

COVID-19 Guidance: Ethical advice and support framework

Feedback Summary

Background

Version 2.3 of the COVID-19 Ethical advice and support framework guidance (“ethical guidance”) was published on the 3rd April 2020 on the Scottish Government website, alongside clinical pathway guidance. These two documents should be taken together. The ethical guidance:

- Outlines the approach in Scotland to ensuring that ethical advice is available when required for challenging decisions
- Outlines the key principles that will underpin the approach to ethical decision making during this pandemic
- Outlines structures to be established locally and nationally to ensure that where ethical advice is needed, it is available in a timely and useful way.

Version 2.7 of the Ethical Advice Guidance, for consideration at the EQIA, has been updated to reflect stakeholder feedback. Key changes include:

- Increased focus on human rights and equality obligations, what these mean in this context, and how the principles underlying human rights and equality influence ethical decisions and care delivery
- Recognition of the needs of individuals with protected characteristics, including disabilities
- Increased focus on shared decision making, and support to enable patients and those they chose to involve in decision making processes
- Greater clarity that guidance should apply fairly to all patients, regardless of characteristics, capacity status or differential diagnosis
- Increased transparency and clarity of language for the non-clinical audience
- Clearer recognition of how these new structures will complement pre-existing ethical advice mechanisms and structures

Process

To aid the further development of this document, the guidance team have:

- Reviewed newly available complimentary documents, such as guidance issued by the BMA, public statements from NHSE, ethical guidance issued by WHO and other nations
- In addition to the call for feedback on the original document, we have engaged in a detailed development process with the EHRC, SHRC and Inclusion Scotland to develop the content around human rights and equality, to ensure that these were truly embedded in the guidance
- Further feedback has been invited from a range of stakeholders on the basis of a more recent drafted version, and where appropriate these comments have been reflected in the guidance

KEY

Change	Colour
Before EQIA Meeting 1	White
Before EQIA Meeting 2	Green
Post EQIA	Orange

THEMES	Source of Feedback	Key Recommendations	Response by Guideline Development Group
Background	EQIA Meeting 2	Reflection on the potential positive impact of highlighting an equality and human rights-based approach to holistic and individualised patient assessment.	This theme is woven through the document
	Previous EQIA	There is a need for clarity around equality and human rights obligations to be reflected earlier in this document	This is now reflected in the front page summary
	Academy of Medical Royal Colleges	Request for greater clarity that any changes in resource distribution or care delivery should impact equally on COVID-19 and non COVID-19 patients, and that any positive changes such as availability of ethical advice should also be available for cases without COVID-19.	This is now reflected in the front page summary.
	Centre for Mental Health and Capacity Law, Edinburgh Napier and University Glasgow Caledonian University	More clearly set out the context for ethical guidance may be considered which notes that there is no specific treatment or prophylaxis option for COVID-19. It is recognised that this may change. As new and different options present then the ethical circumstances may also change. It may therefore be useful to include a sentence noting that the ethical guidance may change to reflect any change in treatment options.	The background section has been expanded to better reflect the points made here.
	ALLIANCE	A much clearer indication is required of what a 'competing obligation to the wider population' is	The context of the pandemic has been further clarified, and the obligation to ensure equity of access in the context of resource scarcity has been developed further in this document, with clarity that this should be non-discriminatory.
Human Rights and Equality	EHRC, SHRC, and Inclusion Scotland	The wording of this document was reviewed by EHRC, SHRC and Inclusion Scotland with key recommendations around clarity of how equality is applied in the context of this framework, how human rights obligations can be best embedded in this framework, and reflecting the importance of distinguishing between “good” and “ethical” decisions.	Through an iterative process, the guidance has been refined in discussion with EHRC, SHRC and Inclusion Scotland to derive wording that they felt comfortable with. Particular points of improvement were around recognising the principles underpinning resource distribution, and clarity of human right obligations in this context.
	Equality and Human Rights Commission, Scotland	Both the Clinical Advice Guidance and the Ethical Advice and Support Framework should be revised to make clearer the	These comments have been reflected in the updated guidance, which now makes far

