

FORSAKEN BUT ENGAGED

An inquiry into the psychological aspects of COVID-19, mental health, and political engagement of immunocompromised people

December 2023



All-Party Parliamentary Group
on **Vulnerable Groups**
to Pandemics



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Foreword

All Party Parliamentary Group for Vulnerable Groups to Pandemics Co-Chairs

From the start of the COVID-19 Pandemic in 2020 it became clear that a large cohort of people with underlying conditions were more susceptible to the illness and more at risk of severe consequences. There were some whose cancer treatments or other procedures were immediately curtailed in order not to compromise further their immune systems.

The APPG Vulnerable Groups to Pandemics was set up to press the Government to represent this group and uncover the extent to which it has been overlooked and marginalised. In the early stages it looked at the deficiencies in research, policy and how patients were being treated and how the risk to the vulnerable was being managed.

The lack of effective policy and delivery to support the extremely vulnerable was starkly illustrated in the provision of the vaccination programme and in the treatments for the changing variants of COVID-19. Whilst the vaccine mitigated this for many people, there remained a large group who failed to make antibodies despite numerous courses of vaccine, and they were in a group with compromised immunity due to blood cancers, organ transplant or organ disease and other conditions like MS. The Government's own figures suggest there are 1.2 million people in this category now facing a fourth year of shielding or restricted living due to fear of catching this virus, having no protection and becoming severely ill, or even dying. The rest of the world has moved on, but they cannot.

Despite issues getting access to new preventative treatments, and to antiviral medicines that mitigate the effects of COVID-19 if caught, not all the effects are physical.

This research, based on a survey launched in July 2023, documents the psychological impact for this group and its effects on their political behaviour. The objective is to show the Government and policymakers how pandemics can impact society, in addition to illness, and to press for action.

We hope that the recommendations set out in this report will shape the thinking for future pandemic planning but also ensure that current needs highlighted are firmly on the political agenda.



Bob Blackman MP



Lord Mendelsohn

Co-Chairs

All-Party Parliamentary Group on Vulnerable Groups to Pandemics

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.

Foreword

A Patients Story

“We entered into lockdown in March 2020 (as did the whole of society) safe in the knowledge that due to my wife, Mandy, having blood cancer we were being supported by the ‘shielding’ policy and had the option of various people dropping shopping off, picking up meds, etc. I was signed off at this point with mental health problems but it gave me the opportunity to care for Mandy and our youngest daughter Mollie who has cerebral palsy.

As the year went on I was furloughed which again helped with caring but it seemed the support that came with shielding was slowly and surely being withdrawn until the whole need for shielding according to the Government wasn’t needed. With this came the end of furlough so I started working from home until my employer said I couldn’t do it anymore. I was given the choice of returning to work (I worked in care) or losing my job. I could not risk returning due to Mandy being severely immunosuppressed from the treatment for her blood cancer. So unemployment it was and going through the mire of claiming Universal Credit which just compounded all our mental health. Financially it has been hell.

We are still shielding now leading not even a half-life, missing out on family gatherings, birthdays, or funerals, all due to the government saying ‘learn to live with COVID’. How can we when Mandy’s consultant said she would not fair well if she were to catch it? So we resign ourselves to living hidden away and forgotten by society all due to the Government’s policy to get the economy back up and running, which we appreciate needed to happen but what happened to protecting the vulnerable? That, like us, has been forgotten which is mad as we could still contribute to the world if only there was legislation and protection in place rather than leaving us on a scrapheap.”

Rob Boxall

Shielding patient family member



Executive Summary

Over 1.2 million people who are immunocompromised continue to shield in their homes in order to protect themselves from the COVID-19 virus. Over the last four years since the virus began to proliferate, those shielding have been profoundly affected by the threat of the pandemic and being confined to their homes. This includes impact on access to healthcare, social isolation, financial impact and mental health impact to name a few. The resulting psychological distress has been well documented.

The APPG on Vulnerable Groups to Pandemics has previously published evidence of multiple and significant failures by Government in its handling of the pandemic for this group of families. However more and newly updated knowledge is needed to understand political orientations, democratic legitimacy, and political participation among immunocompromised people. Political engagement is core to democracy, and it is vital that all are engaged in decision making processes; political engagement is key to preference formation, articulation and aggregation of views. To do this, people need to feel represented by their government.

Based on these premises, this survey aimed investigate how continuing vulnerability to COVID-19 affects mental health and political engagement to gain a better understanding of how the ongoing implications of COVID-19 compare with those of the general population.

A national survey was launched in July 2023 aimed at collecting information on the lived experiences of the 1.2 million immunocompromised people and their families who are still shielding or living restricted lives due to COVID-19, comparing their experiences with the general population. Over 800 people, currently still shielding, responded to the questionnaire.

This report provides a direct comparison between the general public and immunocompromised people on crucial psychological factors related to COVID-19, on mental health and wellbeing, and on a wide range of aspects of political engagement.

In summary, findings reflected that in comparison to the general public, those who participated experienced higher levels of worry due to COVID-19, poorer mental health, lower perceptions of representation, lower trust in government, and poorer satisfaction in democracy and in terms of how the government has handled the pandemic. Participants also reported several key areas they found most difficult about shielding during the pandemic, with 'feelings of loneliness' reported most commonly.

The objective of this latest research is to provide data which will raise awareness and form a foundation from which to develop policy interventions to improve the care and provision received by immunocompromised people, and also to provide evidence-recommendations and call to action.

Background to the Report

During COVID-19 pandemic the UK government identified those who were 'clinically extremely vulnerable' and advised them to shield themselves from exposure to the virus. This included individuals with chronic respiratory diseases, those on immunosuppressive medication, and those above 70. These individuals were encouraged to work from home, avoid contact with others, and ask others to do their shopping when possible. Four years on since the initial identification of the COVID-19 virus, and over 1.2 million immunocompromised people have been identified as still at high risk. This covers a wide spectrum of conditions and illnesses and across all ages. Due to their conditions and medications rendering the COVID-19 vaccines for many in this group ineffective, many are still either shielding or living restricted lives, which limits their social and economic lives, for both them and their families who are trapped with them in this enforced isolation. The national patient advocacy group Forgotten Lives UK has worked to raise awareness of the position such people find themselves in and to try and ensure that protective drugs and mitigations are in place quickly and widely and freely available to all.

Questions were raised regarding the government guidance and scientific advice was adequately available and tailored for those who were clinically vulnerable and shielding. It is vital that lessons are learned from this. Psychological distress during the active phases on the pandemic were highly elevated ^(1,2). The clinically vulnerable were, and continue to be, at serious risk. However, government communications have been primarily directed towards the general public rather than the vulnerable. During this time, questions were raised regarding the government guidance and whether scientific advice was adequately available and tailored for those who were clinically vulnerable and shielding. There were reports that those who were shielding felt unrepresented in communications from the government. Psychological distress during the active phases of the pandemic were highly elevated, particularly in relation to health ^(1,2). Individuals who were and continue to shield are significantly more likely to display clinical levels of anxiety and health anxiety compared to the general population during the pandemic, with research finding that the longer someone was shielding the more distressed they were; levels of generalised and health anxiety in the shielding population to increase with length of time spent shielding. The clinically vulnerable were, and still continue to be, at serious risk from COVID-19. However, government communications have been primarily directed towards the general public rather than the vulnerable. It is vital that lessons are learned from this, however there is still work to do as people continue to shield, as their mental health risks deterioration.

Mental health and political engagement are important aspects of wellbeing that have also been affected by the COVID-19 pandemic ⁽³⁾. Initial survey research among the British public – funded by the British Academy and product of a collaboration between the Department of Politics at the University of Liverpool and the Stanford Neurodevelopment, Affect, and Psychopathology Laboratory – has found that higher worries about life changes due to COVID-19 are associated with higher psychological distress (symptoms of depression, anxiety and stress), but also with lower perceptions of government performance on the pandemic and lower perceived responsiveness of the political system ⁽⁴⁾. Political engagement is core to democracy, and it is vital that all are engaged in decision making processes; political engagement is key to preference formation, articulation and aggregation of views. To do this, people need to feel represented by their government.

Building on this evidence, a policy briefing resulting from a collaboration between the Department of Politics at the University of Liverpool and the Centre for Well-being, Inclusion, Sustainability and Equality of Opportunity (WISE) at the Organisation for Economic Co-operation and Development (OECD) has further investigated what psychological aspects of COVID-19 have particularly affected

the British public's mental health and political engagement ⁽³⁾. First, immediate health worries about infection and illness due to COVID-19 led to increased symptoms of depression, anxiety and stress, and to people believing they are less able to understand and participate in politics. Second, financial worries related to COVID-19 led to increased symptoms of stress, and dissatisfaction with the government and with the economy. Third, being worried about the long-term societal impact of the pandemic lowered feelings of representation, satisfaction with the government on COVID-19 and with the economic situation of the country, and the likelihood of voting.

Although the APPG on Vulnerable Groups to Pandemics has previously published evidence of multiple and significant failures by Government in its handling of the pandemic for this group of families (see the @APPG_VGP Twitter account), more knowledge is needed to understand core political orientations, democratic legitimacy, and political participation among immunocompromised people. Based on these premises, this report provides a direct comparison between the general public and immunocompromised people on crucial psychological factors related to COVID-19, on mental health and wellbeing, and on a wide range of aspects of political engagement.

The objective of this latest research is to provide data which will raise awareness and form a foundation from which to develop policy interventions to improve the care and provision received by immunocompromised people, and also to provide evidence-recommendations and call to action.

