of challenging charging that felt appropriate to the kind of scale of the problem and how things were coming out,



and I suppose that being that the work we were doing was focused on trying to challenge the hostile environment in its *entirety* as a policy in the way it is being enacted in the NHS. (Member of Docs not Cops, March 2020 – *emphasis added*)

Resistance, therefore, also becomes internal to the NHS, the hospital itself, as well as to the system as a whole and might be understood as contributing to a more general disorder of healthcare delivery that emerges from efforts to both border and dis/b/order emanating from everyday bordering and opposition to it.

## CONCLUSIONS

In this paper, I have briefly sought to introduce key aspects of everyday bordering in the NHS, by focusing on some of the ideas supporting the introduction of new legislation in 2014 and 2016. I have shown that the imaginary of a 'national' health service has centred on the NHS as a key site of control for government as it has increased the internal surveillance of populations (Yuval-Davis et al, 2019). I have argued that everyday bordering is disordering the NHS by: (re)shaping relationships between healthcare workers and their patients; changing healthcare delivery by reducing opportunities for preventive interventions and early treatment and increasing the need for urgent/acute care; and by introducing new administrative work both into the NHS as a whole, particularly in relation to cost recovery, but also into the roles of healthcare workers themselves.

However, the introduction of everyday bordering has also been subject to resistance as it has made visible to more and more residents the slow violence of border securitization. This resistance has been particularly strong within health care and has garnered support not only amongst well-established groups but also professional societies and organisations, as well as healthcare professionals themselves. Some healthcare professionals have sought to expand more mundane acts of resistance by individual healthcare workers through the development of direct action initiatives. Overall, I have argued that border studies as a multidisciplinary endeavour has frequently highlighted the disorders of bordering processes and practices, but it has failed to shift the underlying theoretical assumption of the link between bordering and ordering – b/ordering. By centring dis/order rather than order, I argue we can more effectively shift border studies beyond the state (Walters, 2006).

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## **POLISH MIGRATION FORUM: ASSISTING REFUGEES AND ASYLUM SEEKERS IN POLAND**

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Polish Migration Forum

The Polish Migration Forum Foundation is a non-governmental organization supporting the integration of migrants and refugees into Polish society. It was established in 2007 and currently supports more than 5,000 migrants, refugees and asylum seekers per year. Our work combines a two-fold approach. On the one hand we support migrants and refugees by providing them with the information and skills necessary to build links in their host society. On the other, we work within Polish civil society, mainly with youth and professional groups, to develop their ability to understand other cultures. Our organization works extensively with women in the area of women's health, particularly in the context of pregnancy and maternity, which was one of our first health-related areas of engagement. Another field that we have started to explore recently, is the situation of migrants and refugees with complicated and difficult medical conditions, like persons living with disabilities and those living with cancer.

### **WORKING WITH WOMEN**

We are in the process of developing a complex support system for migrant families. A core aspect of this program is directed at expecting mothers and consists of several components. We host weekend **intercultural birthing classes** (labor classes) which combine classic elements for expecting couples (e.g., child development, changes in maternal physiology, the phases of childbirth, breast feeding etc.) and elements related to the status of the mother as a woman. In the latter, we emphasize the importance of cultural differences and the emotional aspects of giving birth far from one's natural support network, but we also address practical, legal issues (e.g., how to legalize the child after birth, how to obtain a birth certificate, etc.). The birthing classes usually involve 5-6 couples, are run by a team composed of a midwife, a multicultural psychologist, and a translator. Although some classes are run in English, the majority are run in Russian.

We have also developed and now distribute three **information packets**: "I am a mom in Poland", "We are parents in Poland" and "Financial support for families available in Poland." We host two regular support groups which meet once a week; the first is designed for mothers of children younger than one-year-old, while the other targets mothers of

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children between the ages of 1 and 3 (which is when the child usually starts attending kindergarten). We also offer a needs-based service of **specialist consultations** with experts in areas relevant for early child development which include, a dietitian, speech therapist, early development expert, and allergist.

### **INDIVIDUAL PSYCHOLOGICAL SUPPORT**

We offer counseling for migrant women, often in relation to maternity. The support groups are usually Russian-speaking and at times, they are bilingual. They are run by a multicultural psychologist, who is herself Polish-, Russian- and English-speaking. Over the years we have hosted mothers and couples from Ukraine (the majority), as well as Russia, Uzbekistan, Tajikistan, Turkmenistan, Belarus, Armenia, Indonesia, Malaysia, Vietnam, Iran, Morocco. These intercultural birthing classes are organized four times a year but we also sometimes offer individual consultations for expecting mothers or a couple – when the language barrier makes it impossible for a woman to participate in a group, or for other logistical reasons. We have also run a workshop for migrant fathers on one occasion—at their request.

The Migration Forum also regularly works with mothers on upbringing issues – in situations of physical abuse in the family, post-traumatic issues, as well as the effects of discrimination of children in Poland. Help is offered for as long, as it is needed. Finally, all maternity-related activities of PFM are funded by AMIF funds (previously by EFI/ERF funds). The psychological counseling for children and mothers is also funded by the City of Warsaw. The service has been functioning since 2013 and is free of charge for the beneficiaries.

### **WORK WITH MIGRANTS WITH DISABILITIES AND CANCER**

This program was launched in 2018, in response to a lack of available services for these groups. We were approached by migrants, who could not find referral systems or available help, and so the organization decided to seek funding to set up a basic service. We have received funds from the City of Warsaw, and now provide:

- Psycho-oncological support (in 2019, 80 hours of such support was provided to 20 patients and family members).
- An information service for migrants with disabilities – on the support system for persons with disabilities in Poland. We have produced an overview of the support system available, in five languages (Polish, Russian, Ukrainian, English, Vietnamese).
- Psychological support, offered in Polish, English, Russian, Dari and Spanish.

We are still early in the learning stages of setting up this service and throughout 2019, we have supported 20 oncological patients and their families. We have also been in contact 15 persons with disabilities, most of them children and teenagers; and more than 50 persons have benefited from psychological counseling. All of this assistance is free of charge for recipients and each situation is very specific. Our work is focused on access to care and helping migrant families understand their rights and possibilities within the Polish system. Sometimes we act as intermediaries between the families and the medical facilities, explaining the legal situation of a migrant or providing translation.

## LESSONS LEARNED

**The system is in crisis.** The Polish medical system is not functioning well and is not efficient for Polish patients too. In this context, it is hard to mainstream migrant patients and ensure that they receive equal treatment. Often, the way to make help available is to find an individual doctor, nurse, therapist ready to offer help *pro-bono*, partly-paid or able to guide a person through the public system. Some **laws concerning people with disabilities do not mention migrants** at all. As a result, there are problems with establishing who has a right to specific services (for example, it is not specified in the law what legal status is necessary for a person to apply for a Polish disability card). Likewise, social services (day-centers, rehabilitation centers) do not always accept migrants, due to lack of provisions.

In some cases, **language is a barrier** in obtaining help, to which a person has a legal right (day-centers, therapy, diagnosis). Some **services are also not available**, or extremely scarce – and there is no information exchange within the medical system concerning those scarce resources. For example, midwives with experience in helping women with genital mutilation give birth. Or psychiatrists working with youth with multicultural awareness, able to work with PTSD patients, or doctors able to work with autistic patients in another language.

Oncological illnesses, as well as disability puts an **additional burden on migrants in terms of their ability to legalize their status**. Illness in a family affects an individual's ability to work and earn money. This in turn results in a loss of the ability to legalize one's stay – a prolonged period of unemployment results in a loss of legal status and, as a result, the deprivation of medical care. We have assisted persons who have lost their jobs because of illness or disability in the family and who face the risk of dropping into an irregular status. From our experience, there is a relatively high number of **single mothers** bringing up children with disabilities. Sometimes, the disability of the child is the reason for migration (in search of better care). More often, children with disabilities are already born in Poland to migrant parents or in mixed families. Finally, we also see that one's **culture of origin plays an important role** in the perception of illness and disability – and that it has an

impact on how an affected family behaves in Poland. If, for example, a culture of origin excludes persons with disabilities, this may make a family reluctant to benefit from help available in Poland. Parents may be scared to admit their child has a disability, fearing discriminatory treatment or exclusion of the child (for example from the educational system).

Despite the problems mentioned above, there are areas that work and function well. In Warsaw, there are two specialist centers that seem to function effectively: one assisting deaf persons of different ages and the other providing complex help to blind children. In both facilities, migrants are regularly assisted. The Deaf Institute assists persons with regularizing their legal status and the Blind Center, run by catholic nuns, accepts migrants with regular status, regardless of their religion. One phenomenon that we have observed is an increasing number of migrant staff in the Polish medical system. This may help overcome language and cultural barriers to a certain extent. It may also improve the attitude and understanding of migrant patients by medical staff.

However, at the moment many migrants still lack access to medical help at a level equal to the Polish population. There are not enough specialists speaking foreign languages with the specific competences needed to work with migrants. Migrants who fall ill, who have a disabled child or become disabled themselves often find themselves in a dramatic situation. We still encounter situations, where we find ourselves helpless and do not know, how to help the person who comes to us for assistance.



## HIV, CITIZENSHIP AND BORDERING MECHANISMS IN BERLIN

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HIV is a life-threatening disease associated in the western world with strong stigmatization and a “dark” history of deadly epidemics and discrimination, both of which have been supposedly overcome following the advent of anti-retroviral therapy (ART). ART guarantees viral suppression, prevents HIV-related infections and avoids premature death. As it reduces the likelihood of virus transmission, access to ART is an issue of public health policy although it is not accessible to everyone. In this working paper, I focus on those who remain affected by the lethality of HIV, in particular marginalized HIV positive Polish migrants in Berlin and their access to health care services and ART. My research reveals the complex cultural and social logic that underpins the routine functioning of state systems and the notions of citizenship, social engagement, discrimination, equal rights and equal treatment embedded in various level institutions within the EU regime. As a life-threatening disease and public health concern that requires continuous medical supervision, HIV facilitates a wide range of political claims while mobilizing different cultural and social resources highlighting its social and cultural productivity. Thus a focus on HIV highlights the relationship between everyday bordering mechanisms<sup>2</sup> and EU-based notions of citizenship.