		principles of equality and non-discrimination from the outset to support frontline staff when making challenging healthcare decisions while fulfilling their legal duties.	more explicit the ethical framework that will be employed, and the human rights and equality legislation that underpin this. In addition, there is an additional human rights section, which outlines the legal underpinnings of the framework and how the guidance relates to human rights and equality law. The specific principles that were outlined in both responses have been directly referenced and addressed in the updated document.
	Scottish Human Rights Commission	During the passage of COVID-19 emergency legislation we called for “an ethical framework for both health and social care in Scotland which sets out ethical and human rights-based principles to guide decision-making”. We believe that the guidance would be significantly enhanced by explicit consideration of and reference to human rights standards and principles, which legally underpin the duties on those on the frontline tasked with making difficult decisions at this time.	
		In recognition both of its impact on disabled people and the general obligations of the UN Convention on the Rights of Persons with Disabilities (CRPD) to involve disabled people in decisions concerning their human rights (Article 4), we recommend that disabled people’s organisations are brought in to work collaboratively on the guidance as it is amended.	We have sought to do this through: <ol style="list-style-type: none"> 1. An open call for response on the original document published 3rd April 2. Through the Equality Impact Assessment Process (EIA), ensuring that there will be appropriate representation of people with disabilities.
	Centre for Mental Health and Capacity Law, Edinburgh Napier and University Glasgow Caledonian University	People with disabilities, including those with mental disabilities, are likely to be particularly affected by the ethical and clinical issues of resource allocation and equal treatment, and it is vital that guidance particularly affecting them is drawn up in consultation with disabled people.	Reference to human rights and equality legislation has now been made more explicit throughout the document. There is an expanded section on human rights and equality legislation and how this should be reflected in clinical and ethical decision making. Particular note has been made of discrimination concerns related to age and disability. The latest version includes reference to the UN CRPD
		It is essential that the Clinical Guidance and Ethical Guidance are clearer about the legal and wider human rights imperatives that govern the exercise of duties and responsibilities of those making healthcare decisions affecting persons with mental illness, dementia or learning disability.	
		Socio-economic equality should also be at the forefront of strategic decision-making, with the Fairer Scotland duty and related impact assessment in operation to minimise any disadvantage to patients living in areas of deprivation.	The importance of equity is now far more prominent in the revised version of this guidance. Further consideration of the potential for differential impact on certain

	Health and Social Care Alliance Scotland	It is critical that equal access to these facilities is ensured, including that of groups and individuals who are often marginalised and unseen. We believe that the Scottish Government should clarify how people who are furthest from accessing support and services will receive information about the local hubs and centres.	groups will be carried out and addressed accordingly through the EIA process. It is beyond the scope of this guidance to consider transport and geographical limitations, as this guidance is centred on clinical decision support, through available ethical advice – which is available to all areas in Scotland, and being a virtual group there is no location specificity.
	Equality and Human Rights Commission, Scotland	Public bodies, including Health Boards (including Special Health Boards) and NHS and local authority Integration Joint Boards (Health and Social Care Partnerships) must continue to pay due regard to equality matters in the course of their work, including through equality impact assessments as per the Equality Act 2010 general equality duty and Scotland specific duties. Socio-economic equality should also be at the forefront of strategic decision-making, with the Fairer Scotland duty and related impact assessment in operation to minimise any disadvantage to patients living in areas of deprivation.	
Disability	Inclusion Scotland	It is important to provide inclusive communications. This applies in many places throughout the guidance (an issue applicable both to disabled people who are patients and disabled people who are members of the NHS workforce) and which could usefully be flagged.	Throughout the guidance documents, we have highlighted the importance of enabling patients and those that they chose to involve to be active participants in conversations and decisions about their health and wellbeing. We have signposted clinicians to patient information on NHS inform which hosts information in a variety of languages including BSL, easy read format as well as audio versions. In addition, Scottish Government Equality Policy Unit have provided funding for Glasgow Disability Alliance, the British Deaf Association, and Deafblind Scotland to ensure that Scottish Government advice is available in a variety of accessible formats so that as many people as possible are able to receive key health messages.

BAME Community	Academy of Medical Royal Colleges	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.	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 utilised community broadcast media where possible and highlighted the availability of translations of information resources. 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. There is limited evidence around how care pathways can be altered to reduce the risk to BAME individuals, and so there are no specific points that we have been able to include in the guidance. To help ethical advice group at the local level be mindful of how COVID-19 may impact groups differentially, we are sharing an evidence summary, which is available on request.
LGBTQ+ community	Mental Welfare Commission	LGBT individuals 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. 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-19 support responses are mainly locality-based and therefore may be less likely to reach them.	Through the pandemic we are aware of an increase in remote consultations, which may mitigate some of the concerns around locality-based services being difficult to access. The issues raised are beyond the scope of the guidance to address.
Inpatient visiting	EQIA 2	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	This is beyond the scope of this guidance to address, but we are aware that there has

