Equality considerations

11 November 2021

Equalities impact assessment during scope development

Is the proposed primary focus of the guideline a population with a specific communication or engagement need, related to disability, age, or other equality consideration?

No. The scope of the guideline is adults, children and young people.

Have any potential equality issues been identified during the check for an update or during development of the draft scope, and, if so, what are they?

Exacerbating inequalities

The existing guideline (NG188 COVID-19 rapid guideline: managing the long-term effects of COVID-19) is being updated. Potential equality issues identified during the development of the previous guideline were documented in an equality impact assessment (EIA) in December 2020.. Characteristics and individual circumstances were considered to ensure that recommendations did not exacerbate inequalities.

Age

It was suggested that ongoing symptomatic COVID-19 and post-COVID-19 syndrome may be more likely to be reported in older people generally, but that older adults with acquired communication impairments may be less likely to report symptoms, or symptoms may be attributed to other conditions. There could be difficulty accessing care for older people who cannot easily ask for help because of mobility or sensory impairments. These factors may lead to older people becoming less likely to seek help. In addition, it was highlighted that prevalence of post-COVID-19 syndrome (PCS) is unknown in care homes.

The pandemic may have led to limitations in carer arrangements. This may mean that some of the difficulties faced by older people who require additional support may be exacerbated.

Existing services may use exclusion criteria relating to age, which could lead to inequality of access.

There seem to be different clusters of symptoms in different age groups, which means that there could be different presentations for children and younger people and adults compared with people aged over 65.

Disability

Healthcare services may be less accessible to people with disabilities due to additional safety measures for patients. They may require reasonable adjustments to be made. In addition, people with disabilities who are immunocompromised may fear accessing care due to the risk of COVID-19 re-infection.

People with learning disabilities and autistic people may present late to services because of atypical presentations or diagnostic overshadowing. People with communication, speech and language difficulties may also not be able to describe, explain or communicate subtle or complex symptoms. Limitations in carer arrangements as a result of the pandemic may exacerbate these issues.

Gender reassignment

Some evidence suggests that there may be a number of factors that can dissuade trans people from seeking healthcare e.g., lack of providers that are knowledgeable on the topic, discrimination etc. This could lead to delayed diagnosis.

Pregnancy and maternity

People with symptoms who are pregnant or caring for young children may have difficulty accessing health and social care services where they could gain advice and assistance. This may increase the likelihood of a delay in seeking help.

There is a lack of evidence about the effect of maternal COVID-19 or PCS on the unborn child.

Race

There is some evidence of poorer outcomes from COVID-19 in black, Asian and minority ethnic populations, related either to higher rates of comorbidities (which may be due to biological factors, or to social determinants of health and systemic racism) or occupation.

People from black, Asian and minority ethnic groups may also have had negative experiences of the healthcare service, which could be a barrier to engagement or help-seeking.

Religion or belief

People may feel or have experienced stigma based on their religion or belief when accessing healthcare services that may create challenges for seeking help.

Sex

While there are known differences in terms of poorer outcomes from COVID-19 for men compared to women, there is emerging evidence that women are more likely to report ongoing symptomatic COVID-19 and post-COVID-19 syndrome compared to men. Lower help-seeking behaviours in men may contribute to this.

Stakeholders highlighted that women may have had negative experiences of the healthcare service, and may have informal caring responsibilities to a greater extent than men, both of which could be barriers to engagement or help-seeking.

Sexual orientation

People may feel or have experienced stigma based on their sexual orientation when accessing healthcare services. There are also higher incidences of mental ill health in LGBTQ+ people. Both these factors may create challenges for seeking help.

Socioeconomic factors

People may feel or have experienced stigma based on their socio-economic background when accessing healthcare services that may create challenges for seeking help.

Poverty may also reduce accessibility of healthcare resources through mechanisms such as distance from healthcare, access to online support and access to childcare.

Other definable characteristics

Refugees, asylum seekers and migrant workers

For people whose first language is not English, there may be communication difficulties and a need for an interpreter especially for seeking help and effective shared decision making.

People who are homeless

People who are homeless may face challenges accessing care or may present late to services, so they may be more likely to have adverse outcomes compared to if they accessed services sooner.

Mental health and pre-existing comorbidities

There may be some situations when pre-existing comorbidities or mental health illness may create challenges for people seeking help and accessing services.

People at higher risk of COVID-19

Stakeholders highlighted that low levels of literacy and pervasive language disorders are known to exist in communities at higher risk of COVID-19 which can create challenges seeking help.

New barriers caused by ongoing COVID-19 symptoms or Post-COVID-19 symptoms

People with PCS may be experiencing symptoms that may prevent access to digital services, such as fatigue. They may also be experiencing new difficulties and may also have new transportation barriers due to new mobility, cognitive, or sensory impairments which may create barriers in attending face to face appointments.

Others identified

Stakeholders highlighted that inequalities are faced by groups such as people in prison, Gypsies and Travellers.

Stakeholders highlighted that groups such as people in prison, Gypsy, Roma and Traveller communities, armed forces personnel and people who have been trafficked should be considered when drafting recommendations.