In this paper, I describe how the enactment and emergence of HIV in one discursive context – a registration office in Berlin – illustrates the complex processes that regulate one’s access to rights and recognition. I show how a series of interrelated diseases (in the particular case below from addictions) and the overlapping and intersecting relations they enter with the legal solutions, medical knowledge and social landscape in one particular place in Berlin may accentuate the vulnerability of those whose lives are already at great risk. The example of Angelika and Marek that I describe below also shows the way these intersecting diseases, together with other accompanying medical, legal and social issues, may generate practical knowledge and further agency, in a way that contrasts with the image of addicted, HIV positive people as largely vulnerable and victimized by unjust legal and medical systems. Such a perspective on HIV underscores the relationship between bordering mechanisms and EU citizenship. Both the form and meaning of these two are

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<sup>2</sup> Understood after Yuval-Davies et al. (2018) as dispersed mechanisms of power that are installed to bar from access to rights and resources.

outlined in the tensions and negotiations over access to rights and recognition alongside the practices in which HIV emerges, as well as the ethical questions surrounding the provision of wellbeing and health to EU migrants in the context of a western welfare state model.

In Germany, all citizens are obliged by law to be covered by health care insurance, and the system is designed in a way that it only grants health care access to those who can make a financial contribution to it. There are four ways to contribute and hence gain access to regular and standard health services: 1) through a work contract with a salary above 450€ per month, 2) through the insurance of a spouse/partner or a parent (*Familienversicherung*), 3) through social welfare provision (when contribution to the health care fund is paid for by the state), 4) through self-contributions/self-insurance. There are no solutions for People Living with HIV/AIDS (PLWHA) without insurance. HIV is not considered as a public health issue in the same way as it is in other countries such as Italy, Spain and France, where people with HIV/AIDS have access to health care in some form at no cost.

Those who are HIV positive and are unable to enter the insurance system in one of the above-mentioned ways (due to addiction, unregulated migrant status, criminal issues, or other – most often psychiatric – diseases, impairments, or discrimination) are taken care of by organizations in place to help PLWHA (also German citizens, as some drop out of the welfare system and have no health insurance). In Berlin, one organization in particular currently focuses on helping PLWHA and is engaged in the field of HIV prevention, healing, community building and political action. It operates at the intersection of multiple fields contemporaneously such as the acquisition of residence permits, health care access and HIV therapy, , asylum law, and healing of other (co-)diseases. HIV legitimates actions in areas such as social welfare access, asylum policy<sup>3</sup>, disease treatment<sup>4</sup>, drug policy as well as facilitating the distribution of medication. The motto of the organization is to help PLWHA. One of the projects run by the organization is a drop-in counseling program for people with unclarified legal and social situations. The actions undertaken in reference to a particular person depend primarily on their physical health. If the most pressing issue is the virus itself<sup>5</sup>, treatment and access to it will be given priority before taking care of other issues, such as homelessness, the regulation of a residence permit, debts or addictions. If there is a psychological or psychiatric problem that hampers the HIV treatment, it will be treated as a priority, although solutions to access ART will be actively provided. Actions are based on legal and bureaucratic procedure and are undertaken in places such as local municipal offices and welfare institutions, while also involving a wide network of doctors, pharmacists,

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<sup>3</sup> Health care services can be accessed once the asylum application is submitted.

<sup>4</sup> HCV, tuberculosis, addictions, and other various co-infections and inborne diseases.

<sup>5</sup> Virus load and CD4 count are indicative here.

clinics, shelters, all of which are based on a principle of assistance and the provision of well-being to PLWHA – whatever their legal and social status may be.

### **BERLIN'S HIV MAP**

There are various locations that are relevant for an HIV positive, marginalized person without access to health care in Berlin. **A clinic** is usually a place where the virus is diagnosed and the German health care and humanitarian system detect an HIV positive marginalized migrant. These people are most often hospitalized due to the life-threatening condition they find themselves in. There are three hospitals in Berlin that provide health care to people without health insurance (on a charity basis) – only temporarily and to a limited extent. One of the clinics in the district of Schöneberg is particularly generous; it is a clinic where HIV has been treated since the onset of the epidemic.

While the **anti-HIV organization** has its seat in one of central districts of Berlin, I see it as a “dispersed institution”, in the sense that it is active in many fields and locations in Berlin where HIV appears as a both social and health issue. The aim of the organization is to provide health care to those who are HIV positive and uninsured: temporary and emergency health care as well as sustainable access to health care and anti-retroviral treatment – through counselling and personal assistance. To reach this aim, it solves problems on an individual basis pertaining to social welfare provisions (and the eligibility of a given person for social welfare benefits), asylum law, criminal law, and addiction treatment, while facilitating health provision (through a network of pharmacists and doctors). An informal network of doctors and pharmacists consisting of doctors' offices, both specialists in HIV (*Schwerpunktpraxis*) and doctors in specialties other than HIV who treat HIV positive migrants (dentists, orthopedist, psychiatrist) on a charitable basis, is sustained by the organization (it was founded as a result of the HIV activism in the 1980s).

To gain social welfare provisions and therefore access to health care and regular access to ART one must turn to a relevant **welfare institution** (*Sozialamt* and/or *JobCenter*). The *Sozialamt* provides pensions to the disabled while the *JobCenter* provides basic security benefits, the underlying aim of the latter is also to bring service users back into the labour market (under the logic of “support and demand”), whereas provisions from the *Sozialamt* go to those who are classified as unable to work. How HIV is emerging in these institutions is a complex issue that goes beyond the scope of this paper.

**In the places of shelter** of those in the focus of this study – on the streets, but also squats, metro stations, and other temporary housing not suitable for permanent living (tents and settlements in parks, benches), HIV statuses are usually either unknown or a very limited number of people are aware of the status of an individual. **Other organizations** providing assistance to homeless people are not necessarily concerned with health care, nor

particularly with HIV; rather, they provide casual and relief help: food, hygiene, clothes, and legal and bureaucratic support. Whether the employees of the organization are knowledgeable of the status of a given person can vary significantly. An important point on an HIV map in Berlin is the **local municipal office** (*Bürgeramt*). It registers EU citizens' residencies at a given address, provides relief welfare aid, and issues marital status documents when relevant.

**The Health insurance fund** (*Krankenkasse*) pays for health care provision<sup>6</sup>. There are various conditions under which HIV positive people (that are not under permanent and full-time employment) can enter the health care fund – public health care funds must accept people with HIV. **Police and emergency** units (in Germany the emergency health sector and the fire brigade are part of one unit) and the judiciary system are also areas of life in which sero-status and nationality may be an argument for different levels of treatment and grants exceptional legal status if a crime is committed. **Imprisonment** equals access to ART.

This may be a somewhat simplified picture of an “HIV map” for marginalized migrants in Berlin, but it does show that HIV as a socio-political problem and a disease appears and disappears, while having differing statuses in various situations and locations in the formal landscape (granting and barring rights and recognition) and in the less formal, everyday lives of those with HIV and AIDS in the city. It does not mean that the virus in different situations does not exist, but it may be made invisible or even particularly visible depending on the situation and relations in which it appears in a given social, legal and cultural context. The aim of the study is to unravel these situations and understand the different factors which shape the emergence of HIV in each location, and between these locations, to impact bordering mechanisms and constructions of citizenship – rights and duties as well as access to recognition, resources and wellbeing. The study describes these productive moments along the HIV trajectory in Berlin – whether it “appears” in real life or otherwise. The assumption is that, as soon as it is diagnosed, it matters and creates particular social and cultural effects, making new relations and new political and social connections possible.

## **CITIZENSHIP AND HIV**

Citizenship has an established position in medical anthropology: therapeutic citizenship (Nguyen 2005) and biological citizenship (Petryna 2013, Rose and Novas 2005) are just two examples. While in more recent notions of citizenship rights and duties are connected to the

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<sup>6</sup> Alternatively, this can often “credit” the health care provision, e.g. when a person was covered by the health care insurance but fell out of the system and received treatment nonetheless – it is the health care fund that then “credits” the treatment.

body (Netz et al. 2019), I build on this literature by showing the way in which HIV may grant rights to resources and recognition to some, yet bar others in different contexts and depending on the contingent ways it emerges as a disease. However, as opposed to Ticktin (2011), I want to show that HIV, as a complex issue, may be socially and politically productive. My research shows that HIV emerges in multiple way and is produced in relations (Abrahamsson et al. 2015) in various locations relevant for the status and situation of an HIV-positive migrant: in a doctor's office, a clinic, a social welfare office, an immigration office, an asylum court, an anti-HIV organization, a police station, a shelter. In this text I focus only on how HIV emerges in a municipal registration office and impacts the legal and health situations of marginalized people affected by HIV.

How do the relations in which HIV emerges in the legal and medical system, while intersecting with substances (addictions) and other issues, reveal the conditions in detail of how borders and everyday bordering mechanisms function and how (EU) citizenship is formed in practice? What can HIV in a trajectory connecting different locations tell us about the notion of borders, access to rights, resources and recognition, and EU citizenship? The issue of access to health care, while taking into account each of these contexts separately and the intersecting elements and effects observed in the case of HIV in these contexts, must also be considered as an interplay between said contexts. Such focus brings bordering mechanisms currently in practice into light in a continuous way (along the HIV trajectory), as well as the notion of (EU) citizenship and the impact of the "HIV complex" on the subjectivities of marginalized migrants.

In such a way bordering mechanisms become visible, not only in the labor market (Yuval-Davies et al 2018) but also in health care, the police and judiciary, and in the legal systems (see also de Koning 2018) that shape the subjectivity of people affected. However, the case of HIV in Berlin also shows that these mechanisms are much more dispersed and unstable than Yuval-Davies et al suggest. Moreover, in order to understand their functioning in each context one has to take into account their formal and informal aspects, where the latter are spaces of power negotiation that create instability and micropolitical tensions, through which borders are strengthened or diluted or moved. The formal aspect of border maintenance is created by the state and implemented – in a varied way – by practitioners and officials through the means of modern bureaucracy and procedure. The informal space where negotiations over borders and citizenship take place consists of the above-mentioned network relating to the formal aspects of implementing citizenship in context of HIV. This network and its functioning is based on charity (or the lack of it) and a central role is played by anti-HIV organizations. It is similar to Ticktin's (2011) depiction of 'regimes of care' but rather than ossifying the political status quo with respect to health for migrants and their

political condition, it expands the spaces of possibility and thus existing notions of EU citizenship.

