

COVID-19: Equality Impact Assessment of Clinical Guidance and Ethical Advice and Support Framework



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Equality Impact Assessment (EQIA) of the Scottish Government's COVID-19 Clinical Guidance and Ethical Advice and Support Framework

Background

The EQIA of the Scottish Government's COVID-19 Clinical Guidance and Ethical Advice and Support Framework took place over two meetings on 29 April and 25 June 2020, with extensive discussion with stakeholders by email in between.

Some of the points made in this report were received after the final meeting on 25 June and it is important they be included in order to fully consider the equality impact of this guidance.

In considering the impact of the guidance, due regard has been given to the needs of the general equality duty as set out in section 149 of the Equality Act 2010:

- to eliminate unlawful discrimination, harassment and victimisation;
- advance equality of opportunity between people who share a protected characteristic and those who do not; and ,
- foster good relations between people who share a protected characteristic and those who do not.

The Scottish Government has also considered whether the measures could constitute direct and/or indirect discrimination

A list of the stakeholders involved in the EQIA process is included at annex A.

Stakeholder feedback and recommendations and how they have been handled is included at annex C.

1. Title of plan, policy or strategy being assessed

COVID-19 Clinical guidance

This guidance was published on 3 April, as a repository to support clinical decision making throughout this COVID-19 pandemic, and to facilitate rapid access to advice based on the best evidence available. It is intended that this guidance will evolve over time as new evidence became available, and to reflect current circumstances.

In considering the impact of the guidance, participants have been asked to consider the key principles of EQIA: i) to eliminate discrimination, ii) to advance equality of opportunity and; iii) to foster good relations.

The Scottish Government has worked closely with a range of stakeholders to agree appropriate language in relation to the Clinical Frailty Score (CFS) and the limitations of using this in practise. A further appendix on the CFS has been developed in collaboration with stakeholders and included in the guidance.

The Scottish Government has also worked closely with a range of stakeholders, including the Scottish Human Rights Commission and the Equality & Human Rights Commission to ensure that the language used in relation to clinical decision making is in line with our statutory equality and human rights requirements. Where possible, the guidance has also been streamlined to replace text with hyperlinks to ensure that clinicians can access to the most up-to-date guidance and information on COVID-19.

COVID-19 Ethical Advice and Support Framework

The ethical guidance was developed to provide further practical support to decision makers during the COVID-19 pandemic.

In considering the impact of the guidance, participants have been asked to consider the key principles of EQIA: i) to eliminate discrimination, ii) to advance equality of opportunity and; iii) to foster good relations.

Following discussions with stakeholders throughout the EQIA process, the proposed formation of local and national ethical advisory groups and mutual aid agreements remains the same. It is recognised that these structures may be less used over time and work is planned to evaluate the impact of these groups.

As per the Clinical Guidance, Scottish Government has revised the language used throughout the ethical advice and support framework to ensure that it reflects equality and human rights requirements.

2. What will change as a result of this proposal?

Clinical guidance

This clinical guidance will support clinicians in their decision making by providing a framework of consistent advice and clinical pathways in order to provide high quality care, in the right place at the right time, during the COVID-19 pandemic. No negative impact on resource allocation is anticipated as a result of this guidance.

Having collaborated closely with EQIA participants, stakeholders have recognised the substantial improvements to this guidance and its potential for positive impact, particularly around helping to ensure provision of holistic and personalised care.

There was broad agreement that previous concerns, particularly in relation to the use of the Clinical Frailty Score, had been addressed within the revised versions of both guidance documents.

Ethical guidance

The substantial improvements to this document and its potential for positive impact were noted, including an increased availability of a range of perspectives to provide advice to support ethical decision making at all levels in Scotland, and other possible pandemics, or crisis situations where required. This EQIA has helped future proof these documents.

Local Ethical groups

There was discussion with EQIA participants about the membership of the local ethical advisory groups. It was agreed that as far as practically possible, the local groups should be demographically representative of the populations they serve.

The ethical advice and support framework will be updated to make clear that : ‘local group membership should be reflective of the population they serve as best it can, given the relatively small membership of these groups’.

Scottish Government will also share the evidence summary produced by NHS Education for Scotland with NHS Boards around the differential impact of the virus across population groups in Scotland.

Children and young people

There was discussion about the wider impacts on services for children and young people as an indirect consequence of COVID-19, for example, on education. It was felt that this was outwith the scope of the EQIA, however; it was agreed that this was an important issue and should be recorded as part of the discussion. It is important to note that ethical considerations must be made towards the involvement of children and young people in family care, for example, some young people are carers and therefore should be included in discussions and considerations.

