South West Regional Health & Social Care Ethics Reference Group

Detailed Terms of Reference

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Purpose

Southwest Regional Health & Social Care Ethics Reference Group (hereafter the SW Ethics Reference Group) is convened to support and advise on ethical decision-making regarding prioritisation of demands and provision of health care in the Southwest of England in the context of, and in response to the national emergency response to a pandemic. Ethical decision-making is required at every level in health and social care provision, quality assurance, regulation, and commissioning; and across the whole care pathway – from the level of individual care-givers working directly with patients to strategic planning of the response to the Covid-19 pandemic.

Scope

1. The primary focus for the SW Ethics Reference Group shall be an ethical approach to the provision of health and social care for people living in the South West of England region during the Covid-19 pandemic.

2. The SW Ethics Reference Group shall also consider ethical issues relating to other (non-Covid-19) health and social care priorities such as the provision of care for other urgent conditions (e.g. cancer, stroke and heart disease); and ensuring that compassionate care is available for specific groups such as people with long-term conditions (e.g. dementia, diabetes, chronic heart and respiratory disease); those requiring palliative care; and those with mental health problems.

3. Ethical considerations regarding the deployment and management of staff considerations shall also lie within scope.

4. Ethical issues relating to mental capacity, safeguarding of adults and children and deprivation of liberty shall be considered in the work of the SW Ethical Reference Group.

Accountability Framework & Reporting Arrangements

The primary responsibility for ethical decision-making lies with the clinician or carer who is working directly with the patient or service user, following the principles and practices mandated by professional regulators. Provider organisations are accountable for ensuring that staff are supported to work within an appropriate ethical framework. Commissioners have a responsibility to ensure that they make provision for care with due consideration to allocative ethics/distributive justice. Local Authorities have accountability for safeguarding of adults and children. The SW Ethics Reference Group, as an expert advisory group mostly comprised of experienced health and social care practitioners, IS NOT intended to remove or usurp any of these existing responsibilities and accountabilities. Its outputs will be advisory to practitioners, providers and commissioners of health and social care.

The SW Ethics Reference Group is a workstream within the SW Clinical Cell. Both the SW Ethics Reference Group and the SW Clinical Cell are accountable to the South West Regional Senior Leadership Team (SLT). SLT is responsible for agreeing the Terms of Reference, Workplan and Membership of the SW Ethical Reference Group. The SLT is accountable for any strategic regional decisions made based on the advice of the SW Ethics Reference Group.

The SW Ethical Reference Group shall provide such reports and progress updates as are requested by the South West Regional Senior Leadership Team.

Terms of Reference & Membership

Objectives

1. To ensure all health and care staff are supported and advised to work with due regard to ethics

2. To identify gaps, where groups of staff may not have the support and guidance they need

3. To make recommendations regarding support for staff in ethical decision-making

4. To advise providers, commissioners and NHS England & Improvement on ethical issues

5. To ensure that any local ethical advice and guidance takes due account of national advice from government and regulators

6. To share learning regarding ethical approaches amongst staff, providers and commissioners

7. To ensure there is an equitable approach to decision-making and prioritisation across the SW region and between different services and care pathways

Membership

Most members will be from a practitioner background and be recognised as leaders by their colleagues and employers and in good standing with their professional body where relevant. Members will be appointed by nomination of the constituent organisations and with the agreement of the Convenor.

The convenor of the SW Ethical Reference Group is the SW Medical Director (System Improvement)

One representative from each Integrated Care System (ICS) / System Transformation Plan area (STP). This will normally be a senior clinician in a significant leadership position in their clinical cabinet or similar. This will provide 7 members.

Representation from networks of clinicians. This will provide up to 3 senior clinicians in a significant leadership position in a clinical network.

At least 2 representatives from social care and social work. These will normally be senior practitioners in social work or social care

SW Regional NHS England & Improvement Safeguarding Lead

SW Regional Lead Nurse for Learning Disabilities & Autism

SW Regional Senate Chair or deputy

Patient & Public representation - two members who are chairs of patient representative groups in the SW

Ethical advisor – senior academic ethicist

Other members may be appointed at the discretion of the convenor and with the agreement of a simple majority of the SW Ethics Reference Group

A communications expert is also to be identified to support the group. This could come from any of the constituent organisations.

A vice-convenor will be identified by agreement with the SW Ethical Reference Group.

Members may represent more than one constituency – i.e. an ICS/STP representative may also represent a clinical network

Quoracy

For meetings to be quorate, the following need to be present:

- The convenor or vice-convenor

- At least three other members

- Representation from at least two ICS/STP

- At least one member from each of medical, nursing and social care

Deputies must be agreed in advance with the convenor or vice-convenor.

Meeting arrangements

The secretariat will be provided by NHS England & Improvement SW. Meetings will be held virtually using Teams. Regular meetings will be held every two weeks lasting for up to two hours. Meetings may be arranged at short notice to deal with urgent requests for advice.