Methodology

A national survey was launched in July 2023 aimed at collecting information on the lived experiences of the 1.2 million immunocompromised people and their families who are still shielding or living restricted lives due to COVID-19, comparing their experiences with the general population. In the first instance, 808 people, currently still shielding, responded to the questionnaire, but only 58% completed the survey. The link to the survey was made available on the website of Forgotten Lives UK and advertised on the association's Facebook page and Twitter account. Multiple reminders were sent on both Facebook and Twitter (fieldwork: 17 July – 4 September). To compare the immunocompromised population with the general population, a survey with the general public (N=1712) and funded by Research England was conducted in June 2023 and administered by the polling company YouGov (fieldwork: 8 – 25 June). The sample was recruited from an online panel using active sampling based on quotas relating to age, gender, social grade, education, region, political attention and the 2016 EU Referendum and 2019 General Election votes.

This report summarises the key findings and themes from this study. A further detailed scientific report will be available in early 2024.

Key findings

Overall, findings reflected that in comparison to the general public, those who were surveyed experienced higher levels of worry, poorer mental health, lower trust in the government, and poorer satisfaction in terms of how the government has handled the pandemic. Participants also reported several key areas they found most difficult about shielding during the pandemic, with 'feelings of loneliness' reported most commonly.

Psychological distress due to the pandemic and mental health

Compared to the general population, immunocompromised people report...

- higher levels of worry due to COVID-19
- lower levels of mental health and wellbeing
- higher rates of diagnosis of mental health conditions
- higher rates of diagnosis of mental health conditions during the COVID-19 pandemic

Political attitudes

Compared to the general population, immunocompromised people report...

- higher levels of attention to politics
- higher levels of understanding politics (internal political efficacy)
- lower levels of perceived responsiveness of the political system (external political efficacy)
- lower trust in government
- lower satisfaction with the economy
- lower satisfaction with democracy in the UK
- lower satisfaction with the way the UK government handled the pandemic

Political participation

Compared to the general population, immunocompromised people report...

- higher likelihood to vote in a national election
- higher levels of political participation in those forms that fit in with their health restrictions and can be undertaken at home (contacting politicians, signing petition, posting or sharing anything about politics online)

What has been the worst aspect of shielding for you?

In addition to the quantitative data, a total of 466 participants responded to a free text question on the questionnaire, asking 'what has been the worst aspect of shielding for you.' Preliminary analysis has indicated eight key themes in the responses:

- 1) Missing medical appointments
- 2) Feelings of loneliness
- 3) The financial and employment impact
- 4) The effects on mental health

- 5) Impact on family and relationships
- 6) Frustration with others behaviours
- 7) Government and societal neglect
- 8) The feeling of fear

'Feelings of loneliness' was the most frequently mentioned theme (149 statements, 32%), followed by 'mental health impact' (79 statements, 17%) and 'impact on family and relationships' (74 statements, 16%).

Key recommendations

1. This data should be used to inform specific action in order to support and protect those currently shielding, and those that may need to shield from an infectious virus outbreak in the future. It highlights to Government and policymaker's specific areas where action and commitment are required to support and protect the vulnerable.
2. The Government and DHSC need to formally recognition and respond to the psychological impact of shielding during the pandemic, including the ongoing psychological needs of those who are shielding. Ring-fenced funding should be provided to NHS trust with accompanying mandatory guidance around the provision of psychological care for those who are shielding themselves or others. This would take the form of evidence-based psychological support in an accessible and inclusive format.
3. Whilst the official opposition party has appointed a shadow minister with specific responsibility for the immunocompromised, the Government party has not designated responsibility for the immunocompromised to a minister. This role would aid the development of a long-term strategy to recognise and support the physical and mental health needs of those who are clinically extremely vulnerable. This would include a communication strategy that would ensure that those who are shielding would receive clear and consistent information regarding the COVID-19 pandemic or other infectious disease outbreaks, and clearly outline the responsibilities the minister holds in protecting the clinically extremely vulnerable, with a mandate to establish fast paced access to protective medicines to lift as many out of this position as soon as possible.
4. Government and health bodies that advise must increase preventative and early pharmacological interventions for those who are clinically extremely vulnerable. The implementation of changes to current regulatory assessment systems and implementation procedures to ensure any new COVID-19 drugs are made available as a priority and rolled out fast pace across all cohorts to ensure that the unmet need of immunocompromised patients is met at speed. Delay and uncertainty only compounds insecurity and is further detrimental to the mental health of and wellbeing of all those affected.
5. Policy must recognise the importance of the use of behavioural interventions to prevent transmission of COVID-19. Social distancing, masks, distancing and air purification systems are vital in reducing the spread of the virus and are likely to be useful in future outbreaks. We call for policymakers to make clear mandatory strategies which can be rolled out and adapted to healthcare and workplace settings. Mandating masks must be recognised as one of the single most important actions to protect those who are at most risk of the impact of infectious diseases in places where they are at heightened risk such as healthcare settings.
6. COVID-19 testing for the clinically extremely vulnerable must be maintained with inclusive access to and the provision of better monitoring data of the incidence of COVID-19 freely published to allow better monitoring and risk assessment. This data underpins all policy decisions that support this group and without it Government is unable to make accurate assessment.
7. Government and all relevant departments must work to ensure meaningful patient engagement is put in place to ensure that the experience and needs of patients are fully incorporated in any new policies or systems implemented.

8. Government action is needed to ensure the immunocompromised have mitigations and reasonable adjustments put in place to allow safe in-person voting. They should be able to exercise the right to vote, without being turned away due to mask wearing and be assured of safe participation in those political activities that require in-person and physical effort including working for political parties and other organisations, working for election campaigns, taking part in lawful demonstrations.
9. Government and all political parties must act in order to increase feelings of representation, political trust and democratic attitudes among immunocompromised people, including. This would include developing specific policies, improving communication with patients and their healthcare providers, and ensuring all processes pertaining to those who are shielding are expedited and delivered as efficiently and as quickly as possible.

COVID-19 worries

Figure 1: Compared to the general population, immunocompromised people report higher levels of worry due to COVID-19 about their own health (92% against 28%)

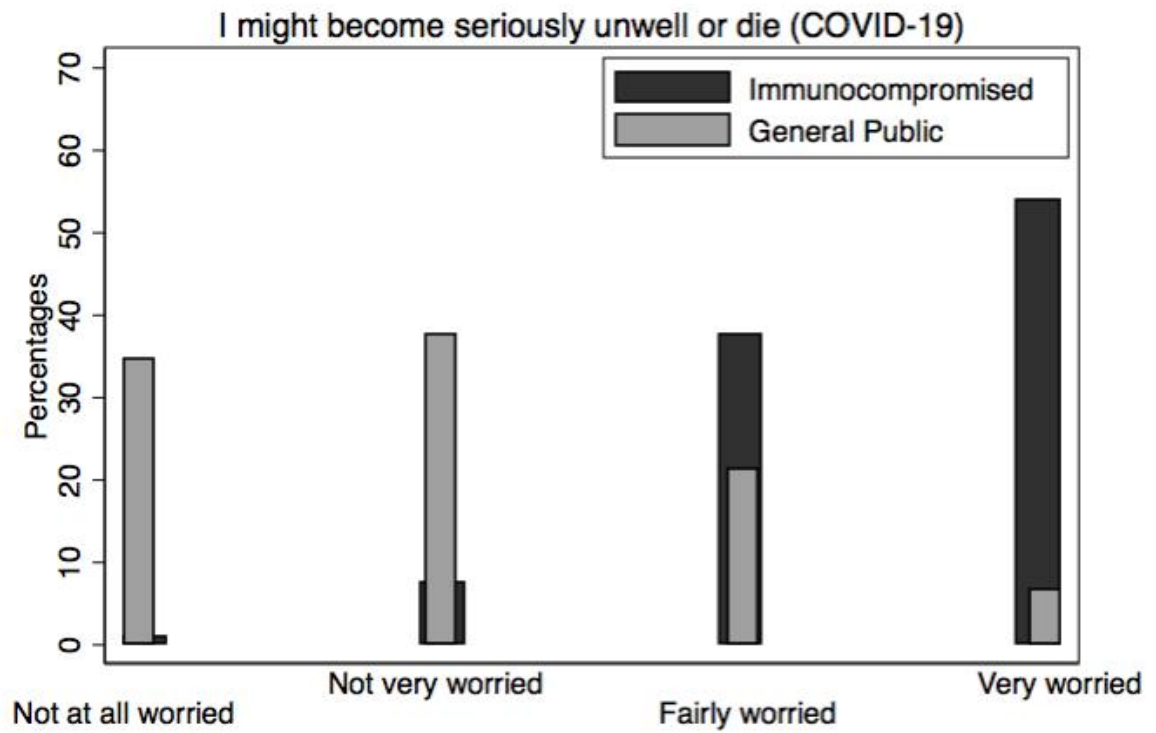


Figure 2: Compared to the general population, immunocompromised people report higher levels of worry due to COVID-19 about the health of their family and friends (80% against 42%)