Digital accessibility

Increased use of digital and virtual methods for delivering healthcare could create challenges for people with disabilities, low digital literacy, or people who do not have the devices or connectivity to use these services. These factors may lead to some groups of people becoming less likely to seek help.

What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee?

The guideline will need to address the potential equality issues by looking at data from studies either focused on the groups identified or by looking at subgroup data. They will be captured by subgroup analyses in the review questions as well as qualitative data on patient experience. No groups will be excluded from the population.

Equalities impact assessment during scoping - final scope

Have any potential equality issues been identified during consultation, and, if so, what are they?

The following points were discussed at the Scoping Workshop for the guideline update.

Age

It was suggested that using a post 12-week referral point might be a barrier for children. 'Post-COVID-19' suggests a time point, whereas it was suggested that children should be assessed over time as they may deteriorate progressively. It was also noted that when considering problems people may have carrying out usual activities, education should be considered a usual activity.

Stakeholders noted that post-COVID-19 syndrome (PCS) may be more common in people of working age than in older people, but this may be influenced by under-reporting among older people. Symptoms experienced by people with PCS may make them unable to work, and therefore may have financial impacts at an individual level and socioeconomic impacts on a population level.

Stakeholders also highlighted that older, frailer people may struggle to attend services which they may be especially in need of. Older people may also have symptoms of PCS attributed to cognitive impairment, leading to missed diagnosis. Older people may also be less likely to report symptoms and the consequent gaps in reporting of PCS should be taken into account in reviewing evidence to avoid exacerbating inequalities for older people.

Disability

It was noted that people with disabilities may be reluctant to make or attend appointments about PCS symptoms due to a fear of reinfection with COVID-19, particularly if their disabilities put them at risk of worse symptoms or outcomes. This may also be the case for people who have been shielding, for example those with health conditions like kidney disease, and may increase the likelihood of a delay in seeking help.

Stakeholders also noted that people with a learning disability may have symptoms of PCS attributed to that disability, leading to missed diagnosis.

Gender reassignment

None identified at this time.

Pregnancy and maternity

None identified at this time.

Race

It was suggested that data from studies shows that the prevalence of PCS is not higher in ethnic minority groups. This is contrary to expectations based on the higher rates of COVID-19 in ethnic minorities, so stakeholders discussed the need to interpret these studies in light of contextual factors. For example, people from black, Asian and minority ethnic groups may have had negative experiences of the healthcare service, which could be a barrier to engagement or help-seeking.

Religion or belief

None identified at this time.

Sex

It was suggested that rates of PCS are higher in women than in men. The mechanism by which this would occur is not known, but stakeholders noted anecdotal evidence related to fluctuating symptoms being linked with ovulation.

It was highlighted that some women may have had negative experiences of the healthcare service and may have had PCS symptoms dismissed and not investigated fully.

Women may also have informal care responsibilities to a greater extent than men, which may be a barrier to seeking help for symptoms.

One stakeholder also suggested that antibody tests may work less well in women, who may sero-revert faster than men. It was noted that any investigations should be considered carefully to make sure that they aren't introducing inequalities.

Sexual orientation

None identified at this time.

Socioeconomic factors

Stakeholders highlighted that symptoms experienced by people with PCS may make them unable to work. Those in vulnerable employment types or with casual contracts may be particularly at risk of losing their jobs.

One stakeholder had observed lower levels of referrals to COVID-19 clinics from deprived areas, indicating an inequality of access.

Other definable characteristics

Refugees, asylum seekers and migrant workers

No further issues were identified specifically for these groups in addition to those identified under the 'Race' section.

People who are homeless

None identified at this time.

Mental health and pre-existing comorbidities

Stakeholders noted that people with pre-existing comorbidities may have symptoms of PCS attributed to those conditions, leading to missed diagnosis.

Geographical location

Stakeholders highlighted that geographical inequalities in service provision exist across the UK, affecting people's access to service and the opportunity for healthcare staff in those areas to develop expertise and greater understanding of PCS to aid management of the syndrome. This inequality may interact with others (for example, socioeconomic inequality), exacerbating the results.

Hospitalisation

It was discussed that people who were not hospitalised for COVID-19 may be less clear on timepoints for disease onset and duration of symptoms. They may therefore experience difficulty in being assessed as having PCS, although the guideline scope specifies that a positive COVID-19 antibody test is not necessary to a diagnosis of PCS. There was a suggestion that people who were hospitalised may also experience more severe symptoms of PCS.

Help-seeking behaviour plays a part in hospitalisation, and so it may be that groups less willing or able to seek help from healthcare services for COVID-19 are disproportionately affected by these factors.

Healthcare professionals

Stakeholders highlighted that 77,000 healthcare professionals contracted COVID-19 last year and should be considered as a group of interest. They noted that many of these are nurses or occupational therapists who fit into the young female risk group and are experiencing significant professional and personal challenges as a result of PCS.

Have any changes to the scope been made as a result of consultation to highlight potential equality issues?