Men (including trans men), Women (including trans women) and Non-binary people (Include issues relating to pregnancy and maternity including same sex parents) Gender reassignment

No specific issues were raised in relation to the guidance. However, experiences differ for people as they access different services, and therefore an awareness of any unconscious bias or discrimination towards involvement of their partner must be included and be recognised sensitively.

Disabled people (includes physical disability, learning disability, sensory impairment, long-term medical conditions, mental health problems)

Constructive feedback from Inclusion Scotland and the Scottish Commission for Learning Disabilities had been received since the guidance had been published in April. It was noted that stakeholder feedback, particularly from Inclusion Scotland and the Scottish Commission for Learning Disabilities, has helped to refine language, clarify intent and inform good practice in a number of areas throughout the clinical guidance to ensure the safeguarding of the protected characteristic of disability. For example, their input to help agree the guidance on use of the Clinical Frailty Score.

Minority ethnic people (includes Gypsy/Travellers, migrant workers, non-English speakers)

For groups where English is not their first language, hyperlinks to accessible resources on NHS Inform & HPS websites have been included within the clinical guidance. Hyperlinks to translated information is not always sufficient however as a significant proportion of Minority Ethnic people across communities are not literate in their own language so written information can be of limited use.

Following local guidance and protocol for provision of interpreting, where appropriate is recommended.

As part of the action plan to understand and address the impact of COVID-19 on ethnic minorities, a targeted marketing campaign was run by the Engagement and Insights Team from the COVID-19 and Ethnicity: Expert Reference Group. This campaign has had a very positive uptake and has helped in developing understanding where discrimination existed and has helped to advance equality of opportunity in terms of people from different communities accessing information. The learnings from this campaign has been shared with marketing colleagues across Scottish Government to ensure that minority ethnic communities continue to receive core COVID-19 public health messages in a way which is accessible to them.

The higher risk of COVID-19 on BAME communities was highlighted both from a patient perspective and from being a clinician/health & social care worker perspective. The growing evidence around the impact of the COVID-19 virus on BAME communities was acknowledged, but there was a reflection that there is limited evidence around how to best support and care for BAME communities differently.

Gather information relating to supports available for BAME communities, such as the new national staff forum etc and promote this to staff to improve care.

The provision of care to Gypsy Travellers was recognised as a challenge due to the complexity of their practical and cultural needs. The importance of being innovative in how we provide care to this population was emphasised. It was agreed that this was out with the scope of this impact assessment, but something that clinicians should continue to be aware of.

EQIA participants recommended that for BAME and Gypsy/Traveller communities, guidance should include contact details for trusted community organisations that may be able to offer advice, support and assistance. Bring this into the national work on the guidance and national action plan,

Sharing a link to the national framework and national action plan with NHS Boards and their local ethical groups may help raise awareness.

In response, Scottish Government has said that direct engagement with communities and grassroots organisations continues to be a major focus for the Scottish Government. This highlights the immediate and long-term priorities for these communities and allows tailored mitigating actions to be put in place. It was also recognised that continuing to develop these links with communities and their representatives will be valuable in fostering good relations between communities.

Recommendation that written translated material supplemented by audio/visual versions.

Ensure access to professional interpreting service within hospital/social care settings to ensure informed decision making.

Preparations for death and dying are different within Minority Ethnic communities – ensure contact is made with chaplaincy services within the NHS setting and which includes hospital settings which will accommodate this.

Access to advocates for communities who have historically had poor treatment or perceived poor treatment from health services.

Involvement of informal carers in decision making made explicit.

A recommendation is suggested that further work was required with the BAME community in terms of awareness raising and discussion re the scale and guidance as we felt it had been a gap in the process.

How can we action the gaps in evidence and improve knowledge?

The Office for National Statistics (ONS) published analysis of COVID-19 related deaths by ethnic group in England and Wales. This provisional analysis showed that the risk of death involving COVID-19 among some ethnic groups is significantly higher than that of those of White ethnicity. It found that the difference between ethnic groups in COVID-19 mortality is partly a result of socio-economic disadvantage and other circumstances, but a remaining

part of the difference has not yet been explained. The Scottish Government has a 5 strand Action Plan to understand and address the impact of COVID-19 on ethnic minorities.

Death and Dying-respect to cultural practices must be followed, and promoted.

Disability

There is further data and information to come with regard to impact on people with learning disabilities. Scottish Government/ Glasgow University and NRS are actively looking at this. We aim to learn from this and encourage local NHS boards to consider and take action where necessary, via the local ethical groups.