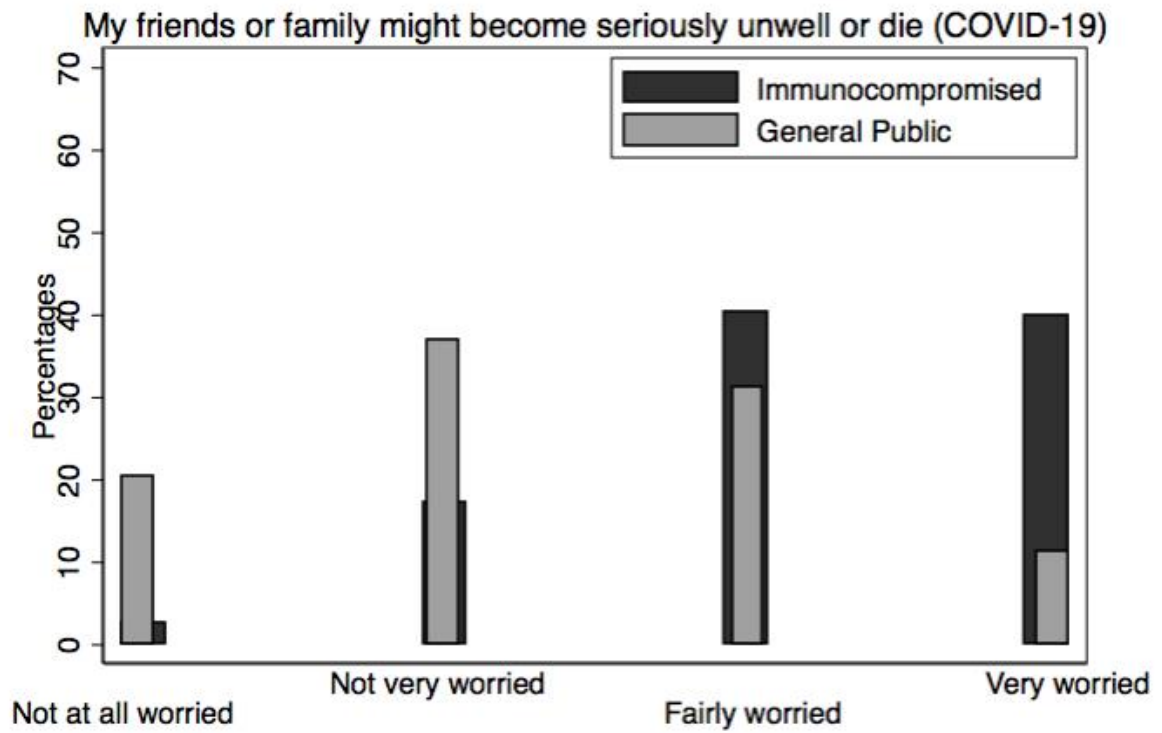


Figure 3: Compared to the general population, immunocompromised people report higher levels of worry due to COVID-19 about their financial situation (57% against 41%)

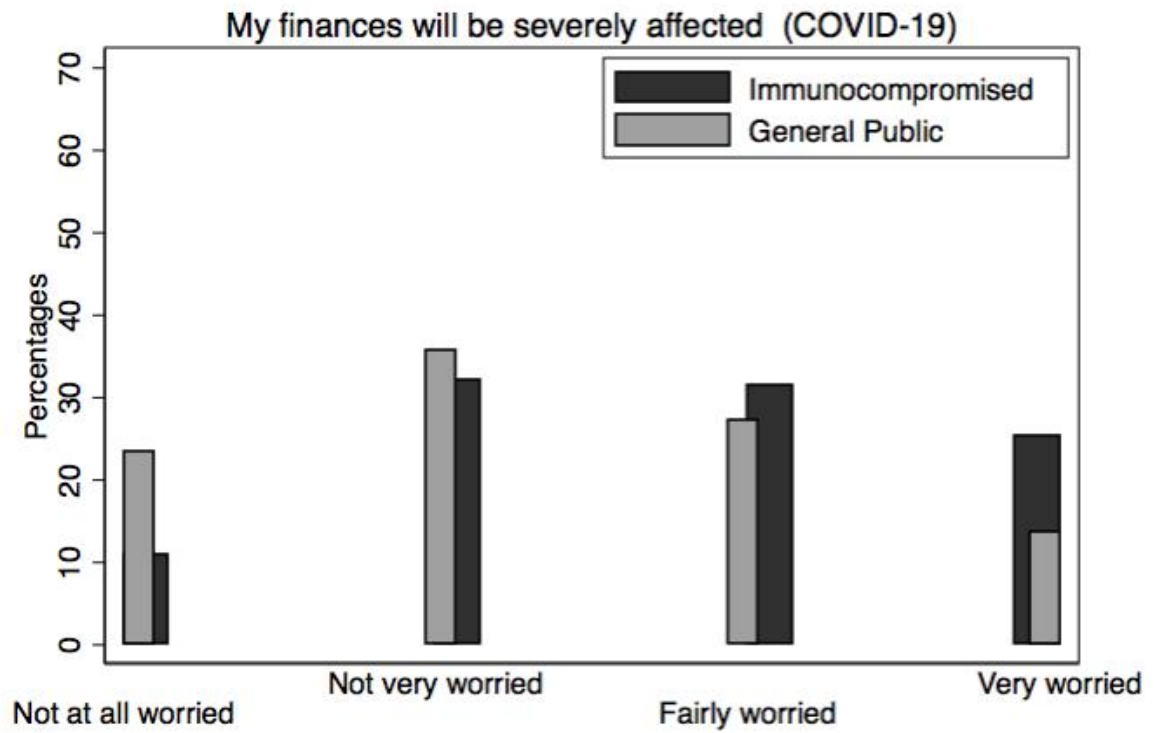
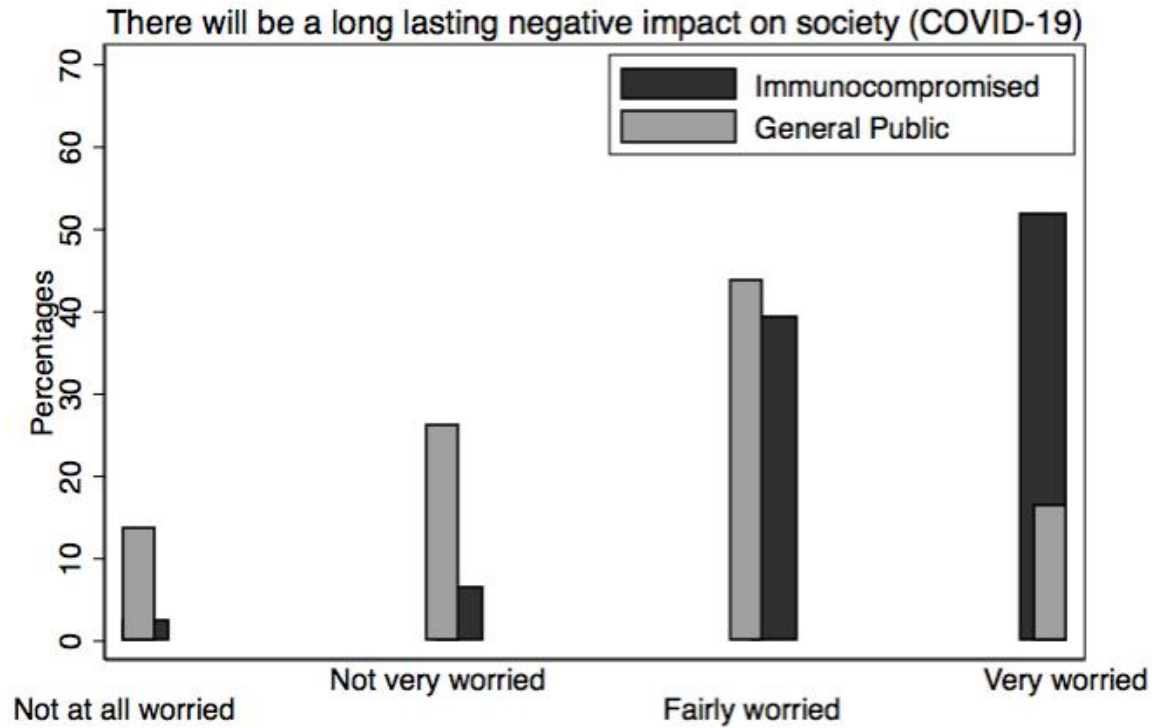


Figure 4: Compared to the general population, immunocompromised people report higher levels of worry due to COVID-19 about the long lasting negative impact of the pandemic on society (91% against 60%)



Mental health and wellbeing

Figure 5: 24% of immunocompromised people report that their mental health was poor compared to 9% of the general public

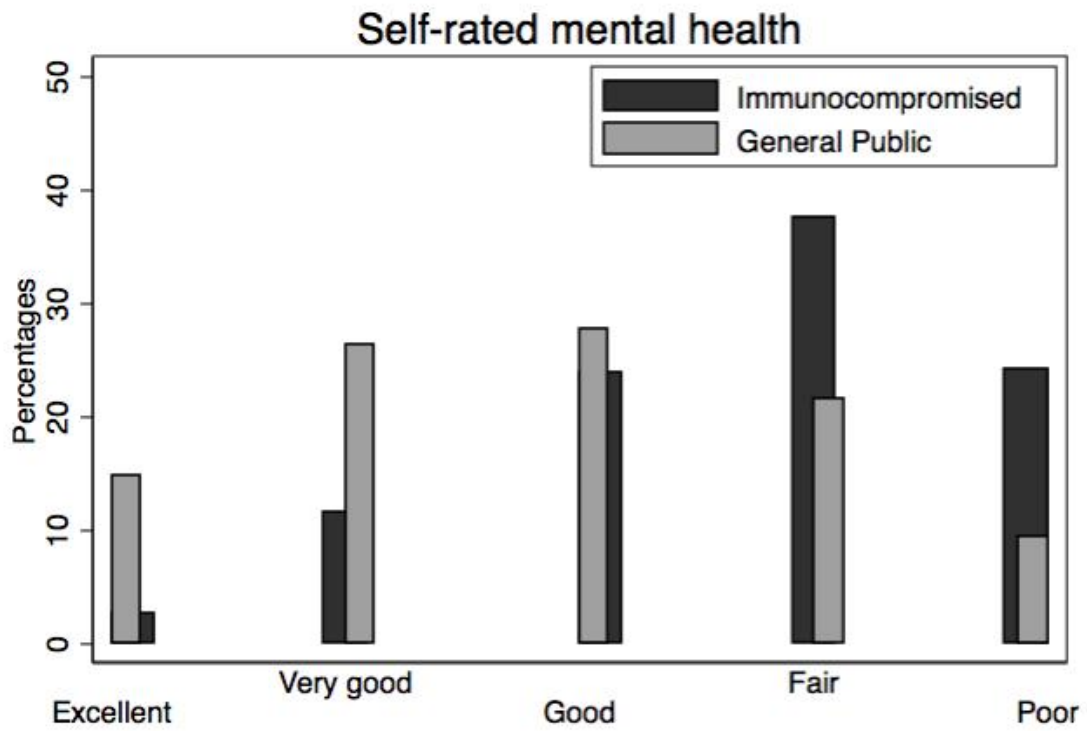


Figure 6: 17% of immunocompromised people report to be in positive wellbeing often or always compared to 39% of the general public (items: cheerful and in good spirits; calm and relaxed; active and vigorous; waking up feeling fresh and rested; daily life filled with things that interest me)

