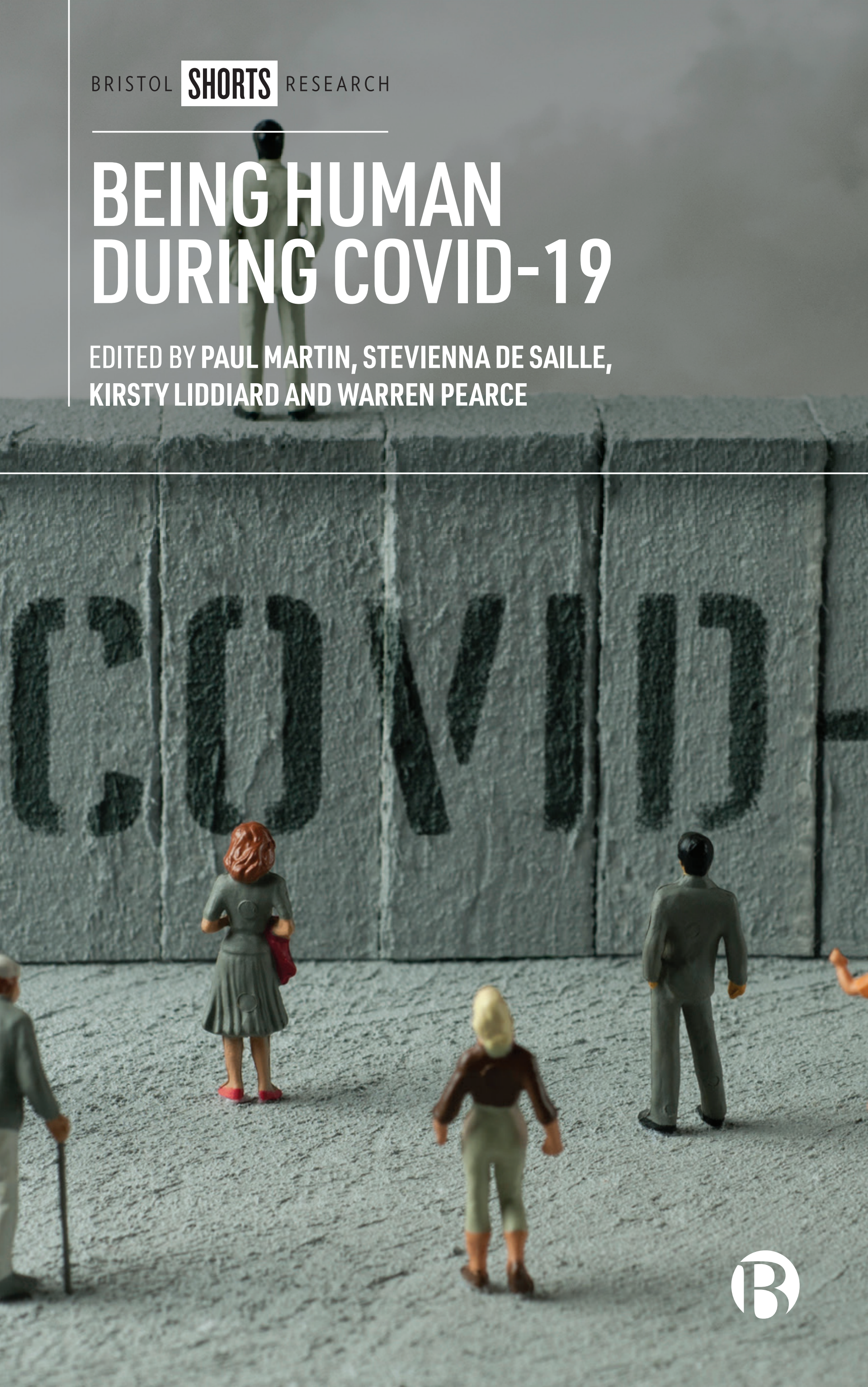
BRISTOL **SHORTS** RESEARCH

# BEING HUMAN DURING COVID-19

EDITED BY **PAUL MARTIN, STEVIENNA DE SAILLE, KIRSTY LIDDIARD AND WARREN PEARCE**



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## TWELVE

# “I’ve Got People’s Spit All over Me!”: Reflections on the Future of Life-Saving Stem Cell Donor Recruitment

### Ros Williams

## Introduction

Like other kinds of tissue donation, stem cell donation systems rely on framing humans as reciprocal, prosocial agents engaging in the communitarian, altruistic act of donation. COVID-19 highlights how, particularly in racially minoritized communities, interpersonal contact in trusted encounters and spaces is a key part of the normative work of encouraging stem cell donation. Thinking through this as an example of how we as humans often need to be co-present to generate affective ties, build new communities and counter forms of inequity and mistrust, this chapter offers an illustration of how the pandemic disrupted this key aspect of being human.