Agreement on Establishment

SW Regional Senior Leadership Team has:

- Approved the establishment of the SW Regional Health & Social Care Ethical Reference Group

- Approved the accountability framework and reporting arrangements

- Confirmed the reporting arrangements for Ethics Reference Group to the Senior Leadership Team

Detail:

1. That a SW Regional Health & Social Care Ethical Reference Group be convened as per these Terms of Reference

2. That the scope of the work of the SW Ethics Reference Group includes issues relating to the prioritisation of health care resources in general, rather than restricted to Covid-19

3. That the scope of work of the SW Ethics Reference Group includes issues relating to the management, support and treatment of staff

4. That the role of the SW Ethics Reference Group is advisory to:

   i) The SW Regional Senior Leadership Team

   ii) The SW Regional Incident Director

   iii) SW health and social care professionals, providers and commissioners

5. That the scope of work of the SW Ethics Reference Group includes considerations relating to safeguarding of adults and children in support of the agencies and individuals who have statutory responsibility for these functions

Background to the Establishment of the SW Regional Health & Social Care Ethics Reference Group

This paper provides the background to the establishment of the group.

Introduction

There has always been an ethical tension in medicine between a doctor's concern for the health and welfare of the individual patient and concern for the health of populations. In dangerous pandemics the ethical balance of all doctors and health care workers must shift towards the utilitarian objective of equitable concern for all – while maintaining respect for all as 'ends in themselves'[i].

The everyday situation where there is a relative mismatch between demand and resources is likely to be exacerbated during the current Pandemic leading to some instances where there will be an absolute lack of some resources for at least some of the time. It will then become necessary to make difficult and often heart-breaking decisions about allocating treatment between people who would, under normal circumstances, be regarded as having the highest priority for treatment.

Groups of clinicians, regulators, providers and commissioners have been considering the question of prioritising access to treatment. A need has been identified to link these groups together in a network to improve assurance that decisions are being made on an ethical basis and that all clinicians and organisations receive the support and guidance they require throughout these difficult times.

Approach

Many ethical and regulatory frameworks exist to inform decision-making generally and some bodies have issued specific guidance in response to the Pandemic. The approach of the SW Ethics Reference Group shall at all times take due account of professional ethical guidance issued by bodies such as General Medical Council (GMC), Nursing and Midwifery Council (NMC) British Medical Association (BMA), Royal College of Nursing (RCN), NICE[ii], UK government[iii]. Part of the role of the SW Ethics Reference Group will be to integrate and interpret advice and to ensure it is used where relevant.

Brief summary of guidance from national bodies

The BMA (cited above as i) states that doctors are unlikely to be criticised where decisions are:

- *reasonable in the circumstances*

- *based on the best evidence available at the time*

- *made in accordance with government, NHS or employer guidance*

- *made as collaboratively as possible*

- *designed to promote safe and effective patient care as far as possible in the circumstances*

The RCN ethical framework[iv] provides guidance relevant to the provision of care at the end of life:

1. *Establish the relevant clinical facts of the case*

2. *Assess the wishes of the patient and those important to them*

3. *Consider the legal perspective*

4. *Consider the ethical perspective*

5. *Be aware of the processes to support the decision making*

The NMC Code[v] states that:

In acting in the best interests of people at all times you must 'keep to all relevant laws about mental capacity that apply in the country in which you are practising, and make sure that the rights and best interests of those who lack capacity are still at the centre of the decision-making process'.

The UK Government produced advice following the 2009 Swine Flu pandemic. This was updated in 2017. It provides an ethical framework for use during an Influenza Pandemic and is relevant to the Covid-19 pandemic. It set out the following principles:

Equal concern and respect is the fundamental principle that underpins the ethical framework. This means that:

- *everyone matters*

- *everyone matters equally – but this does not mean that everyone is treated the same*

- *the interests of each person are the concern of all of us, and of society*

- *the harm that might be suffered by every person matters, and so minimising the harm that a pandemic might cause is a central concern*

The GMC, NMC and other regulators accept that clinicians will be working under challenging conditions and may be forced to divert from their normal practices in order to provide the best care under the circumstances[vi]. CMOs from the four nations plus the medical directors of NHS England and the GMC have written a joint letter to all doctors[vii].

NICE guidance[viii] has been produced which supports ethical prioritisation for access to ventilatory support.

Theoretical Framework

The SW Ethical Reference Group will structure its advice around the work of Beauchamp & Childress[ix]. This framework, based on four principles, is familiar to many health care staff. It is pragmatic and intended to support decision-making in real-life situations in healthcare while being based on a philosophical and comprehensive theoretical academic approach. The four principles approach can be used to balance a strictly utilitarian view which is often viewed by professionals

and the public as cold and heartless. However, other approaches to heath and care ethics provide perspectives which may appear to be missing from the four principles, and considerations such as empathy, compassion and transparency are important and should therefore be added.

The four principles approach

The four principles with a brief description of each are:

1. Autonomy – people should be supported to make their own decisions so far as is possible. This is the principle that leads us into informed consent, advanced care planning, respect for confidentiality.