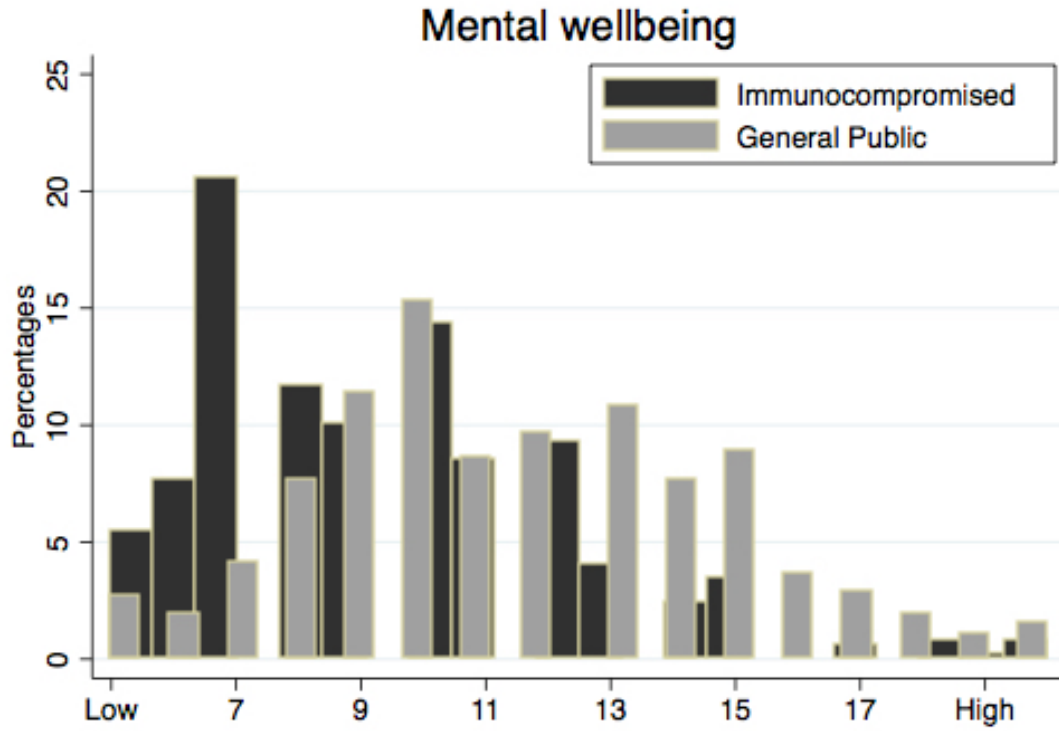


Figure 7: On a scale from 0 to 10, where 0 means extremely dissatisfied and 10 means extremely satisfied, the average level of satisfaction with life was 4 for immunocompromised people and 6 for the general public

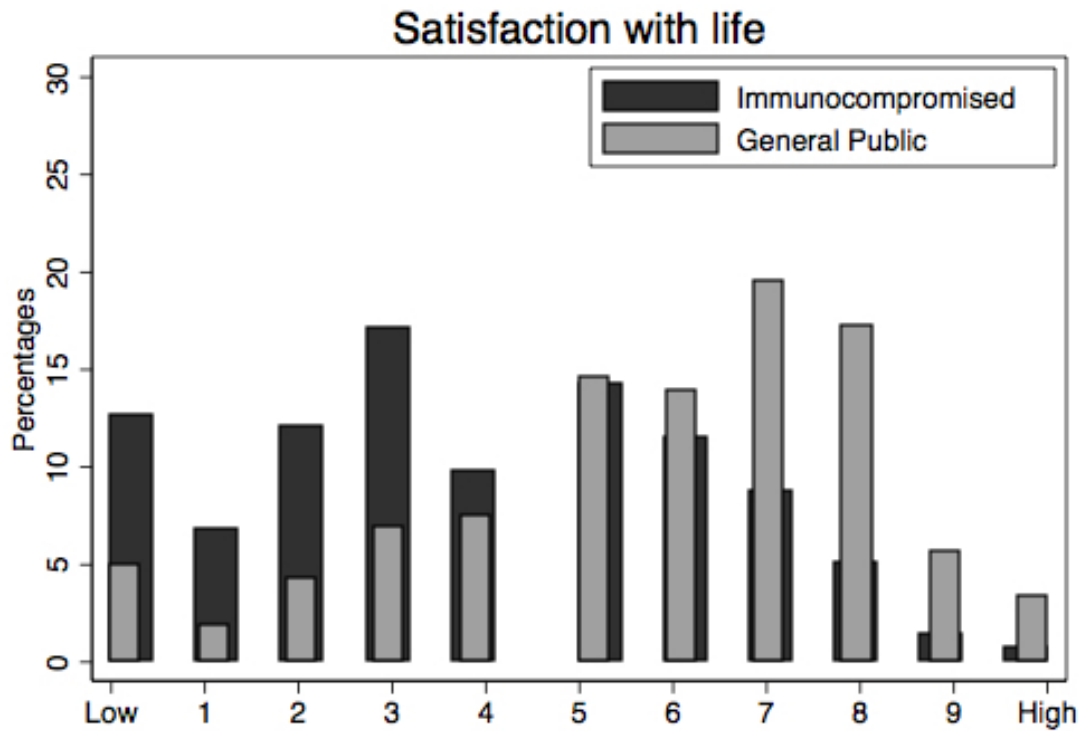


Figure 8: 23% of immunocompromised people report to have experienced depressive symptoms most or all of the time compared to 12% of the general public (scale items: I felt depressed; I felt that everything I did was an effort; I felt hopeful about the future; my sleep was restless; I was happy; I felt lonely; I enjoyed life; I felt sad; I could not get "going")

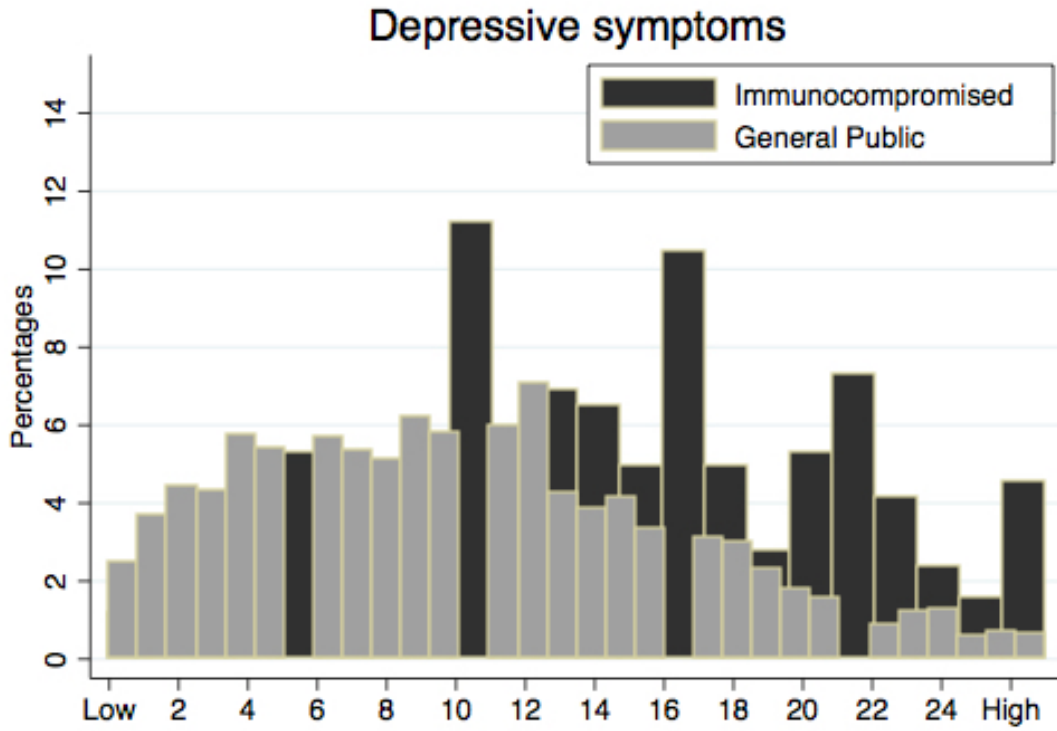


Figure 9: 58% of immunocompromised people report to have experienced symptoms of anxiety often or always compared to 46% of the general public (scale items: calm; tense; relaxed; upset; content; worried)