		important part of death for the remaining relative but also the dying individual. Respect for cultural practices must be followed, and promoted.	been a relaxation of visiting restrictions which is fully outlined in guidance from HIS.
	Inclusion Scotland	There may be a case for people providing communications support, or to enable supported decision-making, to be included as essential visitors (might the need for interpreters also be an issue for people whose first language isn't English)	<p>We have signposted clinicians to patient information on NHS inform which hosts information in a variety of languages including BSL, easy read format as well as audio versions.</p> <p>In addition, Scottish Government Equality Policy Unit have provided funding for Glasgow Disability Alliance, the British Deaf Association, and Deafblind Scotland to ensure that Scottish Government advice is available in a variety of accessible formats so that as many people as possible are able to receive key health messages.</p>
Shielding	EQIA 2	It was noted that there are specific concerns around staff members that are being asked to shield, and how guidance has had a differential impact on some groups.	This is beyond the scope of this guidance, however there is separate detailed shielding guidance and an EQIA will be considered separately.
Access to Care	Academy of Medical Royal Colleges, Scotland	The Academy highlighted the challenges with access to digital resources and healthcare delivery (due to lack of equipment, data, higher prevalence of cognitive impairment).	<p>In relation to the ethical support availability, increased use of digital communication such as virtual meetings is hoped to increase accessibility and availability of advice, independent of location.</p> <p>More broadly, there is active work within the Scottish Government to consider this issue. This falls outside the scope of this document. As part of the response to COVID-19, Near Me was made available in nearly every hospital and GP practice. Prior to March 2020, there were around 300 Near Me consultations a week: by June, it was nearly 17,000 a week. While it has helped deliver care during this COVID pandemic, there is recognition that it</p>

			<p>is not suitable for some. The Near Me team is running a public engagement exercise requesting feedback from the general public which is due to conclude at the end of July. This will help highlight some of the issues around challenges to access.</p> <p>We would also like to highlight the work being carried out by our colleagues in NES Digital service (NDS) as part of the Digital Health and Care strategy. NDS are developing a national digital platform for health and social care. One of the core intentions of the platform is that it will host information that people and their practitioners need at the point of care, and support the recording of shared decision-making conversations. It was due to be trialled in certain Health Boards this year but understandably this will be delayed.</p> <p>As NDS works to design and develop the platform, they are becoming increasingly aware that the challenges of digital equality are of vital consideration and are exploring how they can adapt existing processes to better meet the needs of those that are most disadvantaged. To achieve this aim, they are working with the Equalities Leads across Health Boards and local authorities to explore how digital solutions can have a positive impact on inequalities. They are also working with the National Rural Mental Health Forum to understand in more depth some of the digital challenges faced by the 1 million people in Scotland living in rural areas.</p>
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	Academy of Medical Royal Colleges	There should be recognition that creating relationships of trust and being able to accept care, due to adverse childhood experiences (ACE) and cultural beliefs (e.g. gypsy traveller groups) may impact accessibility of care.	<p>We recognise this important area of work, however this is outside the scope of this guidance to address. However, this is an ongoing area of work for the Scottish Government.</p> <p>The work of our colleagues who lead on the programme of work around ACEs has been put on hold since the start of the pandemic, as they work to support the immediate work of the Covid-19 Children & Families Leadership Group. However, we would like to highlight their long-term action plan which they should hopefully be able to return to in the near future</p> <ol style="list-style-type: none"> 1. Providing inter-generational support for parents, families and children to prevent ACEs (e.g. tackling child poverty programme, Universal Health Visitor Pathway, Family Nurse Partnership Programme, perinatal and infant mental health support). 2. Reducing the negative impact of ACEs for children and young people (e.g. school counselling services, development of Barnahus concept for child victims). 3. Developing adversity and trauma-informed workforce and services (e.g. National Trauma Training Programme, Education Scotland work to support nurture and trauma-informed schools). 4. Increasing societal awareness and supporting action across communities (e.g. children's rights awareness raising, Families and Communities Fund and CashBack for Communities Fund).
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			people with lived experience, to create and deliver quality training resources.
DNACPR	Health and Social Care Alliance Scotland	<p>We believe that more detailed guidance should be issued by the Scottish Government to GPs and other members of primary care, clearly outlining when and how DNACPR discussions should take place.</p> <p>There also needs to be explicit direction about actions that can never be clinically and ethically justified during the COVID-19 crisis, such as the blanket use of DNACPRs on care home residents or assumptions about futility of treatment being made solely on the basis of the existence of a physical or mental disability</p>	<p>This is beyond the scope of this guidance</p> <p>This is beyond the scope of this guidance, but this will be addressed within the public facing summary. The point around inappropriate blanket application of DNACPR forms or decisions has been addressed in version 2.5 of the clinical guidance. The ethical guidance is explicit that each person should be treated as an individual. The clinical guidance reflects the importance of appropriate advanced care discussions.</p>
	Scottish Human Rights Commission	Concerns, exacerbated by stories reported in the media, include blanket non-treatment policies being applied to care home residents, and Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) notices being encouraged for those with long term conditions without full discussion between doctors, their patients and carers or appropriate processes.	
Staff Wellbeing	British Medical Association	Ask to further reflect the risk taken by staff, and the need for reciprocity such as ensuring adequate PPE provisions.	This is reflected in the text, and the role of the groups in signposting to wellbeing resource has been further clarified. Reciprocity principles made more explicit.