Stem cell donor registries – used to source donor stem cells for treating blood cancers – are currently insufficiently ethnically diverse, meaning that racially minoritized patients in the UK have poorer odds of locating a suitable donor. New donors are registered at in-person events organized to target potential racially minoritized donors. Registrants provide saliva to be tissue typed and placed on the registry. This saliva, full of biotechnological potential, is now also a recognized vector for COVID-19 transmission. As the world reopens, it is hard to imagine that these busy events where saliva-saturated swabs swap hands will restart with the same enthusiasm.

This chapter explores the value of these in-person events in generating registrations amongst racially minoritized people who, importantly, are recruited with *less* success through the digital routes that recruitment work is reliant upon during pandemic restrictions. First briefly contextualizing stem cell transplantation and its attendant racial disparities in access in the UK, the chapter then describes the saliva-orientated work of recruitment. It then reflects on the potential consequences of its cessation.

## Stem cell transplantation and racial inequity

Since the 1970s, stem cell transplants have emerged as a well-established and increasingly common treatment (see Passweg et al, 2018). If a patient cannot find a matching donor in their family, their clinician can call upon a global network of registries connecting databases of volunteers to locate donors for their patients. These donors will have initially provided their tissue type via saliva, possibly at a recruitment drive, from which they were logged on a stem cell registry awaiting the rare occasion that they – out of nearly 40 million world-wide donors – might be a patient's genetic match.

Crucially, transplants rely on this genetic match between donor and recipient, and it is understood that unrelated patients and donors are more likely to be a match if they share a similar ethnic background (see Williams, 2018). Given the overrepresentation of white donors on Global North registries, there is therefore a significant health equity issue at play: in the UK, minoritized patients have as little as a 20% chance of finding matches, as opposed to white patients' 69% chance (Smith, 2018).

Such statistics have prompted the emergence of charities seeking to improve registry diversity by running registration drives in places selected based on the chances of having lots of racially minoritized people in attendance. Places of worship, colleges, summer melas and carnivals are just some of the places where such drives might be held (see Williams, 2021). These charities are described as 'crucial' by the registries that provide them with swab kits, and are acknowledged in policy for their central role in improving racially equitable access over recent years (Smith, 2018). They are thus a vital component of the blood stem cell infrastructure, adding thousands of racially minoritized donors to the UK registry each year through in-person recruitment work. When COVID-19 arrived, however, this work stopped.

## Event cancelled: the necessary cessation of recruitment work

Altogether, the process of stem cell registration takes three minutes and three saliva swabs. A form collects donor information before the donor rubs three swabs against their inner cheek. These swabs, once saturated with saliva, are collected, sent to a laboratory for tissue typing, and entered onto the globally searchable donor registry. The process, admittedly, can be messy. Take, for example, a Race Against Blood Cancer (RABC) event in the West Midlands, where the charity had been invited to have a stall at a conference in a large exhibition centre. Charity volunteers register 93 new donors, of whom perhaps ten have a minority ethnicity background, a proportion with which the volunteers are very pleased. During a quiet moment, I take this fieldnote of an observation of a charity volunteer:

> '[she] scrunches her face … like there's a foul smell in the air. She lifts her hands up and, inspecting them, holds them out in front of her like a surgeon avoiding any contact in the moments between scrubbing and gloving: "I'm going to the bathroom to wash my hands. I've definitely got people's spit all over them". She shimmies out from behind the registration desk and dashes off to the bathroom.'

Saliva is a loaded substance (Kragh-Furbo and Tutton, 2017): its attachment with disease transmission has more recently been met with acknowledgement of its biotechnological promise as a non-invasive means of testing for viral particles (for example, a COVID-19 test) or even collecting DNA (for example, ancestry testing). It is how a charity volunteer can be at once disgusted she's got spit on her hands, and thrilled she's managed to collect so many swabs of it. Saliva's loadedness – its capacity to be easily retrieved and then typed in a laboratory – brought us to the exhibition centre, but it was also what would abruptly stop face-to-face donor recruitment work, since respiratory saliva droplets were identified as the primary COVID-19 transmission vector. The same events that stood to save lives through recruiting to registries were also prime opportunities for the spread of disease.

## Goodbye, buy-in? The importance of in-person recruitment work

Registries in the UK have for several years invited people to order their own postal swab kits for at-home registration. One needn't go to an event to be swabbed, therefore, but can order a free kit, post their sample, and be registered from home. UK registry Anthony Nolan, however, note that online recruitment is less effective for ethnic minority registration: 'We know that there are limited options for targeting this group online, and have struggled to reach our target for BAME recruitment, so work has begun on partnering offline with organisations, schools and colleges in diverse areas' (Anthony Nolan, 2019: 14), gesturing to the sense that – particularly for some racially minoritized people – there is value in physical co-presence when trying to engage people in donation.