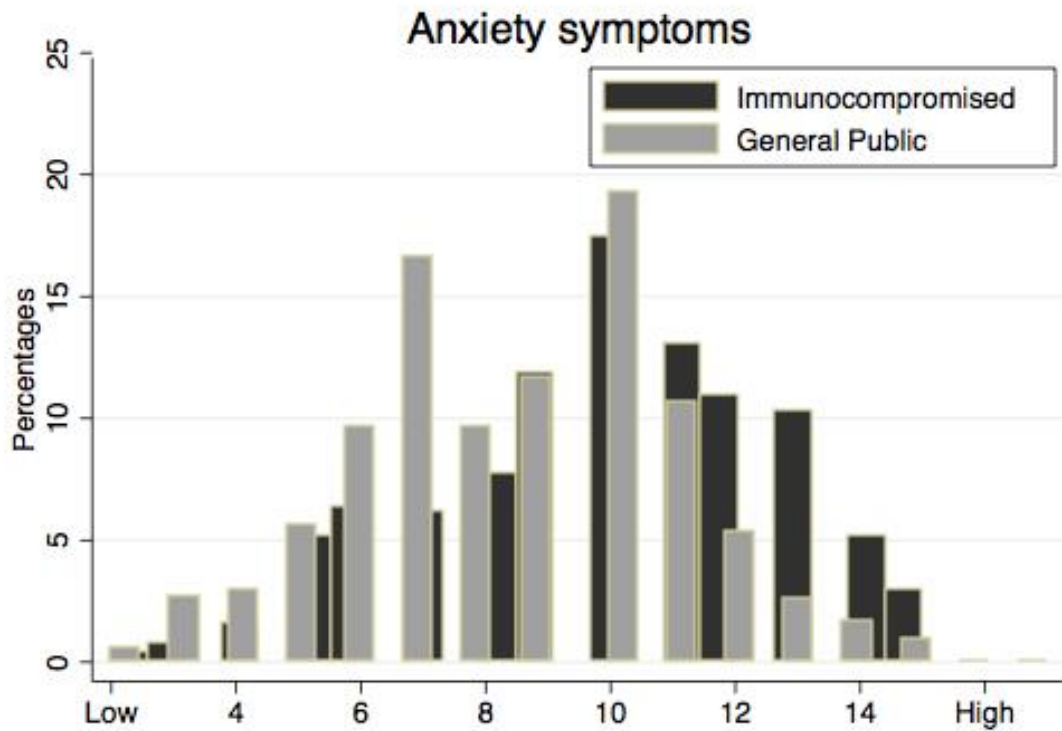


Figure 10: 32% of immunocompromised people report to have experienced symptoms of stress most or all of the time compared to 20% of the general public (unable to control the important things in your life; confident about your ability to handle your personal problems; things were going your way; difficulties were piling up so high that you could not overcome them)

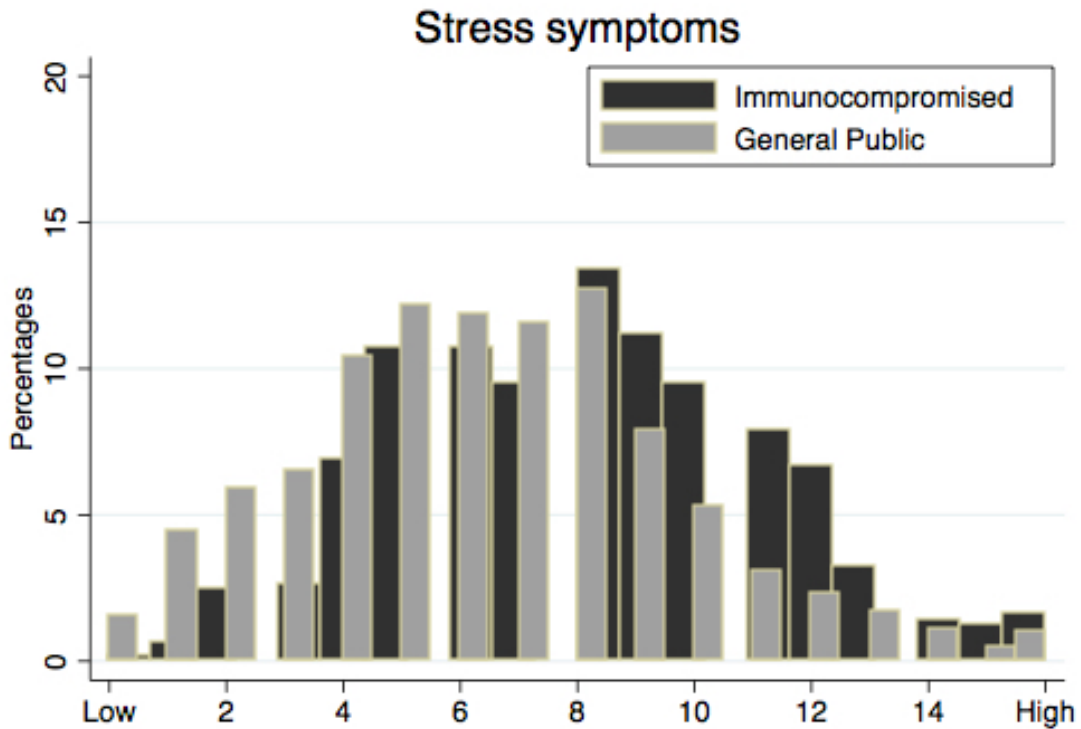


Figure 11: Immunocompromised people report higher rates of diagnosis of mental health conditions than the general public, in particular depression (57% against 14%), anxiety (54% against 15%) and trauma and stress-related disorder (33% against 4%)

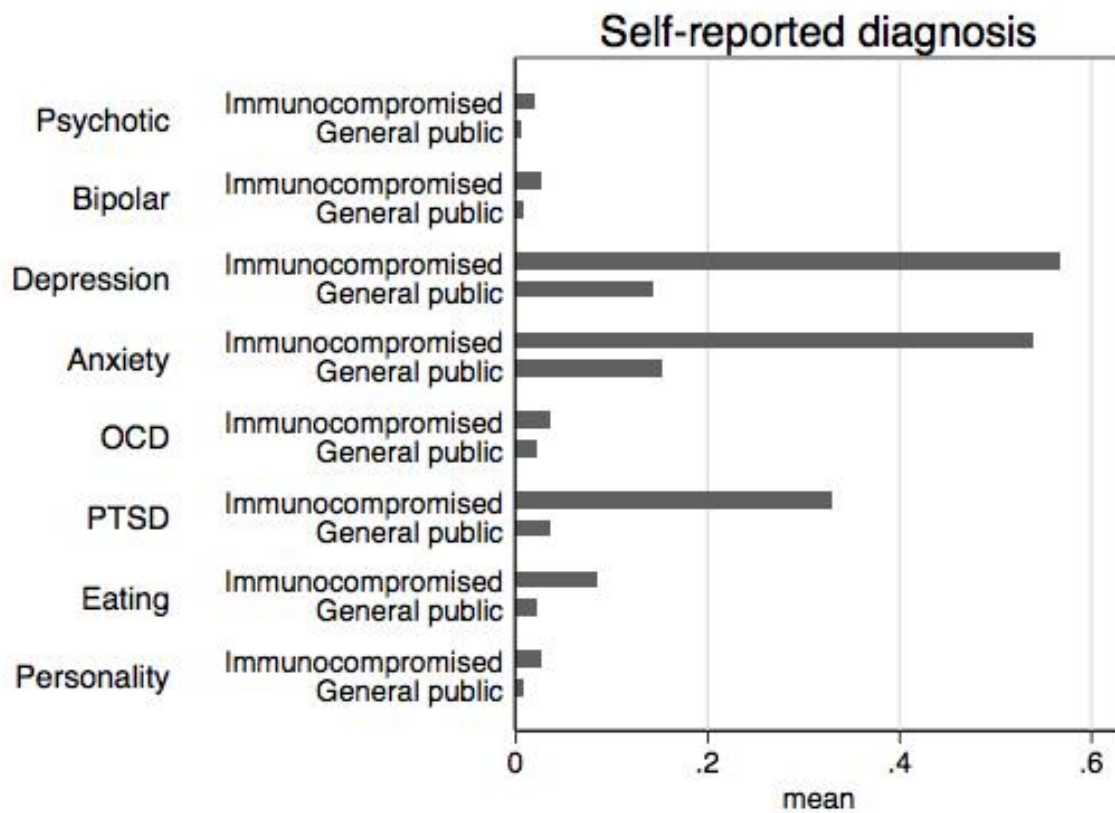
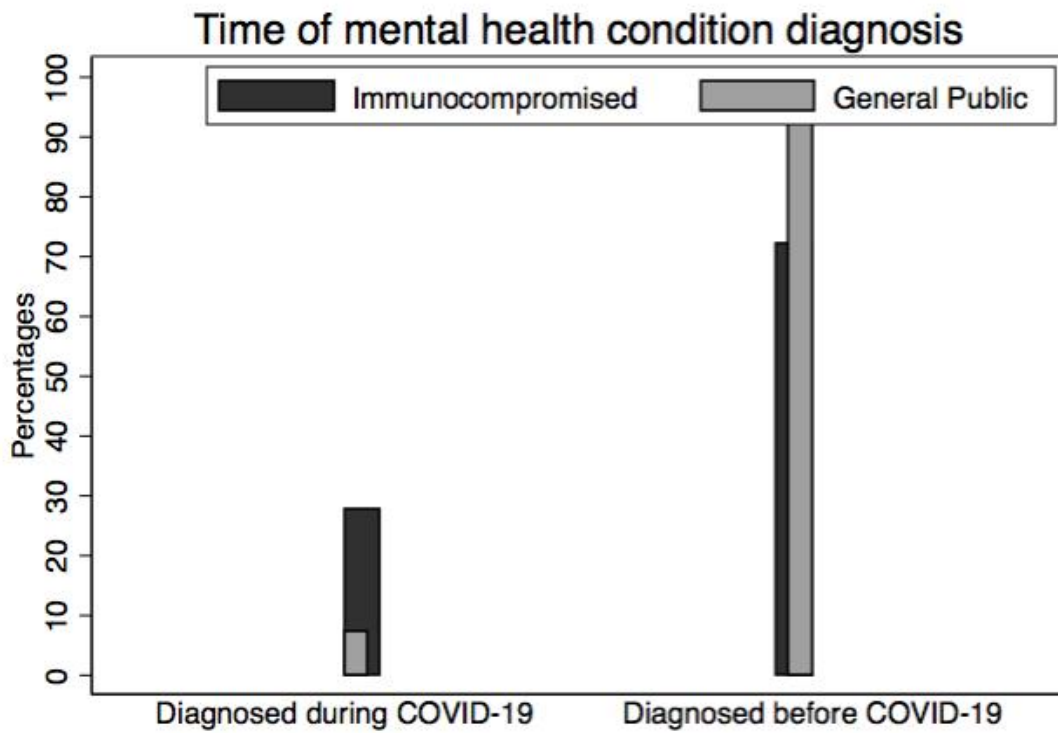


