COVID-19 Ethical advice and support framework

FAIRER SCOTLAND DUTY SUMMARY

Version 1

CMO Directorate

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FAIRER SCOTLAND DUTY
SUMMARY TEMPLATE

Title of Policy, Strategy, Programme etc.	COVID -19 Ethical Advice and Support Framework
To Note **Summary of aims and expected outcomes of strategy, proposal, programme or policy**	It is important that given the rapidly evolving nature of the COVID-19 pandemic, that the ethical advice and support framework is viewed in the current clinical and healthcare context. Scottish Government will aim to keep this guidance up to date, and the need for ethical support at local and national level will be kept under review. **Background** In the early phase of the COVID-19 pandemic, there was concern from the clinical community that challenging ethical issues may arise, outside the scope of normal clinical experience. This guidance was developed to ensure that where ethically difficult decisions arose, decision makers were able to access timely and useful advice to help inform decision making processes. The guidance outlines the introduction of: 1. A national ethical advice group 2. Local health board ethical advice groups 3. Increased clarity around mutual aid agreements **Aims** The aims of this guidance are to: 1. Ensure that timely, useful ethical advice is available to health and care decision makers 2. Set out the suggested approach to ethical decision making, founded upon human rights and equality obligations and existing professional and legal standards **Expected Outcomes** This guidance came into effect on 3rd of April 2020 and has since undergone an iterative process of revision through positive engagement with stakeholders. **Local ethical advice groups** Local ethical advice groups have been introduced in NHS Boards in Scotland and we intend to support an external review of their impact and function. The anticipated impact is: a) Greater availability of high quality ethical advice and support to aid clinical decision makers

	b) An increase in range of perspectives available to input into ethically difficult decisions. As far as practically possible, the lay membership of local groups should reflect the make-up of the populations they serve c) Increase in visibility of the importance of ethical considerations in clinical care delivery and ensure high quality advice is consistently provided **Mutual Aid agreements** The increased use of mutual aid agreements primarily encourages the use of existing networks for advice in ethically difficult decisions, where there is not time to consult with an ethical advice group due to the urgent nature of the situation. The anticipated outcome of this is: a) Formalisation amongst networks of temporary structures for peer to peer advice and support **National ethical advice group** The Terms of Reference of the national ethical advice group are under development and will be published separately to this guidance. This guidance provides a high-level framework, which will be developed further through the Terms of Reference. This group will be guided by a principle based approach and an awareness of the equality and human rights obligations. **This group will offer:** a) a point for escalation, if ethical issues require additional consideration beyond the scope of the local groups or if a second review is requested b) opportunity to review system-based ethical challenges, where these are shared by more than one NHS Board c) consideration of ethical issues relating to complex individual cases, that may be beyond the expertise of the local group d) review of the common challenges that are being encountered and to consider whether review of or additional guidance would be useful The expected outcomes as a result of the introduction of this group are: a) increased fairness for patients across Scotland, as a result of ethical consideration of common challenges and shared learning from these b) increased decision-making support for the health and care community, through offering a point of advice when considering challenging ethical issues c) greater transparency for patients and the public around ethical challenges and considerations, through publication of anonymised minutes d) increased breadth of input into difficult clinical decisions, through diversity of membership of this group

Summary of evidence

Due to the speed with which guidance was required as part of the immediate response to the COVID-19 pandemic, there was not a call for evidence prior to initial publication of this document. Consideration towards the Fairer Scotland Duty took place in the context of a wider Equality and Human Rights impact assessment (EQIA). Stakeholders were invited to submit supplementary additional views and relevant points that came up through the EQIA process considered here. Stakeholders within the EQIA process represented marginalised groups, that are also disproportionately affected by poverty.
The consultation process is outlined below:

Date	Consultation	Stakeholders
3/4/20	Public call for evidence	Submissions requested from all external stakeholders and consideration of how these could be reflected in revised guidance. This evidence is summarised in Annex A (EQIA Feedback)
29/4/20	Discussion with external stakeholders and agreement of next steps	This discussion focused on the human rights and equality impact of this guidance and how the guidance could be strengthened to reflect the importance of this more clearly. Feedback was incorporated into the next iteration.
30/4/20 – 17/5/20	Collaborative development of wording through close work with stakeholders	EHRC SHRC Inclusion Scotland Scottish Care Scottish Commission for Learning Disabilities
5/6/20	Revised guidance circulated to stakeholders for comment	EQIA attendees asked to comment on revised guidance in advance of virtual discussion.
25/6/20	Equality Impact Assessment	(For a full list of stakeholders engaged in the EQIA process please see Annex B)
25/6/20	Call for further evidence specific to impact related to Fairer Scotland Duty	EQIA participants asked to contribute, and to share contact details for other interested organisations.
8/7/20	Final deadline for comments	Points of clarification were explored with stakeholders to ensure we had fully understood.