	<p>Health and Social Care Alliance Scotland</p>	<p>The clinical guidance notes that “physical and mental wellbeing of all staff should be supported” but does not clarify how. We believe that more information on approaches, what works and what is possible should be published to allow for health and social care systems to adopt, share and collaborate</p>	<p>The provision of support for difficult decision making is one form of support for staff wellbeing. No staff member should be forced to make a difficult decision alone. Additionally, this document highlights the importance of people or groups, including staff, not being affected unfairly by decisions and the importance of seeking the views of those that decisions impact. Additionally, there is a body of work ongoing at board and national level to support staff mentally and physically through this pandemic and during recovery. This is highlighted within the body of the ethical guidance, to ensure that local groups signpost staff to it given the nature of issues they will be contacted about.</p>
	<p>Inclusion Scotland</p>	<p>Clinicians, members of the NHS workforce themselves, may have health conditions that put them at high risk of adverse outcomes should they contract Covid-19. They may themselves be in the official shielding group. They may be disabled people and/ or from BAME communities, who in both cases evidence seems to be suggesting are at higher risk.</p>	<p>We acknowledge the workforce issues you have raised. Addressing these concerns is beyond the scope of this guidance. However, Scottish Government Workforce Directorate have provided the following resources which we hope will help:</p> <ul style="list-style-type: none"> • On 30 March, Scottish Government published guidance for staff and managers on Coronavirus, that directs staff to verified sources of advice. This will inform a standard approach to occupational health, for application across NHS Scotland. This advice contains information on risk assessments. (https://www.staffgovernance.scot.nhs.uk/coronavirus-covid-19/guidance/) • The Scottish Government’s Clinical Guidance Cell has published detailed

			<p>information on definitions of underlying health conditions to support Health and Social Care and Emergency Service Workers understand the risks associated with their health conditions.</p> <p>https://www.staffgovernance.scot.nhs.uk/media/1701/guidance-for-health-and-social-care-and-emergency-service-workers-with-underlying-health-conditions-30-march-2020.pdf</p> <ul style="list-style-type: none"> • The Scottish Government's Clinical Guidance Cell is updating its guidance on risk assessments, to reflect the current situation and the latest clinical advice. • Our future policy approach will facilitate individualised decision-making, that considers a range of known risk factors, the nature of an employee's work, steps taken to reduce risk, the expectations of employees, and the prevalence of the virus. • The Business Disability Forum have reviewed our National Wellbeing Hub (www.promis.scot) and made available a suite of resources to support disabled staff which includes resources on everyday needs at work.
Communication	Inclusion Scotland	Health literacy and accessibility of information should be a priority. This should include provision of accessible formats and other communication aids.	The ethical guidance highlights the need to involve people in decisions and to communicate information in a way that people are able to understand. We have included links to external guidance this supports this.
	Inclusion Scotland	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	The principles around capacity, consent and involvement of advocates have not changed from normal practice and are not impacted

		<p>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.</p> <p>Disabled people and their advocates, have the right to know about decisions that may be made about us that will affect them.</p>	<p>by this guidance. This guidance emphasises the principles of Realistic Medicine, including the involvement of patients and those that they chose to involve in decisions about the treatment and care that they choose.</p>
	<p>Academy of Medical Royal Colleges, Scotland</p>	<p>Poor levels of literacy, and health literacy may impact on people’s ability to input into decisions about their health and wellbeing (patient information has to be adapted accordingly)</p>	<p>The guidance highlights that people should be supported to input into decisions about their health and wellbeing, and signposts to resources that are available externally to help clinicians and patients communicate effectively. In particular, the ethical guidance emphasises that advice offered by ethical groups should be explained to patients in a way that they are able to understand.</p> <p>In addition, the following piece of work is underway by our colleagues in the person-centred and participation team.</p> <p>Scottish Government, led by the CMO office, has published a Health Literacy Plan for Scotland which is strongly embedded in the principles of Realistic Medicine. The plan has been developed with the aim of:</p> <ul style="list-style-type: none"> • removing the barriers to health and care system that get in the way of improving population wellbeing • Raising awareness amongst the workforce of the hidden problem of health literacy and helping them respond better, • building a go-to web place for health literacy news and tools • testing ideas for better designed services and more health literacy responsive organisations through a programme of work in NHSTayside.