EQIA participants recommended that:

- existing health conditions or impairments that are related to our chance of benefiting from treatment, must not play any part in decision-making regarding our Equal right to access such treatment. There may be significant levels of social care and support needed as a result of the pandemic. This should not make health staff think that we will not benefit from treatment.
- disabled people have the right to be fully involved in decisions about our own lives, including life and death decisions. All decisions should be made with our involvement, and consideration of our best interests. There is no justification for policies based on age or learning disability that do not treat each of us with respect and as individuals.
- We and our advocates, have the right to know about decisions that may be made about us that will affect us. We would encourage the involvement of our advocates.
- Further development of any guidelines on the assessment, provision, and evaluation of treatment and care provided to individuals during the Covid-19 pandemic must be developed in collaboration with disabled people's organisations and representatives from human rights bodies.
- Provision of accessible formats.
- Ensure use of Augmentative and Alternative Communication (AAC) is provided and other communication aids.

It was noted that the guidance now made it clear that:

- Factors such as age, frailty or the existence of co-morbidities should only be considered when included as part of a non-discriminatory personalised assessment which will assess a patient's overall potential to benefit from an ICU admission, alongside their ability to return to a quality of life that is acceptable to them.
- It is vital that no clinical decisions are made on the basis of any characteristic(s) of a patient, such as age, disability or the presence of existing health conditions or impairments that are not clinically relevant to the potential benefits of a course of treatment. The healthcare response is crucial to ensuring that the rights to life and to health continue to be respected, without discrimination, and that resources reach those who are most likely to clinically benefit.

LGBT

The following points were made by stakeholders:

- LGBT community can often be excluded from their home as a result of their sexual orientation, at times having no fixed home address and being excluded from their own communities.
- LGBT people often use online sites and forums to stay in touch with each other as a safe way of connecting, however they also use 'safe spaces' to meet. These are currently no longer an option of connecting with their own community and therefore without the connection with each other this could lead to mental health and issues associated with isolation.
- LGBT hard of hearing community, will struggle to communicate with the two meters distance rules. They will also find it difficult to perhaps have representation or to access collection of medications etc, whilst shielding as the local services may not be in touch with them or vice versa, and not known to the local services.
- Stakeholders also highlighted that there are differential impacts on LGBT people as a consequence of COVID, for example, the fact that the LGBT community is both more likely to experience mental ill- health and less likely to feel connected to their local community, but community Covid support responses are mainly locality-based and therefore less likely to reach them.
- Isolation from their surrounding community can be a significant factor for LGBT community.
- Exploring LGBT needs and an appreciation of their position should be respected.
- Consideration that at times their physical health or presenting symptoms are not as a result of their Trans status.

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- It is vital that no clinical decisions are made on the basis of any characteristic(s) of a patient, such as age, disability or the presence of existing health conditions or impairments that are not clinically relevant to the potential benefits of a course of treatment. The healthcare response is crucial to ensuring that the rights to life and to health continue to be respected, without discrimination, and that resources reach those who are most likely to clinically benefit.
- The Scottish Government's Covid-19 guidance for those who are vulnerable or need additional support provides additional information. Ready Scotland's additional support page also provides links to information for disabled people, linking people to Disability Information Scotland
- The Scottish Government's Covid-19 guidance on health and wellbeing, including for individuals feeling anxious or depressed, is designed to provide assistance, while Ready Scotland's additional support page provides links to support and guidance for anyone struggling with their mental health and well-being.

Religion and belief

Worship brings comfort and peace to many in their day to day lives. Significant impacts on the ability to worship together as a result of COVID. This may have a long term impact on people who have a strong faith. The charitable work done by churches etc. will also have been limited and therefore causing an impact on those who would normally have received these supports.

Death and Dying-during COVID there has been a policy of limited visiting in hospital settings and care settings, this has resulted in many people not being able to say goodbye to their loved ones, which is a very important part of death for the remaining relative but also the dying individual.

Marriage and civil partnership

No specific issues were raised in relation to the guidance.

Pregnancy and maternity

No specific issues were raised in relation to the guidance.

General points

The revised versions of both the clinical guidance and the ethical advice and support framework were commended and the potential for positive impact through more personalised care for all vulnerable groups was emphasised.

It was also suggested that the positive and inclusive approach taken by all those involved throughout this EQIA was an exemplar for future impact assessments.

Communication and accessibility of the guidance:

- Involving patients and their family members and carers in decision making is of paramount importance, and work has been undertaken to consider how this can be managed within the current restrictions. For example, the promotion of virtual ways of communicating, including Near Me to enable family members/carers to take part in the discussion.
- Through the implementation of Realistic Medicine, there has been an ongoing dialogue with clinicians about the principles of shared decision making, which includes the consideration of communication and health literacy issues.
- The draft ToR developed for the ethical advice and support group note the importance of ensuring that decisions reached are communicated in an understandable way.

The importance of also considering those groups most likely to be affected by socio-economic deprivation was recognised as being a risk factor for COVID. Specifically, the impact on life expectancy as a result of deprivation.

Generally, biological age should not be considered to be the same as chronological age.