Health and Social Care Alliance Scotland

- There should be due consideration of maintaining equal access to all structures, and in particular there is a need to ensure that these are accessible to patients from areas of deprivation.

Equality and Human Rights Commission

- 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

British Medical Association Scotland

- Care must be taken to ensure that the pandemic response does not deepen existing health inequalities

	Inclusion Scotland • Patients must be supported in being able to input into decisions about their care, and where advice is given by ethical advice groups this advice should be explained to patients in a way that they are able to understand. **NHS Board Equality Leads** • There is a need for local groups to be mindful of the unique challenges faced by people of different backgrounds and beliefs. There is a need for the local groups to be as reflective as possible of the populations that they serve, within the constraints of a limited membership. **Academy of Medical Royal Colleges, Scotland** • There should be a recognition of the impact of socioeconomic deprivation on reduction in life expectancy. Socioeconomic deprivation is linked to higher levels of co-morbidity, and chronological age is not equivalent to physiological age. There is a need to recognise early morbidity and mortality related to inequity (shorter lives in sicker health; chronological age does not equal biological age so any guidance that uses age as a threshold is problematic in this regard) • There is a risk that staff members who are socioeconomically deprived will feel unable to refuse to work, due to the financial impact. This may result in staff not appropriately shielding or taking on greater personal risk. • There is concern about the impact of poor levels of literacy, and health literacy (patient information has to be adapted accordingly) • There should be steps to address the challenges with access to digital resources and healthcare delivery (due to lack of equipment, data, higher prevalence of cognitive impairment) in socioeconomically deprived populations • Adverse childhood experiences (ACE) may impact on individuals trust in healthcare, and their willingness to engage
Summary of assessment findings	***Holistic and Person Centred Care*** *Through the EQIA process, it was highlighted that the ethical guidance as worded has a potential for positive impact on groups that have felt marginalised. It was felt that the emphasis on sharing decisions and enabling engagement in decision processes was positive. The guidance emphasises that the patient should be assessed holistically rather than relying on screening tools alone. This may mean that factors such as socioeconomic disadvantage are better placed into the appropriate context, looking at the whole patient. It was noted at the meeting that the impact of the guidance at the individual level would be challenging but important to evaluate. The introduction of ethical advice groups is hoped to*

	increase the availability of a range of advice in the context of ethically difficult decisions for all patients. Through the wider Realistic Medicine programme, led by the Chief Medical Officer in Scotland, there is commitment to delivering personalised care that people really value, and which is based on what matters to them. This remains an ongoing area of work. *Which changes, if any, are being implemented?* ***Physiological and chronological age*** *The reference to age in the guidance documents related only to the use of the Clinical Frailty Score.* Frailty *can affect people of any age and has a strong association with socio-economic deprivation. Given that the CFS has been validated for use in those >65 and over, it is advised this should be used as part of a person-centred assessment of an individual. We feel this is appropriate to reference age in the context of a screening tool. However, the guidance emphasises the need for a holistic and person-centred assessment that should consider the more nuanced concerns around chronological age, physiological age, and mortality and morbidity risk. We feel that this aligns with the approach recommended by the Academy of Medical Royal Colleges.* ***Communication and engagement*** *The consultation process highlighted the importance of considering each patient as an individual, through a holistic and person-centred assessment. Patients should be enabled to engage in discussions and decisions about their health and care, and the guidance emphasises that all possible steps should be taken to support this through use of resources, ensuring accessibility of information, and making sure that information is available in a format that people are able to understand. This is closely aligned with the aims of Realistic Medicine, and the ethical advice and support guidance has been updated with the help of external stakeholders to make sure that these principles are consistently woven throughout.* *The impact of changes to economic and social policy on health are well established*. An example of *a holistic and person-centred assessment approach would be the Welfare Advice & Health Partnerships (WAHP) - a public health response to mitigate this impact on people experiencing disadvantage. Developed in primary care, WAHP are embedded in over 100 GP practices across Scotland, mainly areas of deprivation. They provide patients with expert and regulated Social Welfare Legal Advice, including income maximisation, welfare benefits, debt resolution, housing problems and employability support as well as representation at tribunals. For more information see the film Money Worries in Sickness and in Health; http://www.improvementservice.org.uk/money-worries-in-sickness-and-in-health.html* ***Health Literacy***