			It acknowledges that how low health literacy leads to poor health outcomes and sets out a range of actions to improve health literacy practice across the health and care system.
Capacity	Centre for Mental Health and Capacity Law, Edinburgh Napier and University Glasgow Caledonian University	It is important to appreciate that persons with mental illness, dementia or learning disabilities (with or without an incapacity assessment), and indeed anyone, may have decision-making difficulties, particularly at stressful times and when they are unwell, and so may need to be actively supported to make decisions about their care and treatment.	This was reflected as part of the ethical considerations in the original document, but further expansion on this and greater emphasis has been added in the revised version. In addition, clarity on this point is given in the summary document.
	British Medical Association	Request for clarity that patients who lacked capacity should not be given preferential access to treatments on the basis of a lack of capacity	Clarity added in the text that any changes to care delivery should be applied fairly and transparently to all patients.
Health Board ethical advice and support groups	NHS Board Equality Leads	Reflection that given emerging evidence of differential impacts of COVID-19 on minority communities, it is important that the local groups have the ability to reflect a range of groups effectively.	The guidance has been updated to highlight that where possible, local groups should be reflective of the communities that they serve, within the constraints of the small group size. Additionally, we have proposed circulating the evidence summary produced by NES to NHS Board ethical group chairs, to help inform their work going forward.
	Mental Welfare Commission	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.	The Terms of Reference for the local groups have been developed and defined locally to ensure that the groups are able to meet local needs. The guidance specifies that the national group will take a principle based approach, in line with human rights and equality obligations.
	Inclusion Scotland	I remain of the view that it will be essential to have someone on the ethical groups with expert knowledge of equalities and human rights if the very welcome intentions now clearly set out in the clinical guidance and ethical framework are to be realised in practice.	The membership of the local ethical advice groups should decide their terms of reference. This flexibility will allow them to agree how they will meet the needs of the populations they serve. We are consulting NHS Boards on a proposed evaluation of the local ethical groups that will look at how they interact with other systems locally, including

			<p>their equality leads. Once we have the results of that evaluation, we will be well placed to consider whether the local ethical groups have a role going forward, what that role should be, and whether there have been any positive experiences, learning and good practice that can be shared. In addition, we intend to circulate an evidence summary produced by NHSNES that looks at differential impacts of COVID-19, to the local group chairs, to help inform their advice and engagement going forward.</p> <p>We have been working on the draft Terms of Reference (ToR) for the national group and the ToR will give further detail on the group's role and its membership. We have really valued the advice that we have received from MWC and other stakeholders who have helped develop this guidance. Equality and human rights will play a central role in the national group's the terms of reference.</p>
NHS Board Equality Lead	Request for clarity on how these groups should interact with NHS Board Equality Leads	This should be considered locally within the Terms of Reference documents, but falls outside the scope of this guidance	
NHS Spiritual Care Leads	Request to ensure that the spiritual care perspective is reflected at the national level	This will be further clarified in the national Terms of Reference for the National ethical group, but consensus that this would be a positive addition to the group.	
Mental Welfare Commission	Request for clarification around how this group will interact with other existing structures, such as the MWC	It has been clarified in the document that this is intended to complement rather than replace existing structures. There is no obligation on individuals to approach this group for advice, but it is an available source of support if it is required.	

	NHS Dumfries and Galloway	Request for specific clarification and assistance with terms of reference, and advice as to how local groups will interact with the national ethical advice group.	A response was sent to the lead contact at NHS Dumfries and Galloway, and questions received have been developed into an FAQ document for Health Boards to provide detailed clarifications or direct to other sources of advice where appropriate. The Terms of Reference for the national ethical advice group are under development.
	ALLIANCE	Clarity should be provided on the role of these groups, how they will make decisions transparently, and the principles that will guide them, what equalities and human rights criteria will apply, who they are accountable to, and what independent scrutiny will apply to their decision making.	It is felt that the role of these groups and their governance structure is clear within the document. Further detail on processes should be contained within the terms of reference of the groups. The Terms of Reference for the national group are under development.