I focus here predominantly on Polish citizens, European Union citizens, who are allowed to move freely within the Union and the European Economic Area. EU citizenship is bound to the Citizens' Rights Directive (2004/38/EC) that came into force on April 29<sup>th</sup> 2004, one day before the inclusion of predominantly central and eastern European countries made it the largest territorial expansion in EU history. It guarantees freedom of movement within the EU and EEA countries under four conditions: working as an employee or as a self-employed person, studying, or being retired and/or self-sufficient. The directive explicitly mentions "comprehensive health insurance" as a precondition for freedom of movement and limits it to those who do not rely on public funds to sustain themselves.

While freedom of movement has been a pillar of the EU for many years, recently there has been a growing tendency in Germany and other countries to define this freedom – both legally and practically - only in connection with employment. In 2017, on a wave of preceding racist discourses concerning people from new member states and their "abuse" of the welfare system, access to welfare provisions was limited only to those who were able to prove that they had been in Germany for at least five years prior to the application for welfare benefits and/or that they had worked during those five years (either on the basis of a fully guaranteed contract, meaning earning above 450€ per month, or being self-employed).

Most of the people I followed are not allowed to settle in Germany according to EU law and are not eligible to receive social welfare according to German law (that would give them access to full health care coverage). Most of them are unable to prove that they are working or have worked in Germany in the past (either because of their illicit employment or a lack of documents), neither can they show documentation proving that they can sustain themselves, that they are studying (or have studied), or that they are receiving a pension. Yet despite this, the anti-HIV organization is helping them to formalize their residency in Germany, find registered (often low paid) employment<sup>7</sup> and apply to local welfare funds (i.e., the *JobCenter*) to receive a basic income and/or register their contributions to the health care fund. Receiving social welfare from the *JobCenter* guarantees coverage under health care insurance and subsequent access to substitution and ART. Another way of entering the health care system requires registering at a local tax office as self-employed (this solution is relevant for sex workers), in which contributions to the health care fund are paid by the person in question. However, those in this group are often unable to pay their contributions

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<sup>7</sup> Under 450€ per month which is fiscal tax and social-security tax free.

regularly and fall into debt with the fund (*Krankenkasse*). This often results in them being registered on a debt list (*Schufa*) and becoming embroiled in crime and systemic violence.

Until 2017 the decision to grant social welfare was less restricted and remained at the discretion of a social welfare institution (one could contest their decision in court, but this required access to the necessary resources). It is difficult to control the residence of EU citizens in Germany and there is no coherent federal policy concerning EU citizens applying for welfare. This is linked to the discrepancies between the general registration law (*Anmeldepflicht* – general residency registration duty) and the registration law for EU citizens (*Freizügigkeitsbescheinigung* and *Freizügigkeitsgesetz*) as well as policies concerning the non-discrimination of EU citizens and the equal treatment of EU and German citizens. In each state (*Land*) and commune the practice and implementation of the registration law and welfare policy towards EU citizens differs slightly<sup>8</sup>. Spouses of German citizens who are citizens of the EU or EEA are allowed to reside in Germany upon obtaining a residency permit (that foresees a permit for a spouse and is not connected to the employment and self-sufficiency rule) and not on the freedom of movement permit for the EU/EEA citizens.

The legal complex of social welfare and health care solutions sketched above, is also variously intertwined with the right to move within the EU and of access to rights and recognition; they illustrate the uneven coverage of legal solutions pertaining to EU citizens and the “cracks” or spaces where access is negotiated. HIV provides an entry point to these spaces, and a window into how the practices performed by the various actors and people in question shape EU citizenship in action.

## CASE STUDIES

The case studies in my research focus on people between 28 and 48 years of age, all of whom, except one, suffer from addictions (alcohol or intravenous drugs) and have criminal records in Poland. Some have convictions in Germany but these are usually for misdemeanors. The vast majority are without permanent settlement, with neither regular nor registered jobs, and without access to regular health care (with the exception of one person whose health insurance provision was intermittent due to irregular contributions to the health care fund<sup>9</sup>). Many of them also had HCV and other (in borne) diseases and co-infections that intersected with HIV (once the compliance with HIV treatment became compromised, other diseases and co-diseases became apparent). Most had experienced trauma at some point in their lives and the majority came from economically, educationally and socially

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<sup>8</sup> Berlin belongs to one of the liberal regions to have implemented the residency law, yet differences exist even between districts.

<sup>9</sup> She was a sex worker and paid her contribution to the health care fund as self-employed

disadvantaged backgrounds, having experienced discrimination in Poland due to addictions exacerbated by HIV infection, while also having experienced the addiction treatment (substitution) and HIV treatment (ART) that is – at least formally - widely accessible to Polish citizens.

The research material presented in this paper was gathered during my engagement with the anti-HIV organization between 2015 and 2017. The organization was informed about my research and has given oral consent. All those in this study were informed that I am a researcher and gave their oral consent to collect data on the issues discussed in this paper.

Marek<sup>10</sup> is 40 years of age. He came to Berlin on a train from Warsaw 12 years ago. His trip to Berlin was spontaneous and spurred by the opening of the border in 2007 after Poland entered the Schengen Agreement. Before coming to Berlin, he had lived on the margins of Polish state systems and mainstream society in many different cities, usually spending the night in squats, but also at friends' residences or in abandoned houses. In Berlin he continues to live such a life, in networks of homeless Polish people and of people he knows from his life as a vagabond in Poland as well as organizations providing assistance to them (handing out meals, clothes, washing laundry and giving the possibility to take a shower), which makes survival, as he says, an easier proposition. During the day he begs to satisfy his need for alcohol. At night he seeks shelter in squats, metro stations, or in a tent on a yard between train tracks in one of the post-industrial areas in the district of Kreuzberg. The anti-HIV organization was informed of his existence after his hospitalization in Berlin. However, thanks to the organization, he has been transported (in one case in a coma) to an infectious disease clinic in a big city across the border in Poland on a number of occasions, as both his addiction and virus caused a severe threat to his life. As an HIV positive Polish citizen, he has access to medication and necessary health care there. Once his condition improved, he always returned to Berlin – he says that this is because of the easier access to alcohol and better living conditions there.

Marek has been drinking continuously - with intermittences caused by his imprisonment in Poland for assault and arson - since his first wife and daughter died in a car accident when he was 23 years of age. He also has experience of using intravenous drugs. He is unable to tell when and how he became infected with HIV, but assumes it was in prison while using intravenous drugs and sharing syringes. He would have continued his vagabond life on the streets and engagement with alcohol had he not met Angelika, a cis-

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<sup>10</sup> All names have been changed



woman, German citizen and the daughter of *Aussiedlers* from Poland<sup>11</sup>. It was her idea to turn to an anti-HIV organization (again, as Marek was already known there) for help to formalize his legal status and gain access to health care (as non-employed and never having worked in Germany, he was at least formally obliged to go back to Poland). Both Marek and his girlfriend suffer from mobility impairments; he has to use crutches, while she uses a wheelchair.

One of the ways to guarantee sustainable access to health care provisions is through marriage to a person already in the health care system – a person whose contributions to the health care fund (*Krankenkasse*) are covered either by their employer, by the welfare system or on an individual basis. The anti-HIV organization arranges Marek's HIV treatment in Berlin on a charity basis and with the help of a clinic in Poland (all necessary tests for the treatment were made in the clinic in Poland, medication is transferred from the clinic to employees of the organization that take care of Marek's compliance). The organization is also attempting to formalize his residency status in Germany and collect his and Angelika's papers for them to get married so that he can gain access to her health care coverage. Simultaneously, the organization is helping Marek to apply for social benefits with the *JobCenter* as it is considered to be worth the effort, as a way to enter the health care system more quickly than through marriage, while ensuring that he can receive a basic income. The organization has a wide network of contacts in various institutions that may speed up the formal process.

However, the organization's contact person at the registry office where Angelika and Marek can get married no longer works there and the new officer is not familiar with the anti-HIV organization. At some point during one of the numerous meetings which I attended to clarify the papers and the process, the officer asked me about the role of the organization; who I was and what I was doing. I explained my role (both as an employee of the organization and as a researcher) and my Polish background to him. In the course of these meetings, it transpired that the officer needed to see some archival documents from Angelika, as she is the daughter of an *Aussiedler* from Poland. Angelika has had a German ID since she was 18 and full German citizenship (she left Poland when she was six and can speak very little Polish) but the name on her Polish birth certificate is written in a Polish way and that seems to be a problem, as it is written differently on her German ID – but her German ID does not seem to be of importance now. Her identity must be proven.

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<sup>11</sup> Co-ethnic German return migrants, persons acknowledged as German based on their "affinity to German culture" and assertion of German citizenship based on their ancestry and relocated to Germany from areas of former socialist countries in Eastern Europe.

At one of the many meetings at the registration office, the officer gives me a long lecture about HIV being invented by the pharmaceutical industry and claims that it does not really exist, as he has “thoroughly investigated” the issue. I do not argue with the officer and say that it is one of many possible versions but that I believe in science and have seen people dying of AIDS and that is why the couple needs to marry quickly so that Marek can receive his medication. Finally, after a few months during which all the papers have been collected, translated into German, and the officer’s questions regarding Angelika’s name and identity have been answered—no obstacles remain and a wedding ceremony takes place, with bride, groom and two organization employees as witnesses. Directly after the ceremony, the officer, a person who apparently pays attention to formalities, reveals in conversation that he was astounded by my patience and complicity, while he requested more and more papers. The officer said to my colleague: “he (meaning me, who was tasked with completing the paper work for the couple) did everything without batting an eyelid” expressing both his surprise and appreciation. He also expressed his astonishment as he had expected it to be a marriage of convenience rather than anything else, but that he was now able to see that the couple did share affection for each other and wished them “a long” relationship.