	Health literacy shows strong associations with education, poverty, employment (HLS-EU Consortium, 2012; Rowlands et al., 2015), first language other than the national mother tongue and deprivation of the area of residence (Rowlands et al., 2015). It can thus be considered a social determinant of health. *Inequalities in health exist across many dimensions of social position. Although most routine data highlight inequalities by area deprivation, the inequalities are also marked when looked at by individual socioeconomic position and for particular disadvantaged groups such as those who are care experienced, the traveller community, and some ethnic minorities.* *Scottish Government has published a Health Literacy Plan for Scotland that is strongly embedded in the principles of Realistic Medicine. The plan has been developed with the aim of:* • *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 NHS Tayside.* *It acknowledges 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 such as:* • *Promoting and strongly recommending the* ***key learning points from the body of work carried out in NHS Tayside to promote health literacy****. These include amongst many others the use of health literacy tools and techniques for professionals to use, such as 'Teachback', Sharing clearer information with people before they attend and leave hospital by improving appointment letters and making them more considerate of people's communication needs, and promoting 'walkthrough' and 'wayfinding' approaches that can enable people to access care more easily by removing barriers such as inconsistent signs.* • ***Developing more health literacy responsive organisations and communities*** *where learning can be shared. This includes collaborative action with NHS England National Health Literacy Collaborative to explore areas of common interest to derive clear actions for mutual benefit. An initial focus will be on medications information,* • *Working with the Royal Pharmaceutical Society to further their ambition to* ***embed health literacy within school age.*** • ***Spreading learning from the health literacy work*** *through the emerging welfare reform programme. In particular, the agency established to deliver Scotland's new social security system.*

	Reflective Membership of Ethical Groups *Emphasis was placed on the importance of ensuring that the local ethical groups were able to reflect the values and experiences of those that they sought to serve, which should include representing the socio-economic profile of the area. After the EQIA, we have suggested that we should approach this by:* *1. Highlighting that as far as possible, lay membership of local ethical groups should be reflective of the populations that they serve.* *2. Circulating an evidence summary submitted to the guidance team, which summarises existing evidence around the differential impact of COVID-19 on a range of groups, in order to inform the approach of the groups.* ***Access to advice*** *It was highlighted that locality based care may be more difficult to access for deprived communities. To an extent, the move to increased use of remote consultations may mitigate some of these impacts. In particular, the ethical support structures are intended to meet virtually, enabling participation of a range of individuals independent of locality.* *While it is outside the scope of this guidance, there is ongoing 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.* *As NDS works to design and develop the platform, they are becoming increasing 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.* *Prior to Covid-19* **Near Me** *was introduced as one of the means to reduce inequalities by improving access to services through reducing travel, time off work or school. There were also some local clinics set up which meant patients only had to travel shorter distances but didn't need to have equipment and could be supported.* *In addition, prior to Covid-19, work was underway to understand the needs of those who were digitally excluded for whatever reason. That*

	work is being taken forward by Connecting Scotland and continues to make progress. We have a specific project underway with some deep end GP practices as part of the Connecting Scotland programme to support access for people who may be digitally excluded to date *Within primary care, Deep End practices are key delivery partners in all of these programmes of work. Scottish Government Primary Care division provides funding to the Deep End project, which aims to provide training and shared-learning opportunities to GPs working in deprived areas, as well as raising awareness. The Deep End project has had funding approved for a further three years beginning in 18/19.* *The Scottish Government remains fully committed to its target of recruiting 250 Community Link Workers (CLWs) in GP surgeries by the end of this Parliament. This is a core element of local support to the 2018 GP contract. A CLW is a generalist practitioner based in or aligned to a GP practice or Cluster who works directly with patients to help them navigate and engage with wider services. Their purpose is to improve patient health and well-being, reduce pressure on general practice and tackle health inequalities* *Of note, deprivation was given a greater weighting under the new Scottish Workload Formula, which supports the GP Contract. Of the 100 practices with the most patients living in deprived areas, 77 gained from the new GP funding formula.* ***We will share an evidence summary produced by NES, which highlights how COVID-19 has impacted on individual groups. This should inform the approach of the groups going forward and increase their awareness of the differential impact the pandemic has had on disadvantaged and minority groups.*** ***Adverse Childhood Experiences*** *We know that low income is associated both with greater prevalence of ACEs and that it also impacts on people's capacity, resources and resilience to help counteract the negative effects. As a result, the Government's mission to tackle child poverty is key to our commitment to address ACEs. In turn, action to address ACEs is also an important factor in preventing poverty, which can result from the impacts of ACEs on lifelong learning, health and employment prospects.* *The programme of work around ACEs has been put on hold since the start of the pandemic, as the team 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.*