2. Beneficence – we should always aim to maximise the overall good to society of our actions. This is the principle which will support some of our utilitarian considerations regarding the allocation of scarce resources.

3. Non-maleficence – we should always act so as to minimise or mitigate the adverse effects of our actions. This is the principle which leads us into considering unintended consequences of action and of inaction – for example, considering the effects of cancelling elective care.

4. Justice – we should always seek to act with regard to justice or fairness. This is the principle which leads us to consider equitable access to care across our geography and amongst groups with differing health care needs; ensuring due consideration is given to Human Rights; and supporting equality and diversity with regard to protected characteristics under the Equality Act.

These principles must be balanced when the SW Regional Ethics Reference Group formulates its advice. It is necessary to do this in a compassionate manner, showing empathy not only for our patients but also for ourselves and for our colleagues even when we may not be in agreement with them. It is imperative to continue to provide compassionate care for all, especially when the best recommended treatment may be unavailable.

Scope

The primary focus for a SW Ethics Reference Group will be an ethical approach to the provision of health and social care for members of the public. During the pandemic to date, the focus has quite reasonably been on the very urgent considerations relating to the provision of acute care for patients suffering from Covid-19. However, it is also necessary to consider other health and social care priorities such as the provision of care for other urgent conditions (e.g. cancer, stroke and heart disease); and ensuring that compassionate care is available for specific vulnerable groups such as people with long-term conditions (e.g. dementia, diabetes, chronic heart and respiratory disease) and those with mental health problems. All of these require an ethical approach to service and care provision in the context of the high demand consequent upon the pandemic.

Ethical considerations concerning fairness/justice and welfare maximisation may be relevant to the deployment and management of staff.

Some groups of individuals (children and young people; individuals receiving social care; people living with dementia; families where there is domestic violence) are likely to be at increased vulnerability and disadvantage during the pandemic. This is due to the pressure on health and social care resources and the additional privations these groups may suffer due to the restrictions placed on movement and contact with others. For some of these vulnerable people, there are increasing safeguarding risks. Therefore, issues relating to mental capacity, safeguarding of adults and children and deprivation of liberty should be considered in the work of the SW Ethical Reference Group.

Governance

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NOT intended to remove or usurp any of these existing responsibilities and accountabilities. Its outputs will be advisory.

The SW Ethics Reference Group will be a workstream within the SW Clinical Cell. It will report and be accountable to the South West Regional Senior Leadership Team. Therefore, it will be for the South West Regional Senior Leadership Team to agree the Terms of Reference, Workplan and Membership of the SW Ethical Reference Group.

Membership & Quoracy

The membership of the SW Ethics Reference Group will be multi-disciplinary and multi-agency. The majority of members will be practitioners in health and social care in the region who hold senior leadership roles in their organisations or amongst their professional groups. There will be a full membership of between 12-15. The convenor or vice convenor plus three other members representing the medical, nursing and social care professions and more than two ICS areas will be quorate. This will allow advice on ethics to be rapidly provided if needed.

Conduct of meetings

At its inaugral meeting, the group agreed the following by consensus:

1. That meetings will not be audio recorded. This is on the basis that the group is advisory rather than decision-making and so recording is not necessary. In addition, because of the nature of the work of the group, it is important that members feel able to discuss contentious matters freely.

2. During the meetings, a record of decisions, recommendations and actions will be made and agreed as accurate. There will be no detailed minutes kept.

3. Members agreed that meetings of the group would be covered by "Chatham House Rules" as follows:

•   It is permitted for members to describe the work of the group and the nature of discussions

•   It is not permitted to attribute comments or statements to group members without their express consent.

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Mrs Penny Smith

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References

[i] BMA Covid-19 – ethical issues. A guidance note https://www.bma.org.uk/media/2226/bma-covid-19-ethics-guidance.pdf

[ii] COVID-19 rapid guideline: critical care in adults NICE guideline [NG159] Published date: 20 March 2020   Last updated: 31 March 2020 https://www.nice.org.uk/guidance/ng159

[iii] Guidance: Pandemic flu. Pandemic flu planning information for England and the devolved administrations, including guidance for organisations and businesses. 2017. https://www.gov.uk/guidance/pandemic-flu

[iv] RCN Ethics https://rcni.com/hosted-content/rcn/fundamentals-of-end-of-life-care/ethics

[v] NMC The Code https://www.nmc.org.uk/standards/code/

[vi] Joint statement from chief executives of statutory regulators of health and care professionals 3/3/20 https://www.gmc-uk.org/news/news-archive/how-we-will-continue-to-regulate-in-light-of-novel-coronavirus

[vii] Joint statement: Supporting doctors in the event of a Covid-19 epidemic in the UK 11/3/20
https://www.gmc-uk.org/news/news-archive/supporting-doctors-in-the-event-of-a-covid19-epidemic-in-the-uk

[ix] Beauchamp, T. and Childress, J. (2012) Principles of Biomedical Ethics (7th Ed)