This ethnographic vignette shows how HIV emerges as an ambiguous phenomenon, mobilizing contrasting and sometimes contradictory social forces. On the one hand – through the actions and networks of the anti-HIV organization - it has legitimized and helped Marek to fight his addiction and improve his health across the Polish-German border, and to marry Angelika, thereby reflecting an apparent improvement in his emotional life. On the other hand, it appeared to be an obstacle at the registration office, although in the end the registration officer was bound to allow the marriage of Marek and Angelika, despite his alleged medical knowledge of HIV as being non-existent and his doubts about Angelika’s identity. Certainly, my capacities and knowledge gained through engaging with the anti-HIV organization, as well as my background as a middle-class white man and proficiency in German, and also my status as a researcher, had an impact here. Nevertheless, I would also like to point out that by revealing my identity and role as a member of the organization, there seemed to open a space of negotiation over access to rights and recognition, a space opened and fueled by contrasting medical knowledge about HIV. On the one hand, these negotiations over rights and recognition were conducted during the application for legal requirements and procedural compliancy, while on the other hand they took place regarding the knowledge about HIV and the strategies applied by the anti-HIV organization.

What appeared to pave the way for the marriage to take place at the registration office was the often over-complicated bureaucratic procedure and my status as patient, persistent and knowledgeable about HIV in view of the registration officer. Unlike Ticktin’s

regimes of care, these regimes, in the form of the experience and knowledge of the organization I performed, seemed capable of going beyond mere benevolence. Supported by the organization's capacity, my knowledge on HIV, my status, our negotiations and compliance with procedure enabled the improvement of Marek's legal condition, after which he was able to gain access both to legal residency in Germany and to the health care system and ART. While the virus emerges as productive in terms of the actions of an anti-HIV organization, it seems to be suppressed by the registration officer, and in turn the "nationality" of Angelika seems to be a problem and comes to the fore in the form of the procedure itself.

Here, in the cases of both Marek and Angelika, HIV and citizenship status are deeply intertwined. The virus does seem to matter to the officer as a "complicity" of the pharmaceutical industry and may be the cause of the officer's suspicion concerning Angelika's citizenship status (on which the whole procedure at the registration office is based). On the one hand, he sticks to the procedure, requiring various documents from Poland and Germany for Angelika and Marek to get married, while on the other he questions the procedure that granted Angelika German citizenship and through that her ability to get married. It is difficult to say whether he also thought that Angelika was HIV positive. The actual health status of both Marek and Angelika seems to be irrelevant for him in this situation; it is the virus itself that is relevant and the access it grants (or not) to rights and recognition. After the marriage, Marek is insured as a family member through the insurance of his wife until he begins to receive welfare benefits on an individual basis (also as a consequence of the legal action taken in the registration office). He is dependent on his wife and her insurance. We can see how HIV generates different forces, highlighting citizenship, nationality and gender and revealing bordering mechanisms in practice. The actions of the HIV organization show how the virus may not only set humanitarian regimes in motion (Ticktin 2011) but through the opening of less formal spaces of negotiations also expand notions of citizenship by multi-level strategies that make use of possibilities set out by legal frameworks (over-the-border illicit health care, paperwork, and strategies to cope with "medical knowledge" of the officer) and are legitimized by deadly nature of the virus. Moreover, legal actions undertaken at the registration office (marriage of Angelika and Marek) have further health, political and legal implications for Marek as an HIV positive person. It is the aim of this study to unwind and understand the political implications of interactions between the virus and a multitude of other factors in a particular moment on the map of Berlin. The other aim is to trace the interactions between facets of the state system: the legal and/or migration system, the social and/or welfare system and health care embedded in various social and political institutions in Berlin.

## CONCLUSIONS

This ethnographic example from my fieldwork showcases the complex intersections of HIV and other issues, intersections that matter in various contexts and spaces that are particularly relevant for marginalized Polish migrants that are HIV positive in Berlin. This one particular case reveals practices in which HIV emerges in a particular social and political context, making real-life access to rights and resources visible as well as the ways in which the virus exacerbates vulnerabilities but also highlighting valued social and health statuses that make “livable life” apparent. However, the example shows how the virus is stimulating micro-social and micro-political change by activating networks beyond boundaries, and how regimes of care do not necessarily solidify the political containment of vulnerability and casualty, but also enable the exercise of rights and the acquisition of health provisions. The way in which the virus emerges is either placed at the forefront or pushed into the background in these various situations, revealing heterogeneous bordering and belonging practices, while also highlighting ethical issues in the practice of HIV prevention and treatment in Berlin. EU citizenship – together with open borders – stimulates new connections and new practical solutions in health care and in the provision of treatment of marginalized people, both in Poland (as shown by the example of the clinic that provides medication to people living in Berlin) and Germany (as shown by the example of the anti-HIV organizations). It appears that the legal solutions set out by the policy of EU citizenship and free movement only partially reflect the reality of the migration of EU citizens within the EU itself, while bottom-up initiatives that aim to tackle HIV expand on these solutions in a somewhat unanticipated and multiple approach. In such a way they expand the notion of EU citizenship beyond the frames set out by the EU directives and its implementation in regional and national procedures.

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## ACCESS TO HEALTHCARE FOR ASYLUM-SEEKERS IN TURKEY

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### INTRODUCTION

Although there have been different asylum flows to Turkey in the last fifty years (İçduygu, 2003), asylum applications have increased dramatically over the past decade. In 2000, there were around 6000 asylum applications but an increase in asylum-seekers from Iraq and different African countries pushed this number to 13,000 in 2008. By 2017, as more asylum-seekers arrived from Afghanistan, Iraq and Iran, there were 112,415 asylum applications (DGMM, 2018; İçduygu, Erder, & Gençkaya, 2014, p. 238). According to the United Nations High Commissioner for Refugees (UNHCR), the current number of asylum-seekers and refugees in Turkey is 368,230 (UNHCR, 2019). Turkey is also hosting ca. 3.6 million Syrian refugees that have been accepted under a temporary protection regime (İçişleri Bakanlığı Göç İdaresi Genel Müdürlüğü, 2020).

According to Turkish Law, asylum-seekers and refugees have the same right to healthcare as Turkish citizens, as long as they access healthcare in the cities where they reside (which are called “satellite cities”) and they are registered with the Directorate General of Migration Management (DGMM). The Ministry of Interior (MOI) established 61 satellite cities, which exclude border cities and metropolitan areas and where security issues related to the management of asylum applicants are more easily controlled. However, asylum-seekers prefer to live in metropolises because of the social networks and employment opportunities that are there. This generates differences in healthcare access, particularly in metropolises such as Istanbul, Ankara and Izmir where asylum-seekers are not allowed to reside except under extraordinary circumstances (e.g., requiring access to adequate therapy [Yıldız, 2012, p. 65, 71]). This study describes the barriers encountered by asylum-seekers in accessing healthcare and compares the differences between Istanbul, a metropolis, and Eskişehir, a satellite city.

### METHODOLOGY

This is a descriptive study based on semi-structured interviews with refugees and asylum-seekers in Istanbul and Eskişehir. A semi-structured interview guide with questions on

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demographic characteristics, UNCHR status, health problems and experiences related to access to health services was used to conduct the interviews. The asylum-seekers were also asked to make suggestions about how to improve the conditions of accessing healthcare. A non-probabilistic purposive sampling method, which is a sampling method used for “*hard-to-find populations*”, was used in this study (Bernard, 2006, pp. 189–191).

In-depth interviews were conducted at the Human Resources Development Foundation (HRDF) centers in Istanbul and Eskişehir between November 2015 and January 2016, and from September to October 2016, respectively. Thirty refugees and asylum-seekers were interviewed in each of the two cities and the interviews were conducted with the help of translators from the HRDF. At the beginning of the interview, the participants were informed about the research and their consent was taken; the interviews were facilitated by the researcher, the research assistant (who also transcribed the interview), and the translator. The interviews were not recorded to avoid compromising the trust developed with participants and the sensitivity of the information they shared with us. This research was approved by the Ethical Committee of the Medical School at Koç University, İstanbul.

## **DATA ANALYSIS**

All interviews were transcribed and uploaded to Atlas.Ti 8 program. The context analysis was conducted with thematic topics based upon on Scheppers *et al.*, which analyzed barriers to healthcare access on three levels: a system level, a provider level and a patient level (Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006). The patients in this study are asylum-seekers and refugees; throughout this paper “asylum-seeker” will be used to describe both groups. The abbreviations in the quotations indicate the cities where the interviews were conducted (ESK: Eskişehir, IST: Istanbul) and the number represents individual interviewees. In conducting the analysis, we supplemented the three main themes with further sub-categories.

## **RESULTS**

### *Socio-Demographic Characteristics*

The participants in this study were mostly from Iraq (43.3%), followed by Iran (31.7%), the Democratic Republic of Congo (8.3%) and Afghanistan (6.7%). There was also one applicant each (1.7%) from Somalia, Sudan, Central African Republic, Ethiopia, Cameroon and Palestine. The percentage of women (46.7%) and men (53.3%) among the participants in both cities was the same and the mean age of respondents was  $34.9 \pm 9.6$  years, the youngest being 18 and the oldest 66 years old. Among the participants, 43.3 % (n=26) were higher education graduates whereas 6.7% (n=4) were illiterate. Only 43.3% (n=26) of

participants had refugee status (which took between 1 year at minimum to 7 years at maximum to obtain) and more than half of respondents were waiting to get this status.

#### *Barriers to healthcare access at the system level*

There were two main difficulties encountered by asylum-seekers at the system level while trying to gain access to hospitals. The first barrier faced by asylum-seekers was the lack of a residence permit. In Turkey, asylum-seekers must register with the DGMM for their residence permit. They encounter registration problems at hospitals during the application process or during the yearly renewal period for their residence permit:

“When we arrived in Eskişehir... they told us that we have to wait for 5-6 months to get the residence permit... We needed to go to hospital twice but in the public hospital they told us that they can't help us unless we have a residence permit.” (ESK 18).