	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).* *The exposure of our society to childhood adversity and psychological trauma will have increased significantly as a result of the COVID-19 virus and from the impact of social isolation and lockdown. This can have devastating and long-lasting effects on people's lives.* *Scottish Government is committed to developing a trauma-informed and trauma responsive workforce and services across Scotland to help to bring people together, rebuild relationships and give all members of the community a voice in planning for recovery.* *Scotland was one of the first countries in the world to develop a Knowledge and Skills Framework for Psychological Trauma, led by NHS Education for Scotland. This framework lays out the essential and core knowledge and skills needed by all tiers of the Scottish workforce to ensure that the needs of children and adults who are affected by trauma are recognised, understood and responded to in a way which recognises individual strengths, acknowledges rights and ensures timely access to effective care, support and interventions for those who need it. In 2018, a National Trauma Training Programme was established by NHS Education for Scotland to implement this knowledge and skills framework and to support all sectors of the workforce to upskill staff in trauma informed practice, as well as to embed and sustain this model of working. The programme of work is being led by NHS Education for Scotland (NES) and informed by people with lived experience, to create and deliver quality training resources.* ***Healthcare Workforce*** *The wellbeing of the workforce is considered in this guidance in the context of the ethical principle of reciprocity, and the importance of involving those that decisions impact – such as staff – in decision making processes. More detailed guidance to support the workforce has been developed by Scottish Government:* • *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 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. https://www.staffgovernance.scot.nhs.uk/media/1701/guidance-for-health-and-social-care-and-emergency-servive-workers-with-underlying-health-conditions-30-march-2020.pdf* • *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.* *In addition, Scotland has launched a national wellbeing hub which is available to all health and care workers, including those on lower pay:* • *The National Wellbeing Hub (www.promis.scot) launched in Scotland on 11th May. The Hub is truly innovative, empowering staff and carers to address their physical and mental health like never before. It signposts staff, unpaid carers, volunteers and their families to relevant services, and provides a range of self-care and wellbeing resources designed to support the workforce as they respond to the impact of Covid-19.* • *The Hub is being used widely by the health and social care workforce across Scotland. Feedback has been overwhelmingly positive.* • *On 20 July, a new national wellbeing line for the health and social care workforce launched, based within NHS 24, which provides a round the clock service to those who need further psychological support, including in light of the coronavirus crisis.* • *All health and social care workers in Scotland will now have access to mental health support 24 hours a day, seven days a week through a new national helpline. The number to dial is 0800 111 4191.* • *The Hub and the wellbeing line are part of a programme of work that is in progress to ensure that a range of wellbeing and mental health support is in place for the workforce. Other activity includes:* • *There is ongoing work by territorial Boards to provide a range of wellbeing support for staff across health and social care, including: wellbeing 'hubs', common rooms / rest areas,*

	helplines and listening services, links with Occupational Health and Chaplaincy services, peer support, leadership development, coaching initiatives, mental health guidance and digital offerings *While there may be some evidence to suggest that staff on lower pay bands are at increased risk of adverse psychological impact, this hypothesis is not currently supported by a robust evidence base. The Scottish Government response has been to ensure that all the wellbeing initiatives, including the wellbeing hub, are as inclusive as possible for all bands of the workforce, Initial data suggests that the uptake of these initiatives, including coaching for wellbeing, have been accepted by a diverse range of staff members including child care workers, staff nurses, porters, care home staff and unpaid carers.*
Sign off	**Name: Craig Bell** **Job title: Realistic Medicine Policy Lead, Scottish Government**

Annex A: Ethical guidance Feedback Summary

ANNEX - COVID-19 -
Ethical Advice Feedba

Annex B: List of EQIA Participants

EQIA participants

1.	Craig Bell	EQIA Chair – Scottish Government
2.	Cathy Asante	Scottish Human Rights Commission
3.	Savita Brito-Mutunayagam	Scottish Government
4.	Chris Bruce (facilitator)	NHS Lothian
5.	Dave Caesar	Scottish Government
6.	Arun Chopra	Mental Welfare Commission for Scotland
7.	Eddie Doyle	Scottish Government
8.	Mark Evans	Head of Spiritual Care & Bereavement Lead, NHS Fife
9.	Kate Fearnley	Mental Welfare Commission for Scotland
10.	Mike Gillies	Scottish Government
11.	Jennifer Graham	Scottish Government
12.	Laura Hutchison	Equality & Human Rights Commission
13.	Jacqui Lambert	Scottish Government
14.	Carey Lunan	Scottish Academy of Medical Royal Colleges
15.	Donald Macaskill	Scottish Care
16.	Louise MacLennan (facilitator)	National Services Scotland
17.	Charlie McMillan	Scottish Commission for Learning Disability
18.	Suzanne Munday	MECOPP
19.	Sarah Ramsay	Scottish Academy
20.	Katharine Ross	National Services Scotland
21.	Alice Rutter	Scottish Government
22.	Adam Strachura	Age Scotland
23.	Bruce Sutherland	Scottish Government
24.	Sian Tucker	Scottish Government
25.	Michelle Watts	Scottish Government
26.	Dianne Williamson (facilitator)	NHS Fife
27.	Sally Witcher	Inclusion Scotland