Nonetheless, just as COVID-19 resigned many to homeworking facilitated purely by digital platforms, recruitment work moved online too. The African Caribbean Leukaemia Trust (ACLT) hosted social media interviews with Black celebrities, from Paralympian Ade Adepitan to entertainer Alesha Dixon, where charity organizers interviewed them about their lives, interspersing this with why and how audiences (hopefully predominantly Black) might register from their own homes. Charities so adept at face-to-face work had instead to encourage people to order swabs in their own time and join the registry from home, a process noted to be less effective for recruiting minorities.

Charities like ACLT and RABC are seen in policy as key conduits between registries and racially minoritized communities, able to generate trust because of their distance from statutory actors, and to make the recruitment message more legible to racially minoritized audiences by adopting a particular mode of communication (see Williams, 2021). This work can be challenging, with those undertaking it acknowledging that there is good reason why some racially minoritized people may say 'no' to requests to participate. For example, the following fieldnote captures a fragment of my conversation with a recruitment coordinator at RABC. He describes how growing up as a Black male in London, surrounded by Black friends, he encountered a reaction that is also common amongst the racially minoritized people he approaches to recruit:

> ' "People take your stuff. The government takes this, the government takes that. It's distrust. What will they do with my DNA? With my details?" I asked if this reaction didn't make some sense, given the context in which those opinions will have been formed. "100% I get it, There's no part of me that doesn't get it".'

The same coordinator thus regularly goes back to the same places, both recruiting new donors, and developing relationships with local contacts, to gradually persuade those who are less inclined to register because of the 'distrust' they may have, particularly of statutory systems. Vitally, though, this work is done in-person. In an interview with an ACLT leader, I ask him about the effects of all the cancelled events because of COVID:

> ‘The amount of stem cell donors that we’ve recruited … will be minuscule in comparison to what we would normally be doing in terms of hundreds, if not thousands … when you’re in physical face-to-face, there is a much stronger buy-in because they’re feeding off your body language, your terminology, your presence and you’re there afterwards for reassurance if they want to maybe talk to you or the team. So there is a strong buy-in at the time, you’ve got them hooked … emotionally, physically, so you’ve got a stronger chance of them saying, “yes, I’m going to do this now, this is my moment”, rather than going away and thinking about it. Online, yes, you lose that first-hand connection.’

In-person events, as I’ve argued elsewhere, rely on physical proximity to develop a personal connection between charity workers and would-be registrants that mobilizes an *ethico-racial imperative*, a sense of donation as a morally good course of action within a racialized community (Williams, 2021). But events are also, as the extracts gesture towards, spaces where highly embodied reassurance work is undertaken. Body language, presence and talk combine as volunteers attempt to foster sufficient will in potential donors, perhaps to overcome a concern about where their data will travel, to register. You “lose that first-hand connection”, as the interviewee describes it, with online recruitment work.

## Conclusion

Alongside other face-to-face interaction, an important but underacknowledged kind of work – the in-person donor recruitment drive – was also lost to COVID-19. These events serve a crucial purpose, bridging many racially minoritized donors with a system that, in its current state, isn't offering sufficient provision for racially minoritized patients. The evident value of in-person recruitment, particularly for bolstering some donors' trust in the recruitment process, cannot be disregarded. Though we cannot know, future patients, who might have otherwise benefited from stem cell transplants from donors that did *not* join the registry during the pandemic, might now not receive their life-extending transplants. It is something of a cruel calculus that the very actions designed to save lives – lockdowns and restrictions on movement – stymie work that has its own life-saving potential.

More broadly, though, events like these, which rely on being physically together, highlight how we as humans often rely on co-presence to build community and affective connection. Such conditions are, as we see in the example of donor recruitment, also central to redressing inequity. We might exercise some caution, then, at the suggestion that things may simply 'move online', for a key part of being human risks being lost.

## Acknowledgements

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> **“There has never been a more important time to think about questions of what it means to be human. This book is a challenging read, inviting readers to consider the breadth of people’s experiences during COVID-19, and is thought-provoking for post-pandemic times.”**
>
> Jenny Fisher, Manchester Metropolitan University

Cutting across disciplines from science and technology studies to the arts and humanities, this thought-provoking collection engages with key issues of social exclusion, inequality, power and knowledge in the context of COVID-19.

The authors use the crisis as a lens to explore the contours of contemporary societies and lay bare the ways in which orthodox conceptions of the human condition can benefit a privileged few.

Highlighting the lived experiences of marginalized groups from around the world, this is a boundary-spanning critical intervention to ongoing debates about the pandemic. It presents new ways of thinking in public policy, culture and the economy, and points the way forward to a more equitable and inclusive human future.

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