Figure 12: Immunocompromised people report higher rates of diagnosis of mental health conditions during the COVID-19 pandemic compared to the general public (28% against 7%)



Political engagement

Figure 13: On a scale from 0 to 10, where 0 means no attention and 10 means a lot of attention, the average level of political attention for immunocompromised people was half a point higher than for the general public (6.5 against 6.0)

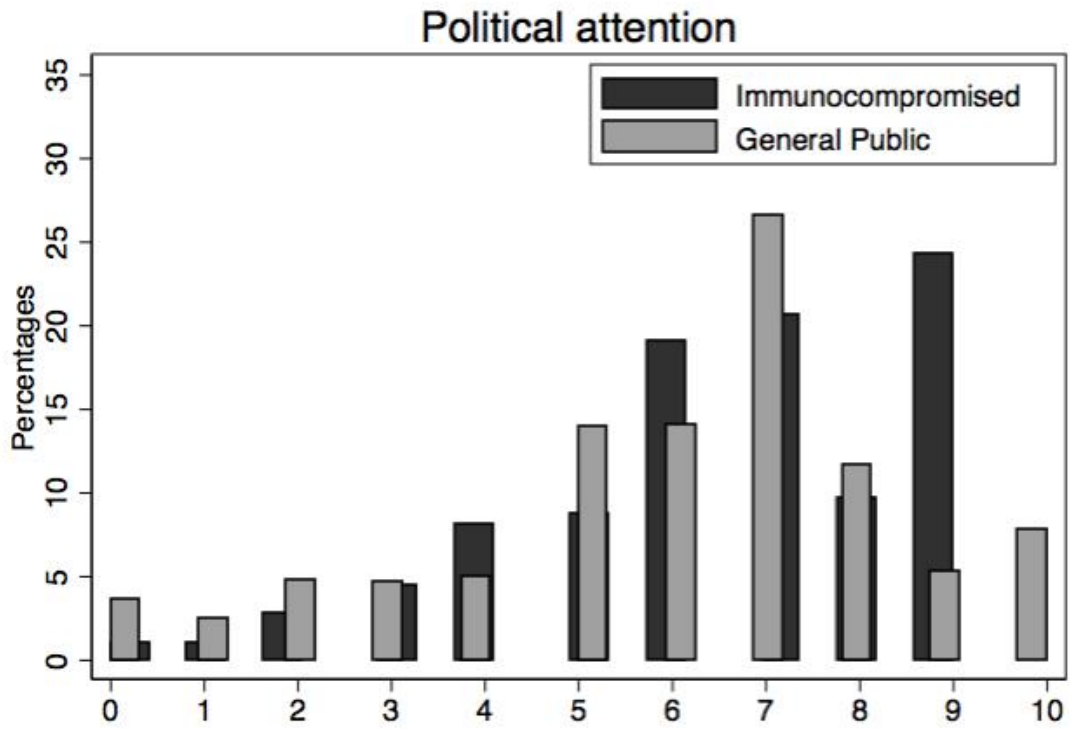


Figure 14: 73% of immunocompromised people agree that they understand quite well politics and the most important political issues that affect the country compared to 48% of the general public

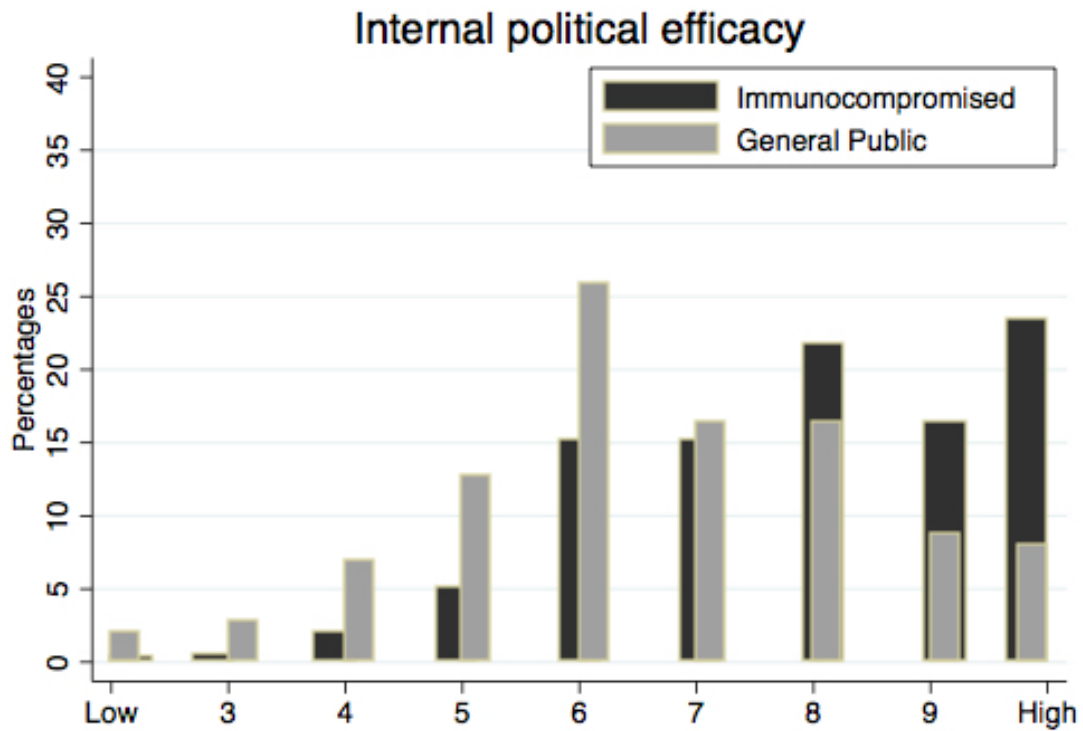


Figure 15: 85% of immunocompromised people disagree that public officials care about what they think and that they can influence government policy compared to 72% of the general public

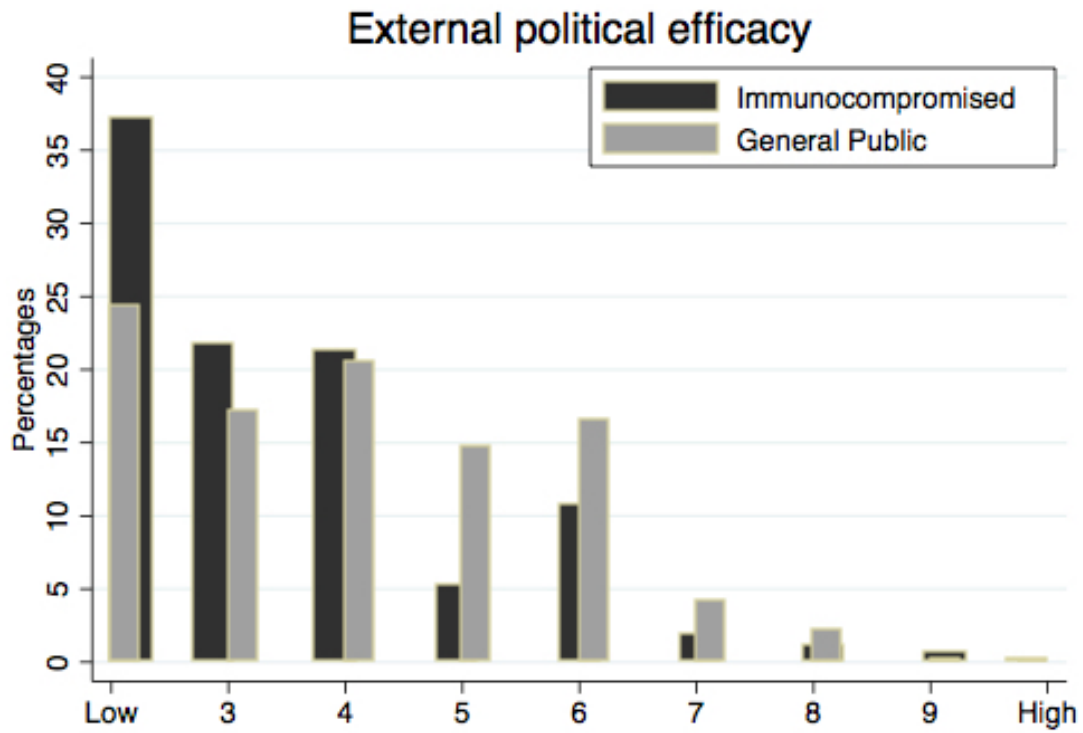


Figure 16: On a scale from 0 to 10, where 0 means do not trust at all and 10 means trust completely, the average level of trust in government for immunocompromised people was virtually 2 points lower than for the general public (3.18 against 1.19)