The potential value of the ethical groups in supporting clinicians around difficult decision making beyond COVID was highlighted, and further consideration to be given to the future remit of these groups.

There was some discussion around how the guidance impacts on the shielded population – both in terms of vulnerable patients and staff.

It was noted that comprehensive shielding guidance is being produced by colleagues and there is an intention to undertake an equality impact assessment on that guidance.

Whilst the focus has been on potential impact of the guidance, the group advised that further work should be carried out to develop processes/systems to evaluate actual impact.

Ethical groups (local and national) should have defined principles and have a discussion around values that underpin decisions and discussions. The national group might take a lead on supporting the setting of these as parameters to set a context for ethical decisions to be taken in.

Ethical groups to consider reporting on their demographics and the nature of advice that is sought from them to help ensure that they are representing their all of their community - both in terms of who uses the groups to seek advice and whose needs are served by them.

3. Briefly describe public involvement in this proposal to date and planned

We made this guidance available to the public via the Scottish Government website on 3 April 2020. We made it clear that the guidance had been produced in a fast paced and ever evolving situation and we welcomed feedback on how it could be improved. Since that date, we have received and considered feedback from a wide range of stakeholders.

4. Specific to this EQIA only, what actions have been, or will be, undertaken and by when?

Please see the feedback and recommendations we have received from stakeholders and how they have been handled (Annex C).

5. How will you monitor how this policy, plan or strategy affects different groups, including people with protected characteristics?

This guidance is intended to support good clinical decisions, which are shared between health and care workers and patients. This guidance focuses on clinical aspects of decision making, and is primarily aimed at clinicians in the context of the COVID-19 pandemic. The approach to achieving this aim has been described. We will seek to evaluate whether this guidance has impacted the approach to, and support for, decision making for the clinical community.

We plan to carry out an evaluation of the local ethical advice groups to help ensure they are operating effectively and to share good practice and learning. This evaluation is expected to be complete by the end of 2020.

We shall discuss the impact of the guidance with NHS Boards to help us understand how they have used the guidance to inform local care pathways .

We will also monitor the impact of the clinical guidance by inviting the public and stakeholders to alert us to any concerns or positive experiences regarding how clinicians are making decisions about the treatment and care about people with COVID-19 using this guidance. We shall provide a contact email address to send feedback to.

6. Publication

This EQIA report will be published alongside the guidance documents on the Scottish Government website.

7. Sign off by EQIA Chair

Craig Bell

PAG & Clinical Guidance Cell Secretariat

Directorate for Chief Medical Officer

DG Health & Social Care

The Scottish Government

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13 July 2020

EQIA participants

1.	Craig Bell	EQIA Chair - SG
2.	Sarah Ramsay	Scottish Academy
3.	Carey Lunan	Scottish Academy
4.	Arun Chopra (TBC)	MD, Mental Welfare Commission for Scotland
5.	Kate Fearnley	Executive Director, Mental Welfare Commission for Scotland
6.	Mark Evans	Head of Spiritual Care & Bereavement Lead, NHS Fife
7.	Donald Macaskill	CEO, Scottish Care
8.	Charlie Macmillan	CEO, Scottish Consortium for Learning Disabilities
9.	Sally Witcher	CEO, Inclusion Scotland
10.	Suzanne Munday	CEO, MECOPP
11.	Katharine Ross	Health and Social Care Integration Advisor, NSS
12.	Adam Strachura	Head of Policy and Communications, Age Scotland
13.	Laura Hutchison	Senior Enforcement Officer, Equality & Human Rights Commission
14.	Cathy Asante	Scottish Human Rights Commission
15.	Savita Brito-Mutunayagam	SG
16.	Alice Rutter	SG
17.	Mike Gillies	SG
18.	Dave Caesar	SG
19.	Sian Tucker	SG
20.	Michelle Watts	SG
21.	Eddie Doyle	SG
22.	Jacqui Lambert	SG
23.	Jennifer Graham	SG
24.	Bruce Sutherland	SG
25.	Chris Bruce (facilitator)	Lead on Equalities and Human Rights, NHS Lothian
26.	Dianne Williamson (facilitator)	Equality & Diversity Lead, NHS Fife

Evidence

Evidence used to inform the guidance:

- Emerging evidence and advice from SAGE
- Emerging evidence and advice from Scotland's CMO Scientific Advisory Group
- NHS NES evidence summary (available on request)
- Evidence summary produced by St Andrew's University (available on request)
- Feedback from stakeholders and how it has been handled (Annex C)

Feedback received on the guidance and how it has been handled

1. Ethical Advice and Support Framework feedback:



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Advice Feedback Sum

2. Clinical Guidance feedback:



COVID-19 - Clinical
Advice Feedback Sum