On the other hand, some respondents expressed their problem-free registration experiences when they had the residence permit: *“If the residence permit was valid... I didn't have any problems.”* (ESK 27). Health insurance has an important role in making health expenses affordable and its absence was identified as the second important barrier at the systemic level. However, another issue was raised by some of the respondents who claimed that *“generally, asylum-seekers don't know that they have the right to have health insurance.”* (IST 11). Furthermore, health insurance is valid only in the city where an asylum-seeker is registered and it is not possible to benefit from it in other cities even if there is an emergency situation. One of the respondents stated that she was required to make a payment before any medical treatment, which could be provided in the emergency room of a hospital in Istanbul, because she was registered in another city and therefore could not benefit from her health insurance: *“Once I went to a hospital in Beylikdüzü... they asked me for a payment, then they said that I don't have a health insurance.”* (IST 12). Such problems were observed more frequently in the metropole, revealing a barrier to accessing healthcare services. Another barrier pointed out during the interviews was the differences in the procedures between the hospitals or in the same hospital at different times: *“At the hospital sometimes they ask for the payment at the registration desk.... Every hospital has different procedures.”* (IST 11).

#### *Barriers to access to healthcare on the provider level*

In the interviews, there was a general consensus that language barriers are a fundamental problem for the effective use of the healthcare system. Some participants expressed this in terms of health workers not knowing any foreign languages: *“I had some problems in communication. I do know English but some of the doctors do not know English, therefore we*



*couldn't communicate*" (ESK 1). Language problems prevent health workers from explaining hospital procedures and health professionals from informing the patient about the diagnosis or the therapy: *"I don't know the language... There is no one giving me information in the hospital"* (IST 10). One of the respondents complained about the lack of information regarding the therapy: *"They didn't tell me to drink water while I was having chemotherapy, now I have pain in my kidneys."* (ESK 4).

Another issue stressed by some participants involved the attitudes of health workers. Respondents complained about health workers' medical approach and their lack of attention towards asylum seekers:

"The doctor... doesn't take care of me. In the past six months I visited 4 or 5 doctors for inguinal hernia, doctors tell me that I have to be operated but surgeons do not want to operate. I have the insurance and when I say that I'm a refugee they say that this problem can be healed by itself" (IST 15).

Furthermore, several asylum-seekers stated that the attitude of the administrative staff was sometimes discriminatory: "The medical secretary treated us really bad. She shouted at us because we were talking in Farsi and said that we should speak in Turkish" (ESK 22). A few participants described situations where race may have been a factor: "Once a nurse in Eskişehir State Hospital behaved odd because I was black, I think it is not racism but only ignorance" (ESK 2). As a consequence of these and other experiences, some participants claimed that they fear going to the hospital and this leads to the under-use or non-use of healthcare services by asylum-seekers.

#### *Barriers to access to healthcare on the patient level*

One of the main barriers mentioned by the asylum-seekers in accessing healthcare on the patient level involved communication problems linked to asylum-seekers' inability to speak Turkish: *"At the hospitals the biggest problem is the language problem"* (ESK 26). Firstly, the respondents are unable to make an appointment or a call for an ambulance due to the language barrier: *"I had problems making an appointment on the phone because the appointment phone line is in Turkish"* (IST 14). Secondly, a lack of translators in the health centers also hinders appropriate access to healthcare: *"There were no translators at the hospital. My daughter knows Turkish, she did the translation"* (IST 21). As in the above example, some participants mentioned that they pay professional or have their children or relatives serve as translators: *"I went to the hospital with the translator... I paid 50-70 TL to the translator"* (IST 28). Communication problems cause challenges for both asylum-seekers and health workers resulting in difficulties in understanding each other or explaining themselves.

“There is no one helping because we don’t know the language. I understand them (health workers) too because they can’t understand us. They asked for several MRs but we couldn’t get any results. We couldn’t come to a conclusion” (ESK 17).

Language or communication problems were mentioned by almost all the respondents except for the few who said that their Turkish was good enough to communicate with health workers: *“No communication problem, I used a mix of Turkish, Arabic and English”* (ESK 11). However, even their Turkish skills were sometimes insufficient to understand the explanations because of the medical terminology used by health professionals: *“Even if I’m good in Turkish I’m not able to understand them. Their medical language is not understandable; I don’t know what epilepsy is”* (ESK 6). Another issue raised by the respondents was that *“most of the asylum-seekers here don’t know their rights and the healthcare system in Turkey”* (IST 11). They emphasized that the newcomers do not know where they should go or where to ask for information. Other asylum-seekers noted how helpful the translators had been and appreciated the economic support provided by NGOs or by public institutions: *“HRDF office buys medication for me because we don’t have money”* (ESK 14). The need for economic support was important in both cities but discussed more frequently in the metropole due to tighter constraints on accessing health insurance.

## **DISCUSSION**

In accessing healthcare, the first barrier encountered by asylum-seekers was the registration problem which was mainly caused by lack of a residence permit. According to the Turkish Law, these documents are required at the hospital but it cannot be an obstacle for seeking healthcare. This situation can only be explained by a health worker’s ignorance concerning the right of asylum seekers to healthcare.

Previous research and this study have pointed out the fact that the health workers don’t have adequate information about the asylum-seekers’ right to health, and this is a reason why health workers health rights by health workers (Almeida, Casanova, Caldas, Ayres-de-Campos, & Dias, 2014; Bahadır & Uçku, 2016, p. 56). In order to access to healthcare, the asylum-seekers need to know about their rights to health and healthcare. They also lack the information regarding where they can obtain information. In addition to this, the language barrier prevents them from obtaining the information available, like calling an ambulance or making an appointment. This causes asylum-seekers to become dependent on the social support of family, relatives or NGOs.

Furthermore, it is obvious that there is an urgent need for translators not only in Arabic, as is the case of some hospitals, but also in various languages. In parallel with this, there is a significant need for easily accessible telephone hotline of translators. Language barrier that determines the quality of communication influences the trust in the doctor-patient

relationship (Baker, Hayes, & Fortier, 1998, pp. 1461-1470) and also causes misdiagnosis (IOM, 2013, p. 44). The situation leads to patient dissatisfaction with healthcare services and consequently results in under-use or non-use of healthcare services which was also pointed out in this study (Carrasquillo, Orav, Brennan, & Burstin, 1999). It also suggests that missing the appointments or delaying the diagnosis aggravates the mistrust engendered by language problems.

In conclusion, improving the access to healthcare is necessary to enhance the utilization of healthcare services by asylum-seekers and thus its benefits. It clearly reveals that this can be achieved by creating responsive healthcare services and by arranging them in compatible with the exact needs of minorities and vulnerable populations. On the other hand, training is required for both health workers and administrative people who are indispensable parts of a responsive healthcare system.

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## EMOTIONAL BORDERWORK IN THE NHS

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In this working paper we draw upon work in progress which seeks to explore and theorise *emotional borderwork*. Whilst Isabel's empirical work explored the everyday lives of people seeking asylum in a UK context, here we present empirical data focusing on Jessica's research exploring the experiences of healthcare professionals working within the NHS.

The UK Home Office's hostile environment policy, first announced in 2012 under the Conservative-Liberal Democrat coalition to create a "safer Britain", is a set of administrative and legislative measures designed to make people staying in the UK without leave to remain as uncomfortable as possible. One particularly violent site of the intensification of border enforcement in the UK is the British National Health Service - the NHS. Borders within healthcare prevent people from accessing services through fear of punishment, detainment, deportation and financial hardship. Across successive governments, but escalating over the past decade, changes in law, policy and practice facilitate a policing of the border of the NHS and the identification of individuals not eligible for free care (Potter 2018). The most striking legislative change came in 2017 when the NHS charging regulations stipulated non-urgent care could be denied in lieu of payment (GOV.UK 2017). Such practices not only move the negotiation of who has the right to be here into everyday encounters within the health service, they also present particular ethical and moral dilemmas for healthcare professionals who are forced to perform borderwork.

This paper explores what we call *emotional borderwork*. We define *emotional borderwork* as the emotional labours that people have to perform and navigate as a result of encountering, working or negotiating the border. The aims of this paper are threefold: 1) to explore under what conditions affect and emotions become transformed into a mode of power by states in the context of everyday bordering, 2) to illustrate how states as well as those negotiating state power mobilise emotional tension and distances, and 3) the need to situate resistance and the ways differently positioned actors negotiate *emotional borderwork* beyond existing norms of political practice.

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## METHODOLOGY

Empirical data presented here is drawn from a project exploring how migrants experienced accessing healthcare in the UK when they became unwell with tuberculosis (TB) (Potter 2019). This research was conducted in London between 2014 and 2018 and includes 10 semi-structured interviews with individuals performing gate-keeping roles in the NHS, in addition to 14 in-depth interviews with recent migrants. In addition to these interviews Jessica draws from her own experiences working as a doctor in the NHS and as an advocate and activist campaigning for the healthcare rights of migrants. The borders we are interested in exploring are the everyday constructions of borders, rather than “physical” borders of states that mark territoriality. We share a common understanding with recent work in border studies, geography and the wider social sciences in looking at borders and boundaries as constantly in the process of becoming, reconfiguration, dislocation and reconstitution (Cassidy, Yuval-Davis, and Wemyss 2018). We follow Nira Yuval-Davis, Georgie Wemyss and Kathryn Cassidy in recognising everyday bordering as *situated* and in a constant process of *becoming*. Borderscapes are sites that are represented, perceived and lived-in as a “fluid field of a multitude of political negotiations, claims, and counterclaims” (Rajaram and Grundy-Warr 2011). Depending on the social positioning of the subject, borders are experienced and negotiated differently (Yuval-Davis 2013).

As a large body of scholarship has argued, states mobilise technologies of power and violence to control and punish racialised and colonialised others. We argue that *emotional borderwork* is central to this technology of governmentality (Foucault 2008) which is often not assessed in terms of the feelings and emotional realities it creates. We want to look at borders here as emotional and affective spaces that intentionally produce certain emotions and affects and leave people who are forced to negotiate the border on a daily basis emotionally worn out.

Emotions are political and can be used to sustain certain power structures rather than being individual, subjective responses to external factors (Ahmed 2013; Almeling 2009; Wilkinson 2009). States mobilise politics of fear (Ahmed 2004; Zembylas 2011), anger (Lorde 1981; Zembylas 2007), shame (Ahmed 2004; Munt 2008; Zembylas 2008) and discomfort (Meier, forthcoming) against racialised others to uphold existing power structures. An emerging body of scholars has framed these emotions as a specific technology of governmentality that aims at creating as much discomfort as possible. De Vries and Guild (2019) developed the notion of a “politics of exhaustion” to speak to emotional politics of duration and their consequent accumulated effects over time in the context of today’s migration management. Other scholars have explored the politics of unease (Huysmans and Buonfino 2008) and discomfort (Meier, 2019).