The scope did not exclude any groups. However, children and young people have been added as a named subgroup to clarify that they will be included in the update.

Inequalities will be considered throughout the update, and recommendations will aim to reduce inequalities identified.

Have any of the changes made led to a change in the primary focus of the guideline which would require consideration of a specific communication or engagement need, related to disability, age, or other equality consideration?

Not applicable.

Equalities impact assessment during guideline development

Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Age

A recommendation has been added that alerts clinicians to be aware that long-term effects of COVID-19 may present in children and adults as reduced performance or increased absence in education or work.

There is an existing recommendation which was unchanged at the update which alerts clinicians to be aware that children and older people may not present with the more common symptoms associated with post-COVID-19 syndrome and that their symptoms may not be picked up by initial screening. Advice has been added about which symptoms are less commonly reported in children.

An existing recommendation which has been retained alerts clinicians to be aware that when investigating possible causes of a gradual decline, deconditioning, worsening frailty or dementia, or loss of interest in eating and drinking in older people, bear in mind that these can be signs of ongoing symptomatic COVID-19 or suspected post-COVID-19 syndrome.

Disability

There are existing recommendations which have been retained that encourages healthcare services to support access for people in underserved or vulnerable groups and sets out a number of suggested proactive actions to reduce barriers and improve awareness and contact. An exisiting recomendation has been amended to prompt healthcare professionals to consider additional support for vulnerable people, for example older people and disabled people.

An existing recommendation in the section on assessments details that the user of the guideline should talk to family members about the person’s symptoms for people who might need help with describing symptoms, for example people who have learning disabilities.

Race

Existing recommendations which were retained at update encourage healthcare services to support access for people in underserved or vulnerable groups and sets out a number of suggested proactive actions to reduce barriers and improve awareness and contact.

Sex

The evidence identified did not provide any subgroup data to that compared prevalence of symptoms by sex.

It was highlighted at scoping that women may have informal care responsibilities to a greater extent than men, which may be a barrier to seeking help for symptoms. Recommendations have been retained which encourages healthcare services to support access for people in underserved or vulnerable groups and sets out a number of suggested proactive actions to reduce barriers and improve awareness and contact.

Socioeconomic factors

The guideline contained recommendations which state that users of the guideline should provide information to people with symptoms after acute COVID-19 illness about sources of support and how to get support from other services including social care, housing, benefits and employment.

Other definable characteristics

There are recommendations that encourage clinicians to use a holistic, person-centred approach and to include a comprehensive medical history, including co-morbidities and history of acute COVID-19 when assessing patients.

Have any other potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Sex and race

The evidence suggested that being female is a possible risk factor for developing ongoing symptomatic COVID-19 and post- COVID-19 syndrome and that Asian ethnicity maybe a protective factor. However, the panel agreed that the evidence was not sufficient to draw strong conclusions. The panel considered that introduction of these risk factors in the recommendations could have unintended consequences such as males or people of Asian ethnicity being overlooked when presenting with ongoing symptoms after acute COVID-19 illness.

Have the Committee’s considerations of equality issues been described in the guideline for consultation, and, if so, where?

Equalities issues have been discussed in the recommendations outlined in the first section above, and the relevant rationales (assessment, information and follow-up after acute COVID-19, assessment, planning and agreeing management, sharing information and continuity of care and accessing care).

Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No. No recommendations were deemed to make it more difficult in practice for a specific group to access services compared with other groups.

Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No. No other adverse impacts on people with disabilities as a result of the recommendations were identified.

Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services, or otherwise fulfil NICE’s obligation to advance equality?

The recommendations acknowledge and seek to address NICE’s obligation to advance equality. The panel acknowledged that particular issues may make it more difficult for certain groups to access services, for example due to mobility issues or location, and the recommendations emphasise the importance of options for contact with services, including remote or face to face.

Equalities impact assessment final guideline

Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

One stakeholder identified a new potential equalities consideration for people who have had negative experiences of healthcare in the past which might mean they are more reluctant to seek treatment for the long-term effects of COVID-19. The stakeholder suggests healthcare providers should reach out to these patients and ensure a supportive relationship is in place.

One stakeholder noted that those who have no fixed abode may be lost to follow up through the healthcare system.

The recommendations encourage a holistic, person-centred approach which encourages discussion around personal experiences. The recommendations also encourage the use of shared decision-making where appropriate which should accommodate patient preferences and ensure a supportive relationship. There is also a recommendation to follow-up people in vulnerable and high-risk groups which will go some way to minimising loss to follow-up in the healthcare system.

If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

None.

If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

None.

If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified above, or otherwise fulfil NICE's obligations to advance equality?

None.

Have the Committee's considerations of equality issues been described in the final guideline, and, if so, where?

Recommendations and the corresponding rationales outline the panel's consideration of equality issues. This includes encouraging a holistic and person-centred approach to assessment, providing extra time or additional support during consultations and raising awareness about possible symptoms and how they might impact on daily activities. One recommendation and corresponding rationale encourages following up people in underserved or vulnerable/high risk groups who have self-managed in the community.

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