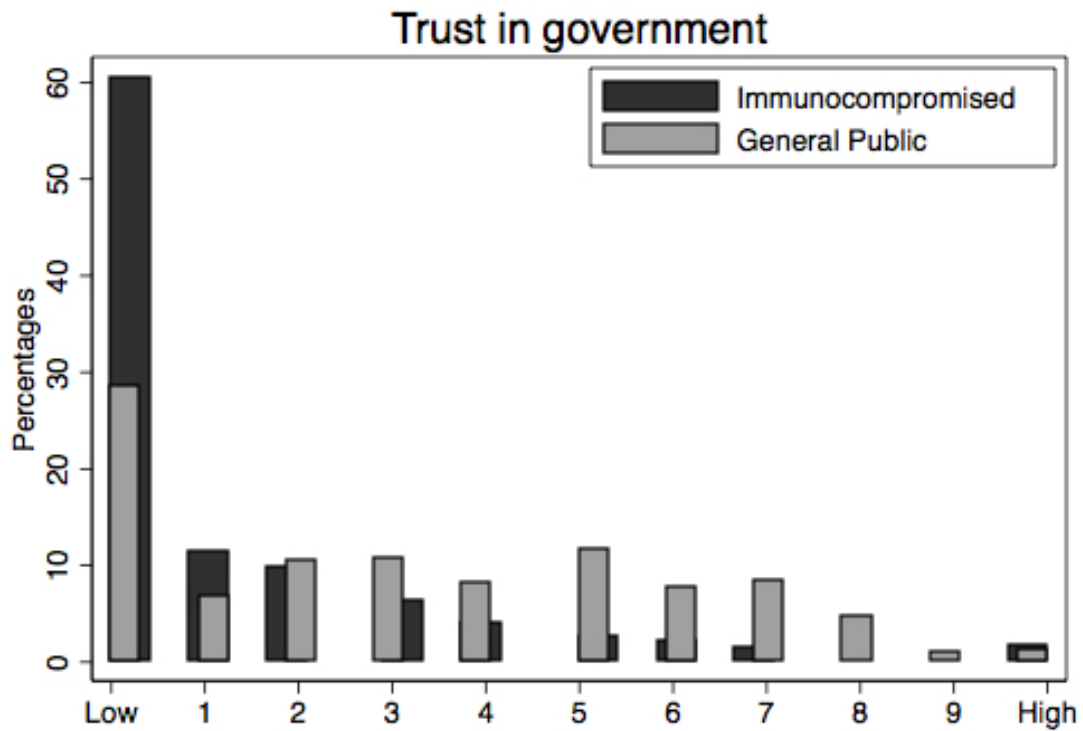


Figure 17: On a scale from 0 to 10, where 0 means extremely dissatisfied and 10 means extremely satisfied, the average level of satisfaction with the economy was about 1.5 points lower for immunocompromised people than for the general public (1.35 against 2.79)

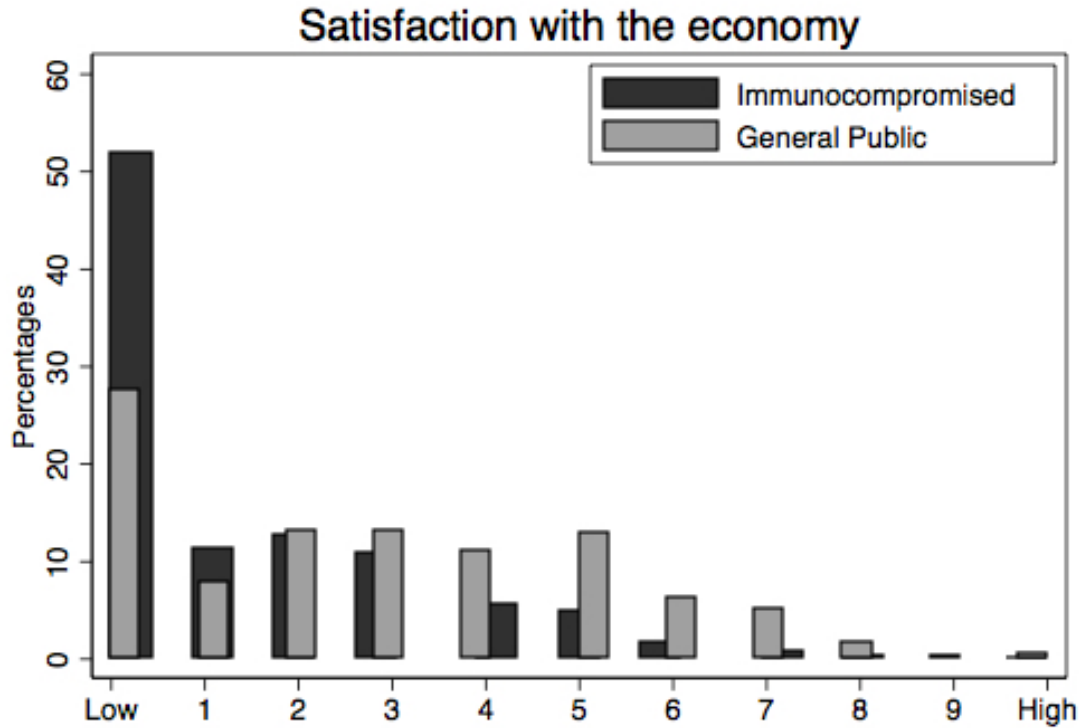


Figure 18: On a scale from 0 to 10, where 0 means extremely dissatisfied and 10 means extremely satisfied, the average level of satisfaction with democracy was virtually 2 points lower for immunocompromised people than for the general public (1.99 against 3.89)

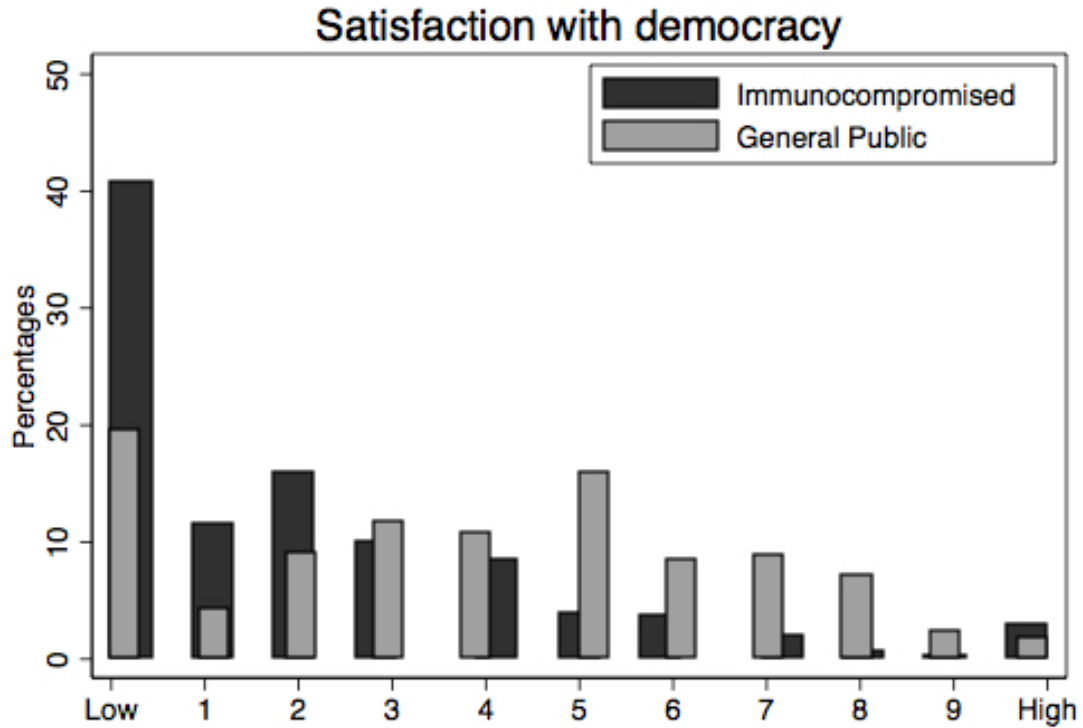


Figure 19: 70% of immunocompromised people reported that the government handled the pandemic very badly compared to 30% of the general public

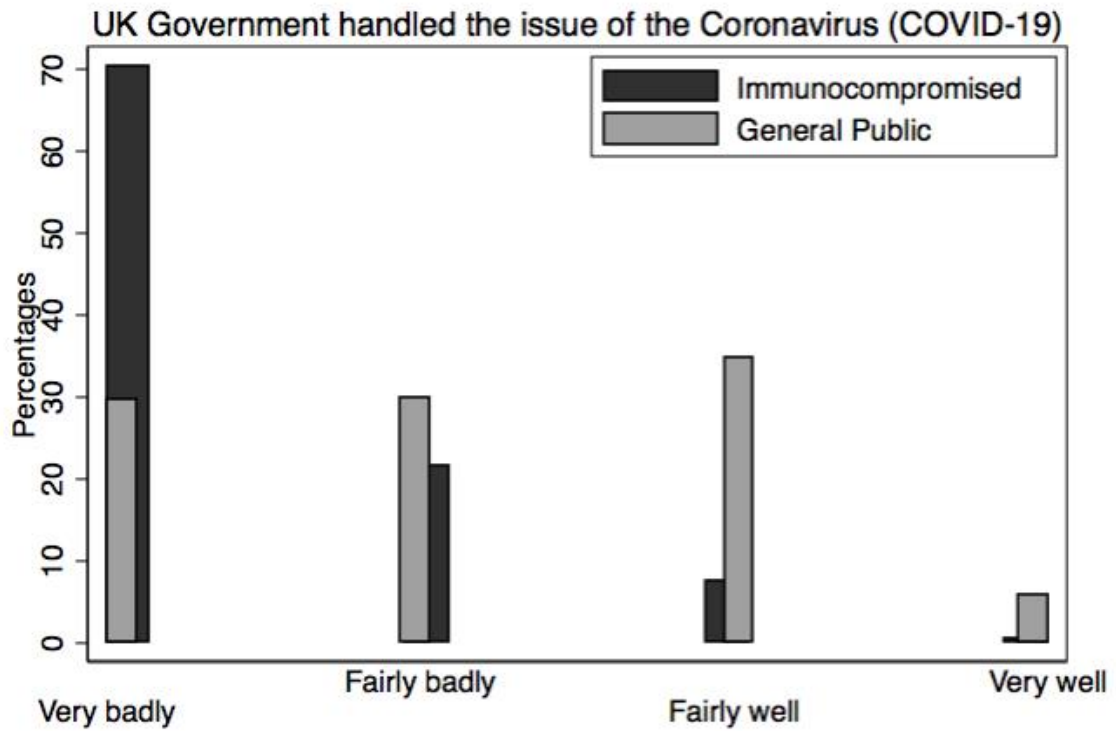


Figure 20: Compared to the general public, immunocompromised people report higher probabilities to vote if there were a general election held tomorrow (75% against 69%)