We think of emotions as practices that are productive and, accordingly, can be mobilised in a biopolitical (Foucault 2009), necropolitical (Mbembe 2003) and disciplinary *governing* function. We use the term *affective governmentality* to speak to a diffuse set of strategies and tactics including state regulations through affect and emotion that manage asylum seekers' and healthcare professionals' bodies, time and space. We thus follow other scholars (Ahmed 2013; Hochschild 2012) examining emotions as practices. These scholars have challenged the idea prevalent in much of the traditional emotion literature that feelings are something we possess internally and then express. Rather emotions produce surfaces and the boundaries of bodies (Ahmed, 2013, p. 10). Moreover we wish to echo others scholars' (Ahmed 2004; Brennan 2019; Thien 2005) experience of the impossibility of telling apart affect from emotion and the need for research to try to go beyond the ontological dichotomy between cognition and bodily affects.

James (1992) and Hochschild (2012) originally developed the concept of emotional labour to theorise the unpaid and unrecognised emotional work performed by women in the home and workplace. Healthcare professionals, who are trying to negotiate the border from within the NHS have to manage feelings of distress, worry, sadness and anger. While previous work has pointed at the emotional politics of border(ing)s, here we want to pay particular attention to how emotional tension and distances are mobilised by different actors to negotiate emotional resources.

## **GOVERNING THROUGH EMOTIONAL TENSION**

In this first section we reflect on how states mobilise tension in a healthcare setting that demands *emotional borderwork* to navigate it. My project was not designed to explore the emotional aspects of everyday bordering engendered by current policy and practice in the NHS. Nevertheless, across interviews exploring healthcare access for migrants in the UK, Jessica observed key stakeholders: including an outreach worker; hospital doctors; a general practitioner; a nurse; an overseas visitor manager and policy makers describe feeling *distressed, worried, sad* and *angry* when discussing their interactions with the border regime.

Whether participants explicitly labelled their own feelings or not, the underlying affect appeared to be one of tension. For example, a hospital consultant described being prepared for a "fight" to ensure a patient under their care got the treatment they needed - a hip replacement that would allow them to walk again. The patient was an undocumented migrant and was therefore only eligible for free treatment of their underlying infectious disease but not its sequelae – in this case, destruction of the hip joint:

So I think the nursing staff on the ward are being asked to check where these patients are or where the ward clerks are having to highlight who's on the ward, their nationality, their NHS numbers, blah blah blah and if anything lights up then they have to be called, but in this particular case the hospital worked very well with us to get him resolved and get him some treatment rather than... but I think that relies on being the advocate for your patient, rather than just saying, sure, he's got no recourse to public funds. You have to fight for your patient's best interests, that's our job after all. That's our job. Patients first. (Interview with a tuberculosis consultant, 2017)

Alongside this commitment to advocacy, stakeholders explicitly discussed a need to protect the NHS as a resource-limited asset. Restricting access to healthcare based on citizenship status produces conflict in a number of ways. Firstly, feelings of internal tension are generated by pitting a desire to “save the NHS” against a commitment to deeply held values of universalism and non-discrimination as laid out in the NHS constitution (NHS 2015) and a duty of care to patients (Anon 2013). Even people employed to uphold the border such as overseas visitor managers described wanting to turn a blind eye when individuals they positioned as deserving of care became caught up by the hostile borderscape:

...we had a lady that, unfortunately was a sex worker and she had been abused and, ooh, it was just her injuries that she had – it was like, I am going to close my eyes to this one – I haven't seen you! (Interview with an overseas visitor manager, 2016)

As well as producing internal dissonance, the hostile borderscape positioned staff at odds with each other. An A&E nurse described an incident when:

He [A&E doctor] had seen someone in EA [Emergency Assessment] – I think it was someone who was not accessing their GP struggle for, I think a headache, a chronic headache – so a pretty innocuous, not A&E type thing but they presented at a pretty quiet time um because they were failing to access care anywhere else. And he had gone to see them and was telling me about him, 'Ah you know he came in with like a three-month history of a headache and his GP wasn't seeing him,' and I was like, 'Oh yeah, I mean yeah, it sounds like he's struggling' and then he was like, 'And then I found, and then he said he's an asylum seeker and then I thought well I just can't be bothered then'. And I was like, 'excuse me?' You know, he hadn't even said like, I don't know - anything 'I'm a migrant' or anything, like literally 'I'm an asylum seeker'. And that was enough for this person to say, to disregard any of the legitimacy of his health-seeking desire. And you know I said to him, 'you know there's just a clinic they can go to just down the road for like nothing – even if you don't want to see him you can just refer him to that place.' And he said to me, 'I forgot you were a patient advocate.' And I was like 'yeah' (Interview with an A&E nurse, 2017).

Being sneered at by the doctor for being “a patient advocate” reveals some of the tensions between the different duties, responsibilities and pressures experienced by



healthcare workers. Within challenging working environments, staff are at one and the same time expected to perform the role of border guard (by identifying people ineligible for free care), “make the patient your first concern” and “maintain trust” (Good Medical Practice, 2013). GMC guidelines of good medical practice also require healthcare workers to “establish and maintain partnerships” with colleagues. Different from a moral dilemma, moral distress is the experience of knowing the right course of action to take but being constrained from doing so by particular obstacles (Jameton 1993).

These episodes of tension were shaped by the subjectivities of those involved. For example, when interviewed, an outreach worker described a “very frustrating” situation within which a doctor chose “not to advocate for the patient in any way whatsoever”. Not only did the outreach worker position him as not advocating for his patient but suggested he was “perfectly happy not to advocate”. The outreach worker went on to state, “He’s [the doctor] African by the way, he’s African with a very, very posh English voice. He’s obviously born with a silver spoon and gone to a public school and is very up himself and has zero ability to empathise.” The patient was a national of an East African nation who was not eligible for free NHS care but had cancer and required chemotherapy. The outreach worker even gave a number of specific actions they felt the doctor had the power to take. They expressed clear frustration and disappointment that the doctor in question chose instead to “paste three pages from the charging regulations and sent it to me in an email”.

The guidance on the implementation of the charging regulations stipulates overseas visitor managers are responsible for determining eligibility based on immigration status and clinicians are responsible for determining whether care is deemed immediately necessary, urgent or non-urgent. If considered non-urgent, treatment can be withheld in lieu of payment. In practice the clinicians in this scenario are usually senior doctors (consultants). Andrew Jameton described moral distress as a phenomenon commonly experienced by nurses. This can leave other staff involved in the care of a patient feeling disempowered and distressed when they are denied the opportunity to “do the right thing” by their patients (Jameton, 1993).

## **MOBILISING DISTANCES AND THE POLITICAL POWER OF DETACHMENT**

In this section we explore how distances are mobilised by and against the border and how these distances are shaped by affective modes of governmentality. We conceptualise distance here as an emotional and mental space between two bodies. In the context of healthcare, these distances are organised as a process to manage racialised and colonised others, through different affective technologies that disengage, disconnect and create distances that keeps employees from challenging these violent practices. One of these technologies is bureaucracy. The distancing of the act from the effect for those people

employed within the NHS borderscape (as opposed to those who are the target of it) creates an emotional and mental distance, reducing the stakes and therefore facilitating an acceptance of the status quo and dampening the impulse to resist practices which would otherwise create productive tensions within the actor opening up political possibilities. This resonates with Arendt's work describing bureaucracy as "[contradicting] the essential human condition of plurality, the acting and speaking together, which is the condition of all forms of political organization" (Arendt, Canovan, and Allen 2019:202).

Administration of the NHS charging regulations involves assessing an individual's eligibility for free care followed by a determination of the urgency of that care. The former assessment may be flagged by front-facing clerical or medical staff to the overseas visitor's team who then undertake a more formal appraisal. The latter determination of urgency is made by medical staff, predominantly senior doctors and is important because non-urgent care will not be provided without upfront payment by the patient in accordance with the NHS Charging Regulations of 2017 (Department of Health 2017). For overseas visitor teams, their primary duty of care is to their employer rather than the patient. Conversely, while contractual obligations towards employers exist, clinicians delivering healthcare are first and foremost directed by professional duties of care for their patients and, in the particular case of the NHS, are relatively shielded from the profit motive present in other health systems. This difference is important to note because with increasing conflict between courses of action, greater distances between act and effect may be required to ensure "the moral oddity of one's action will ever be discovered, and once discovered, made into a painful moral dilemma" (Bauman 1991:159).

Practicing medicine on the wards within hospitals Jessica has witnessed the labelling of people who 'may not be ineligible for free NHS care' within their patient notes and thus positioning them as 'preemptive suspects' (Lynn Stephens 2018). Stephens describes preemptive suspects as individuals categorised as 'dangerous and/ or disposable' (ibid, p8). This label is often then copied and pasted to begin each subsequent entry re-inscribing undeservingness at each new clinical encounter. Such labelling may perpetuate inequality and influences health outcomes (Holmes 2013). This particular expression of 'undeservingness' (Willen 2012) associated with labels of ineligibility for free care within the NHS is strengthened by policy and legislation used, as demonstrated by the experience of the outreach worker highlighted in the previous section, to strengthen and distance the refusal of care from the professional responsibility of clinicians to provide it. Speaking at a departmental seminar on the NHS Charging regulations, one clinician in the audience spoke to Jessica about the challenge they faced working within a resource limited setting. Distressed they could not give appropriate treatment to everyone who needed it, and acknowledging they did not agree with rationing based on identity rather than need, they

described turning a blind eye to individuals refused treatment under the remit of the NHS regulations, the policy doing the rationing work for them.

Made aware of the everyday impacts of these policies and practices through both research and activism, Jessica has been acutely affected by the hostile borderscape and feels unable to turn a blind eye. For her, the notion that healthcare may be withheld because of a person's identity is at odds with the NHS values she embodies as someone born within the NHS, cared for by the NHS and employed to work in the NHS. For others, like the OVM she interviewed, this tension was overcome by positioning the work of upholding the border as “all to save the NHS”. However, such positioning ignores the ways in which the hostile borderscape undermines NHS values of universalism and equality - values embodied by staff and that are consequently the backbone or soul of the NHS.

