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## If not now, when? COVID-19, lived experience, and a moment for real change



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In a Position Paper published in *The Lancet Psychiatry*, Carmen Moreno and colleagues<sup>1</sup> recommended bolder language and framing with respect to the meaningful involvement of service users in mental health planning, policy, and research in the wake of COVID-19. It is always gratifying to hear enthusiasm for goals the user and survivor research movement has long fought for. We were similarly gratified to read an Editorial in *The Lancet Psychiatry* arguing for pressure from service users to more actively shift societal discourse.<sup>2</sup> And yet, as welcome as these statements are, we worry that the primary problem we are all up against is not a paucity of articulated support for service-user involvement but rather the gap between rhetoric and reality.

Our collective experience suggests that both before, and now many months into, the COVID-19 pandemic, meaningful service-user involvement remains unevenly implemented in some places, and non-existent in others. In some regions, involvement could be reduced from pre-COVID-19 levels, whereas in others, attestations to the importance of inclusion might have long been unaccompanied by concrete action. The same sentiment—anger and frustration about decades of inaction—has also been at the forefront of the Extinction Rebellion, March for our Lives, and Black Lives Matter movements. At a specific point, one feels the need to say “enough talk”. And if there was ever a moment when we, as a field, might take deeper stock of where we really want to head, it is arguably now. Involvement efforts are too often accompanied by empty promises, insufficient funding or commitment, and superficial gestures (eg, membership on advisory

boards), with no real power to set agendas, influence decision making, or bring about structural change.<sup>3–5</sup>

Concretely then, what actions might be taken at this pivotal cultural moment? As activists across multiple under-represented social groups have long argued, leadership roles and power over decision making are fundamental.<sup>4,5</sup> From a systems perspective, this situation means addressing barriers specific to both academic training and advancement and research funding. Beginning with addressing barriers in academia, explicit proactive support for students and investigators with lived experience must be provided across the training pipeline, from undergraduate studies through to independence as mid-career investigators. Ideally, such support would be pursued with the primary goal of supporting junior scholars to ultimately obtain their own grants as primary investigators, particularly in fields in which extramural funding is *sine qua non* for promotion and advancement.<sup>6,7</sup> In supporting such trajectories, senior researchers must take care to ensure that service-user trainees and researchers, when included in studies and grants, are not there primarily to check a box or shore-up involvement plans, but to substantively shape research activities and, above all, advance their own careers and research agendas. Attention to diversity within this pipeline is also important, certainly of race, ethnicity, gender, sexual orientation, and class, but also with respect to level of disability and intersectional experiences of homelessness, incarceration, discrimination, addiction, and poverty.<sup>8</sup>

Research funders, in turn, must implement safeguards against discrimination, communicate and enforce robust

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expectations for service-user involvement and leadership in research proposals, and ensure that established bodies of research do not become barriers to authentic community-led innovation.<sup>4,9</sup> Too often, funding processes re-inscribe existing hierarchies and established interventions by rewarding proposals that build on, and hew to, existing published work. High-risk high-reward funding streams are typically present in the basic and translational sciences or new research areas such as digital health, with such language rarely used to refer to or fund user-led innovations. To achieve deeper change, funders must be open to new ideas and new directions, guided by those on the receiving end of services.

Is the above pipeline merely a pipe dream? Our belief is that senior researchers, large research centres, and training programmes could readily take the steps described above, including substantially greater hiring, mentoring, and support of under-represented students and researchers with lived experience. Were it a priority, research funding bodies could—with relatively minor modifications to programme announcements—directly support meaningful involvement and leadership.

Failure to do the above is neither a fault of structures over which the field has no control nor stigma among some other group, but it is an individual choice on the part of those in positions of power to remain stagnant

and perpetuate processes and lines of research that marginalise the experiences and knowledge of the very populations this research aims to serve. Rather than bold language, we call for bold action.

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## Mixed signals about the mental health of the NHS workforce

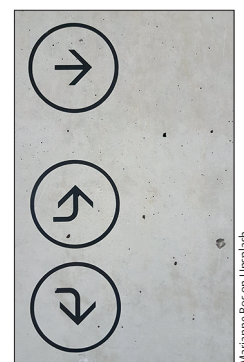


In the past few months, media headlines regarding the mental health of the UK National Health Service (NHS) workforce during the COVID-19 pandemic have reported or predicted large-scale problems ahead—eg, “Coronavirus is whipping up a mental health storm for NHS workers”, and forecasting a “tsunami” of mental health problems having “catastrophic consequences”. A 2020 systematic review of the mental health of health-care workers during previous pandemics also suggests an increase in distress and post-traumatic stress.<sup>1</sup>

Anyone working in the health service at present has likely noticed another tsunami—a proliferation of surveys on health-care workers. If the generated evidence led to improved conditions and support for staff, multiple studies might be acceptable; however, concerns about the quality of some of these surveys mean that survey fatigue seems a more likely outcome.

Many studies lack explicit sample frames and appear to have very low response rates, making the representativeness of their results questionable—eg, a survey of health-care workers done in May, 2020, had a response rate of around 0.06% (868 responses from approximately 1.5 million NHS staff). Many surveys are cross-sectional, which, while potentially useful as snapshots, offer little to identify which factors might be predictive of mental health problems, and hence few possible foci for interventions. Also, we must remember that mental health questionnaires are not diagnostic. They overestimate rates of disorders when compared with gold standard structured psychiatric interviews, especially when completed by non-representative participants recruited through convenience sampling.

Studying health-care workers in isolation prevents us from understanding whether the effect of the pandemic



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