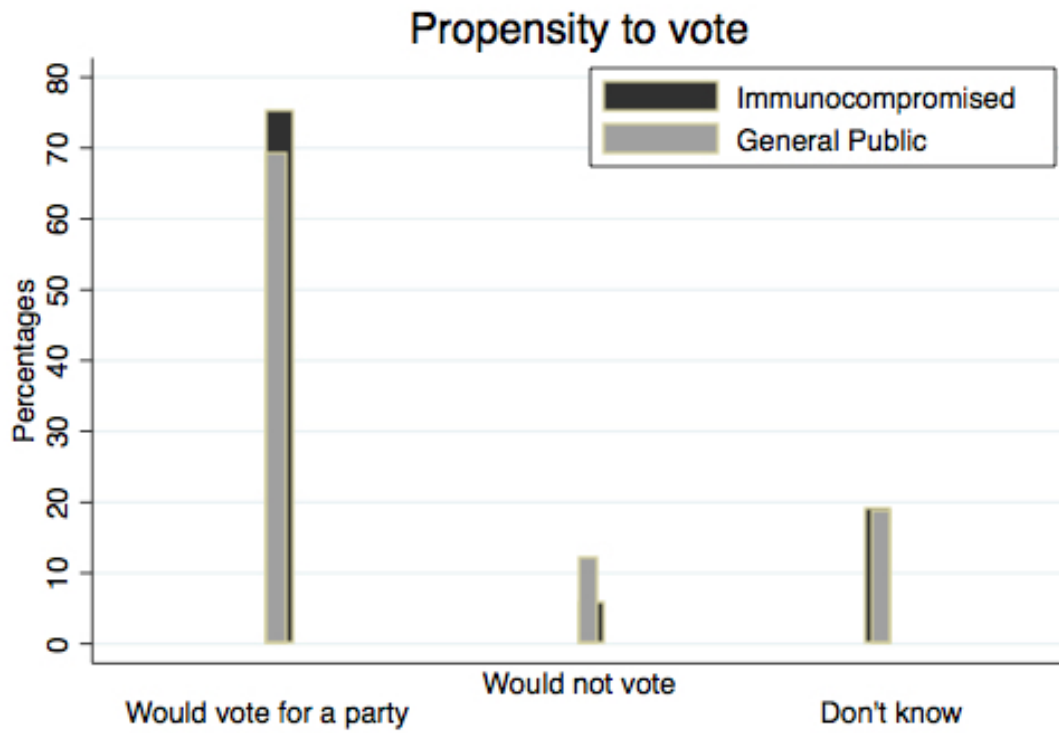
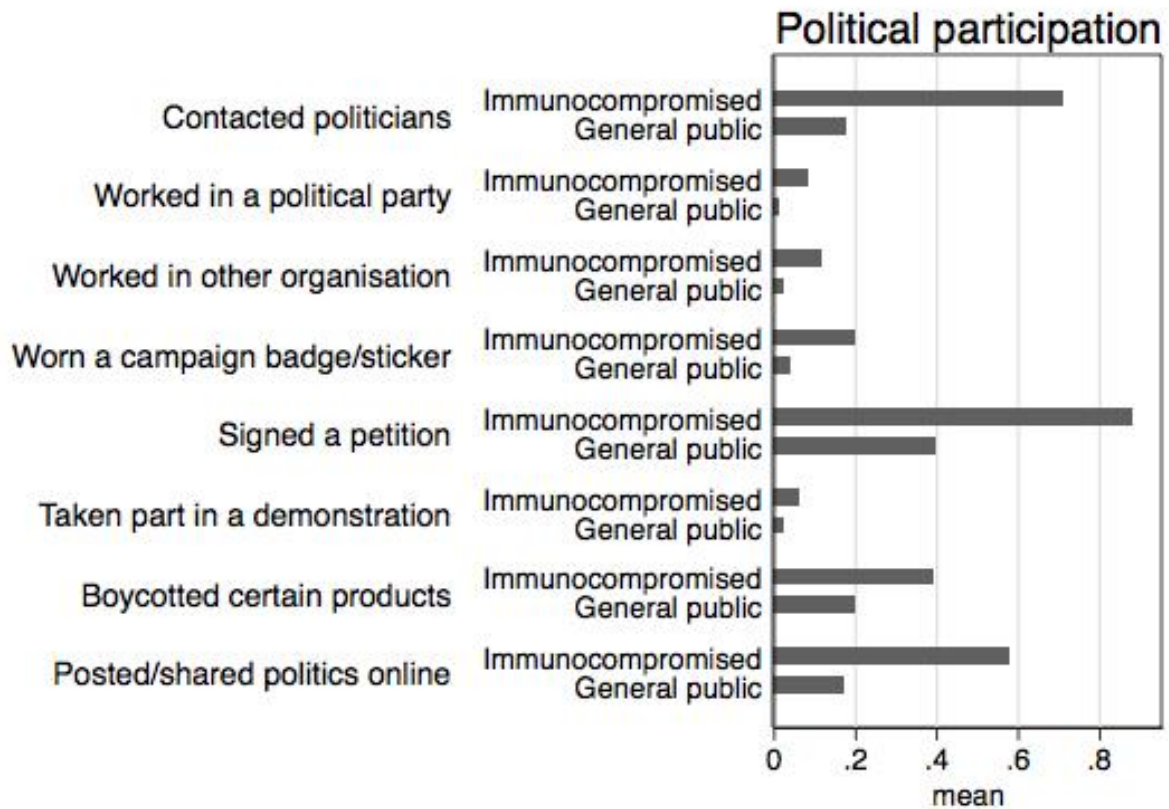


Figure 21: Compared to the general public, in the past 12 months, immunocompromised people report higher levels of political participation in those forms that fit in with their health restrictions and can be undertaken at home, including contacting a politician, government or local government official (71% against 18%), signing a petition (88% against 40%), boycotting a product (40% against 20%), and posting or sharing anything about politics online (58% against 17%)



Profile of survey respondents

	General Public	Immunocompromised
Female	56%	76%
Male	44%	24%
Age	54	57
Lower Education	30%	13%
Secondary Education	18%	8%
Higher Education	52%	79%
Single	25%	17%
Married/Civil Partnership	60%	68%
Separated/Divorced	10%	11%
Widowed	5%	4%
Paid Employment	53%	39%
Unemployed/Not Paid Employment	11%	24%
Student	3%	1%
Pensioner	33%	36%
English/Welsh/Scottish/Northern Irish	88%	88%
Left-Right Self-Placement (1=Left, 7=Right)	3.8	2.8
North East	5%	4%
North West	12%	11%
Yorkshire and the Humber	9%	7%
East Midlands	8%	5%
West Midlands	9%	7%
East of England	9%	12%
London	9%	9%
South East	15%	18%
South West	10%	13%
Wales	5%	4%
Scotland	9%	10%

Acknowledgements

- This is a collaborative project between the APPG on Vulnerable Groups to Pandemics, Forgotten Lives UK, the University of Liverpool and the University of Bath.
- The work has been carried out by project leads Dr Luca Bernardi, Senior Lecturer in Politics at the University of Liverpool and Dr Jo Daniels, Senior Lecturer and Clinical Psychologist at the University of Bath, the Forgotten Lives UK patient group and the National Clinical Expert Group.
- The National Expert Group for immunocompromised patients represents over 125 clinicians, across 4 nations and 17 medical specialities treating immunocompromised patients.
- The clinical group works in parallel with the APPG-VGP to safeguard and protect this vulnerable group during the pandemic. Immunocompromised patients are at greater risk of severe COVID-19 outcomes than the general population as many of these patients respond poorly to SARS-CoV-2 vaccines.
- Forgotten Lives UK (leads of the Forgotten500K campaign) is a patient representative and advocacy group working across the UK and with international patient groups to represent the interests of the immunocompromised vulnerable to COVID and obtain faster access to protective drugs. www.forgottenlives.uk
- Dr Luca Bernardi received funding from a Research England Public Policy Support Fund (PWG10029) to conduct the survey with the general public which was administered by YouGov.
- The mental health scales used in this study are: a short form of the Center for Epidemiological Studies Depression scale, a short form of the State-Trait Anxiety Inventory, a short form of the Perceived Stress Scale, and the World Health Organization-Five Well-Being Index.
- We thank Mark Oakley and Nikola Brigden who were the leads and key representatives of the Forgotten Lives UK Patient group involved in this study.
- We thank the APPG and Tracey Allen for her guidance and input into the report.
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