Distress generated by witnessing patients being refused care prompts action. However, attempts at organising resistance against the NHS charging regulations generates fear of punitive legislation such as detailed in the implementation guide of the NHS charging regulations which threatens prosecution for fraud for any attempt to subvert the regulations. In addition, as an employee there is anger towards a seeming indifference of NHS Trusts who use a legal obligation to implement the NHS Charging Regulations to defend their practices and fear that speaking out on this issue might be punished by laws that demand employees not bring their employer into disrepute. Finally, there is worry about what will happen to people when they move into other spaces within the health service, interact with other people who do not share both an unwavering duty of care *and* the knowledge to overcome the border and shame of not doing more.

Next to bureaucracy, neoliberalism positions individuals as responsible for their own health and wellbeing, creating distances through de-politicising and individualising the effects and affects of racism and everyday bordering. The outreach worker Jessica interviewed described the huge “effort” and “emotional commitment” involved in advocating for patients summarising:

I find it depressing, I feel quite burnt out about it. But I don't want to, I'm approaching retirement, I don't want to retire with leaving that situation where we are much less effective than we are able to be. (Interview with an outreach worker, 2017)

Burn out is a phenomenon increasingly witnessed within the NHS. Staff are being asked to do more with fewer resources and this limits their capacity to resist. In addition, there has been an increasing focus on individual responsibility relating to health, obscuring structural causes of health inequities such as institutional racism, migration and poverty. This can be seen, for example, within a media article calling for “feckless patients” to be put to the back of the queue (Fogues, 2018) and in articles demonising so-called health tourists. These

public debates of deservingness play out in the day to day interactions between patients and the health service.

Research conducted by the National Centre for Social Research as part of their survey of British attitudes in 2014 demonstrated that 1 in 3 people admitted to racial prejudice (Kelley, Khan, and Sharrock 2017). In addition the MacPherson Report highlighted the problem of institutional racism within the NHS and the 'Snowy White Peaks' of the NHS highlighted racial discrimination experienced by Black, Asian and Minority Ethnic staff working within the NHS (Kline 2014). That the NHS, the 5th largest employer in the world, should be home to attitudes reflective of broader British society should be of no surprise. Yet, the implementation guide of the NHS charging regulations invokes legal obligations to the Equalities Act, obscuring the grey areas of implementation within which people are racialised as foreign and discriminated against as a consequence.

These examples show how, in the context of multiple asylum precarity, people mobilise distances as a skilful emotion-management. They pay attention to their own well-being and then adjust their involvement accordingly, allowing them emotional sustainability.

## **EMOTIONAL BORDERWORK AND ACTIVISM**

Whilst Isabel's work describes a reclaiming of the right to *not* resist. Healthcare workers are more often situated at an opposing position - for them passivity is the status quo; resistance to policies requiring considered action. For example, for unwell patients requiring admission to hospital, the majority of their care will be deemed urgent or immediately necessary and so clinicians can continue to practice medicine aligned with NHS values without considering the consequence of being charged on the patient in front of them. Bills for care are either presented to patients by overseas visitor managers during a patient's stay or delivered to their home address afterwards. Methods of recovering costs from patients include both the use of debt collecting agencies and repayment plans. These processes and experiences are rarely visible to healthcare workers. When a patient fails to turn up to an appointment or self-discharges from hospital against medical advice it takes investigation such as conducted by the BBC's Victoria Derbyshire show to uncover the hostile borderscape at work.

For individuals working within the health service, motivation to resist these policies is tempered by other concerns as outlined in the previous section. Doing nothing may result in some moral distress on the part of those aware of the consequences of their (in)action but is rarely if ever life-threatening in the way it can be for those who are the target of the hostile borderscape. Jessica may have left work hours late and cried when faced with a patient holding her hands, begging for treatment but in the end she could walk away. When another patient moved off her ward, she decided she did not have the capacity to continue to follow up their case and advocate further. These decisions are illustrative of the ways the affective

border is experienced from a situated perspective and reveal the potential imbalance of power between those who are not directly targeted by the hostile border regime.

## CONCLUSION

Here we have presented a working paper on the *emotional borderwork* engendered by the UK “hostile environment” from the situated perspective of healthcare workers. Through our work we propose that emotions are mobilised as a technique of governmentality in order to uphold a mode of governing which positions migrants’ lives as less valuable than citizens within a global racialised hierarchy of deservingness.

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# **BLOOD MOBILITIES: VITAL MOBILITIES IN THE CLIMATE CRISIS<sup>1</sup>**

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## **BLOOD MOBILITIES**

Blood is on the move. Inside a body, blood enables life; outside a body, it is a product controlled through labs and supply chains. Both bodies and blood products are subject to regulation. By describing the mobilities and immobilities of blood in and beyond the UK, I juxtapose the societal circulation of medical products with that of mobile populations discussed by other contributors to this collection.

Just as practitioners care for increasingly mobile populations, the medical goods upon which healthcare systems rely are enmeshed in global, spatially diffuse, vulnerable networks. Take, for example, blood transfusion in the UK. Blood bags, the pliable containers that hold blood are made in Tunisia, assembled in Poland, then transported to the UK. Filters used for processing donated blood are made in Puerto Rico. In terms of patients, demand for specific blood types is rising as the country's ethnic profile diversifies. Increased international air travel, from migration and tourism, translates to higher risk from non-endemic blood borne diseases, such as Zika and West Nile Virus. Further, global warming contributes to disease migration. West Nile Virus, now endemic in southeastern Europe, seasonally migrates Westward and is included in routine testing of blood donated in the UK (Semenza, Tran, Esinosa, Sudre, Domanovic, & Paz, 2016).

This paper has three parts. First, I describe my research on vital mobilities, that is, the movements of goods, people and information that save lives. Second, I look at the case of severe weather, increasing under the climate crisis, as one type of disruption. I juxtapose three events, local, national and global: roads flooding in northeast England; the flooding of a blood manufacturing centre in southeast England; and the impact of Hurricane Maria on Puerto Rico, a global manufacturer of medical devices and pharmaceuticals. Third, I conclude with a discussion of blood mobilities and mobile populations.

## **VITAL MOBILITIES**

Vital mobilities are movements of goods, people and information that impact life chances. Lack of mobility translates into decreased quality of life and, at an extreme, death. Vital

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mobility constitutes ongoing circuits of care that are required in everyday contexts and can be intensified during crisis. This framing privileges the physical requirements of life, highlighting and blurring perceived boundaries between external supply chains and internal biological functioning. Such mobilities are vital but often taken for granted until they are missing in action and the “infrastructural backstage of ... life becomes startlingly visible” (Graham, 2014, p.471).

Vital mobility is a sister concept of Adey’s emergency mobility (2016). Adey observes that emergencies demand “intensive . . . movement that radically transform one’s life chances and quality of life” (2016, p.32). Healthcare services, both emergency and non-emergency, entail pervasive but often, overlooked mobilities. Vital mobilities can be categorised based on what needs to move: goods (e.g. oxygen tanks, vaccines); people (e.g. chemotherapy patients, home care workers); and information (e.g. patient records, votes). And they can also be categorized in terms of the circumstances that trigger mobility: acute medical conditions (e.g. defibrillators, EpiPens); chronic medical conditions (e.g. insulin, pharmaceuticals); emergency transport of humans (e.g. temporary evacuation, forced migration); human tissues (e.g. blood, organs); humanitarian goods (e.g. shelter, food); social services (e.g. food banks, safe houses); utilities (e.g. electricity, water); and vaccinations (e.g. measles, HPV). Drawing on the metaphor of blood, the successful movement of vital goods, people and information can be termed ‘circulation,’ while blocked or failed movement is ‘coagulation’ (Sodero, 2018).

## **SEVERE WEATHER**

Medical supply chains are geographically expansive and rely on the carbon-intensive transport (e.g. ships, planes) that contributes to climate change. At the same time, health care and emergency services, as national infrastructure systems, are vulnerable to climate change impacts (Iacobucci, 2016). Especially significant are the acquisition of emergency medical supplies during extreme weather events and the impact on essential medical travel (Marsden, Anable, Shires, & Docherty 2016; Pitt, 2007). Severe weather, such as flooding, is one of the many compound challenges facing contemporary health systems. Other challenges include, but are not limited to: bombings (Doughty, Glasgow, & Kristoffersen, 2016), disease outbreak (Law, 2006), Brexit (Hinde, 2019), fuel protests (Law, 2006), malware attacks (Grierson and Gibbs, 2017) and, most recently, the COVID-19 pandemic (Tapper, 2020). In what follows, I focus on three cases of severe weather experienced at local, national and global scales.



### *Case 1: Storm Desmond - Local*

In 2015, northwest England was hit by Storm Desmond, an extratropical cyclone. More than 55,000 households lost power and approximately 50 severe flood warnings, indicating risk to life, were issued (BBC, 2015). In addition, the storm disrupted the blood collection network. In the short-term, flooding prevented the movement of donors and blood workers. Blocked roads meant staff and volunteers could not access blood donor clinics. Temporary disruption shifted into prolonged disruption in the form of road closures, detours and construction that carried on for several months. One established donation centre was permanently closed, requiring the reconfiguration of regional blood collection logistics including volunteers, staff, facilities and transport (MFDW, 2017). Sociologist Satya Savitzky describes the 'scramble' to demobilize and remobilize complex systems following Storm Desmond: "The ways in which shocks 'travel through' arrangements invite a range of questions regarding vulnerability, culpability and preparedness, as well as the boundaries of contemporary disruption processes" (2018, p.663).

### *Case 2: Filton Flood - National*

The Filton Blood Centre is the institutional heart that permits the circulation of blood throughout England. Located in the southwest, the Centre is the largest blood-manufacturing centre in the continent of Europe. Approximately 40 per cent of all the blood donated in England is processed at this 24-hour facility and more than 60 per cent is tested there. In September 2012, after a wet summer, there was a 1-in-30-year precipitation event. The risk of flooding in the area was known, but the Centre was designed to withstand a 1-in-200-year flood. While the facility itself was protected, a culvert on an adjacent property collapsed, resulting in a flood. Water entered the Filton Blood Centre at 8:00am on a Monday morning. Within 20 minutes, the floor was covered in water. Within an hour all communication, data and electrical service was lost. NHS officials ordered an evacuation: 600 staff, 12,000 blood products and equipment.

Evacuation, while the immediate priority, was only the first-wave effect. Receiving facilities not only accepted blood products, but attendant workloads. The labour of testing, manufacturing and stock holding was redistributed, resulting in longer work hours, longer delivery journeys and donated blood being redirected to different sites. After initial flooding, it took 14 days to return to business-as-usual. Externally, disruption was unnoticed as production was maintained and service to hospitals undisrupted. From a business continuity perspective, this is a key marker of success. The aim is not an unrealistic one of entirely avoiding disruption, but rather to manage disruptions so that the users of the system – medical staff, patients, and families – are unaware that contingency plans were enacted.

### *Case 3: Hurricane Maria - Global*

Many medical products are sourced globally in low-wage, low-tax regions with minimal consideration of potential climate impacts. Puerto Rico, a U.S. territory, is also a major manufacturer of medical supplies. More than twenty pharmaceutical companies operate in Puerto Rico, creating more than 1,000 products from scalpels to pacemakers. Located in the Caribbean, Puerto Rico is vulnerable to more frequent and intense hurricanes due to climate change. In 2017, Hurricanes Irma and Maria, both Category 5 storms, hit. Locally, healthcare was severely strained. In the aftermath, power outages caused more than 4,500 deaths as people with chronic conditions could not access care (Sou, 2019). There were also global effects: the storm resulted in uncertainty about the availability of blood transfusion products in the UK; widespread saline solution shortages on mainland U.S.; and antibiotic shortages that drove prices beyond the reach of low resource countries, like Malawi (Street, 2019).

The issues around UK blood transfusion products were resolved with relative ease. I describe the impacts on saline IV solution to illustrate potential UK supply chain impacts. Power outages resulting from the hurricane shut down a major producer of saline IV solution, already in short supply. This is the mundane but vital substance used in IV bags to dilute and transport all other medications into patients' bloodstreams. Lack of production in Puerto Rico translated into shortages on the mainland United States. As a result, numerous adjustments were made on the fly to accommodate the shortage. For example, nurses administered medication directly into patient IV lines, which is comparatively time-consuming and risky (Wong, 2018). Months after the hurricanes hit, regions of Puerto Rico were still without power and mainland U.S. hospitals continued to ration saline solution.

## **DISCUSSION**

Blood is mobile, as are populations. Severe weather disrupts health care delivery: from flooding that impacts local blood donation services, to flooding that triggers the evacuation of a nationally significant blood manufacturing centre, to the impacts of a hurricane on global medical manufacturers. Severe weather also disrupts populations, from temporary evacuations to permanent relocations in different regions. More than 100,000 Puerto Ricans relocated following the hurricanes, creating a 'Maria Generation' (Sutter, 2018). Climate change is a contributing factor to global population displacement, with knock-on effects for health care provision. Addressing the needs of mobile populations and health care providers occurs within the context of parallel mobilities and immobilities, or put otherwise, circulations and coagulations, such as goods and severe weather systems.

Anthropologist Peter Redfield states that the "field of humanitarian concern is clearly focused on the fluid and expansive conception of vital need, spread beyond the citizen to the

figure of the human” (2008, p.163). Geographers Pete Adey and Ben Anderson relate this to decision-making in the space-time of emergency, arguing that such decisions call on “us to ask about the relation with life that is enacted, or promised, as decisions are made and taken” (2011, p.2883). Amid a global climate emergency, this prompt takes on even greater import. Likewise, Adey and Anderson observe that “decisions are almost always taken at the limits, edges, or just inside established, previously exercised, plans or protocols” (2011, p.2895). To this end, I conclude with four questions for reflection:

- How do we deliver health care within a disrupted global climatic ecosystem?
- What does patient-centred care look like in the Anthropocene?
- Can disruption be managed through continual adjustments or is a dramatic rethink needed?
- Are displaced people from countries that manufacture medical goods as readily welcomed as the goods they manufacture?

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## AFTERWARD: THINKING AHEAD IN THE GLOBAL PANDEMIC

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The papers collected in this volume were written just a few months before the beginning of the COVID pandemic. Yet many of the themes outlined by the authors were brought into greater relief as a result of the crisis. In many localities, the pandemic mapped onto and deepened existing health inequalities, it disrupted and arrested migrant trajectories and, perhaps more permanently, significantly reshaped the mobilities and immobilities associated with the delivery of healthcare and the governance of health all over the world. These papers provide a pre-COVID snapshot of national health systems struggling to cope with the mobility of migrant and international populations, as well as widespread efforts to curtail access to health care for these groups by embedding bordering mechanisms and eligibility policies within the very functioning of these systems.

**Stephanie Sodero's** discussion of medical supply chains and their structural vulnerability to environmental crises anticipates key lynchpins in many government's navigation of the current public health emergency. Global supply lines that involved everything from the chemical reagents necessary for producing testing kits to the medical grade cloth required for manufacturing personal protective equipment were severely disrupted (and sometimes redirected entirely), leaving systemic shortfalls with cascading, real-time effects for public health and access to treatment. **Gwyneth Lonergan's** paper describes how the category of temporary migrant became a fertile repository for nationalist discourses and everyday bordering practices but it also foregrounds the central place occupied by the NHS in the British imaginary. This is a prominence that at the height of the pandemic was elevated to the part slogan, part central strategy: "Stay at home. Protect the NHS. Save Lives." And yet the weekly observance of "Clapping for Carers" did little to resolve the inevitable frictions wrought by exclusionary immigration practices on a health service that recruits many of its core health staff from abroad. **Kathryn Cassidy** elaborates on the far-reaching disorders generated alongside the everyday pursuit of an orderly border. This disorder impacts migrant lives, state institutions and the delivery of state services as well as the wider social structure. A dynamic visible at multiple stages and levels of this crisis but perhaps most vividly captured by the experience of UK asylum seekers who were snatched from their flats within hours' notice and shuttered in hotels where the tenuous routines they had developed were abruptly upended and social distancing was impossible.

Similarly, **Jess Potter and Isabel Meier's** discussion of emotional border work and the fraught affective terrain generated by contemporary health policies provides a window

into the pre-COVID state of mind of NHS workers. Potter and Meier's respondents are stressed, anxious and overworked as the political system attempts to refashion them into its soft agents of border control. **Deniz Mardin** and **Nuray Özgülnar's** overview of the barriers to healthcare access asylum seekers face reminds us of the spatial impact of this crisis. Although asylum seekers in Turkey are entitled to healthcare, this can only be accessed in the "satellite" cities where they are supposed to reside and not in the "metropolises" where many relocate seeking job opportunities and steady work. In Turkey, as in much of the rest of the world, the crisis impacted these mobilities, forcing lockdowns, stuttering commutes and greatly complicating healthcare access. **Agnieszka Kosowicz** describes the work of the Polish Migration Forum, an organization which supports migrants, refugees and asylum seekers' access to the Polish health system. Much like the mobile populations described in other papers, these patients who already faced significant challenges accessing health care because of their difficult medical conditions or the cultural complexities associated with pregnancy and maternal care must now negotiate the health system at the sharp edge of COVID risk hierarchies. Finally, **Pawel Lewicki's** depiction of the sometimes counterintuitive interactions between positive HIV status and the varying institutional, clinical and symbolic positions and capacities this opened for his respondents in Berlin's social care systems reminds us that disease vacillates: it can complicate and deepen existing structural hierarchies but it can also sometimes transform them. Indeed, COVID has transformed the lives of the homeless, the HIV positive and addicted as much as it has the status of an expanding list of once humble occupations which are now dubbed "essential" and mark their bearers with a hazardous honorific.

In the swell of COVID's second wave we have been told that compared to the first wave, some things have changed. There are new treatment protocols and therapies for intensive care patients that promise lower mortality rates and shorter hospital stays. There is also an expanding list of vaccine trials underway that world leaders hope will herald a gentler spring. More broadly we are told that we know more about the disease, its circulation patterns and infection vectors. Yet clearly, as of the autumn of 2020, not enough has changed. Many of these promising developments target the disease but fail to capture its multifaceted consequences or the devastating impact of the revolving door of public health measures put in place to arrest its seemingly irrepressible advance. The year 2020 will likely go down in history as a year of lockdown ebbs and flows, a shifting patchwork of restrictions whose impact will continue to play out long beyond the pandemic's peaks.

According to Dr. David Nabarro, the World Health Organization (WHO) Special Envoy on COVID-19, lockdowns should only be considered as a "last resort" in efforts to control the virus (World at One, BBC Radio 4, 13.10.2020) because their unintended consequence is that they push those who are already poor even deeper into poverty.

Indeed, even as office workers and other white-collar professionals adapt to working from home and their industries embrace networked technology as ushering in a new virtual workplace, the local economic ecosystems set up to support now empty office buildings and industrial parks collapse. Those precariously employed in a faltering service economy face the greatest uncertainty and the gravest economic danger. Where this structural precarity intersects with a lack of secure legal status and racial discrimination, the damaging effects are compounded.

Not all forms of movement are equal and neither are all forms of stasis. Arresting the everyday mobility of the service economy has a very different effect for those who depend on it than halting the train network or air travel, and hence impacting a trader's train commute or an executive's business travel. 'Circuit breakers' and lockdowns at local and regional levels are mirrored by nationalist re-entrenchments and a hard tightening of borders throughout the world. Under these conditions, those that are economically deprived and devoid of legal status end up being doubly marginalized.

This requires new research on the scalar and multi-dimensional effects of COVID (im)mobilities and how this crisis feeds into, exacerbates and widens existing forms of structural inequality, while at the same time producing novel categories of exclusion and hierarchies of less-eligibility—that is, eligibility that theoretically exists but is invalidated by barriers to access so significant as to render it meaningless. The **Doctors within Borders** project's original purpose was to establish a research network that could bring together experts in health and migration, non-governmental organizations, the NHS and health professionals across Europe who deliver care to individuals and groups that lack a settled status, permanent address or are otherwise classed as 'on the move'. We find a renewed sense of urgency in addressing how these ongoing concerns are transformed in the context of the present crisis and continue to welcome collaboration and engagement with researchers, activists and medical practitioners involved in work relating to these broad aims.