5.2 Ethics - National Principles
   National Principles - Ethics
   The Patient Pathway During The Covid19 Crisis - A Resource Document
GUIDANCE

Coronavirus: ethical values and principles for healthcare delivery framework

Guidance for healthcare services when making decisions during the coronavirus outbreak.

Contents

1. Core values
2. Using the framework to deliver health services equitably
3. Principles and law underpinning ethical delivery of health care

1. Core Values to inform planning and decision making for healthcare delivery for all people in Wales

In addressing healthcare provision during the Covid19 Pandemic in Wales, the core value underpinning this ethical framework is 'equal concern and respect'.

This promotes the core constitutional commitment to equality, and the protections for all people, enshrined in law in Wales in respect of governance and language.

This means that:

- everyone matters — health service delivery will follow the principles set out in equality and human rights legislation
- everyone matters equally – this does not mean that everyone is treated the same, but does require health services to work effectively in partnership with each person equitably according to their needs
- the interests of each person are the concern of all of us, and of our society
- the harm that might be suffered by every person matters, and so our actions aim to minimise the overall harm that a pandemic might cause

2. Using the framework to deliver health services equitably

The core value ‘equal concern and respect’ draws together a number of different ethical principles. When a particular decision has to be made, the following list of principles can be used systematically to help those delivering health services discharge their duty to ensure that the full range of ethical issues is considered.

3. Principles and law underpinning ethical delivery of health care

Respect

Means:

- holding a view of the person as a whole, taking into account their rights, wishes and feelings as a unique individual
- keeping people as informed as possible, ensuring that communications are available in accessible formats in their preferred language
- giving people the opportunity to express their views and take part in decisions on matters that affect them
- responding to people’s personal preferences about their treatment and care, including communication and support needs
- when people are not able to make a decision, those who have to decide for them take decisions based on the best interests of the person
- maintaining confidentiality

Minimising the overall harm from the pandemic

Means:
• cooperate to limit infection spread, especially to more vulnerable groups
• minimise the risk of complications if someone is ill
• avoid causing harm by inappropriately giving or omitting treatment or intervention
• learn from experience both at home and abroad about the best way to provide optimal healthcare to people who are ill, and contribute to research to increase knowledge about it
• minimise the disruption to society caused by the pandemic, including physical, psychological, social and economic harm
• minimise the impact of the pandemic activity on other essential health services needed for people’s survival and wellbeing

Fairness

Means:

• everyone matters equally, so people with an equal chance of benefiting from healthcare resources should have an equal chance of receiving them
• ways of assessing potential benefits and harms from a health intervention or its timing must respect individual rights

Working together

Means:

• healthcare services must work together with other services, statutory agencies and third sector, to plan for, and respond to, a pandemic
• different parts of the overall health service must cooperate to help one another
• citizens and health workers all take responsibility for their own behaviour, especially by not exposing others to risk
• healthcare services being prepared to share information (for example, on the effects of treatment, or particular risks to some) that will help others

Reciprocity

Based on the concept of mutuality between healthcare users, workers giving care and institutions providing services, means:

• any person asked to face increased risks or burdens during the pandemic should be supported on doing so by physical, mental and social wellbeing measures
• service leaders should ensure that risks and burdens are minimised as far as possible for all, responding proportionately to the risk

**Keeping things in proportion**

Means:

• those responsible for providing information will neither exaggerate nor minimise the situation and will give people the most accurate information that they can
• those taking decisions on actions that may affect people’s daily lives, aiming to protect the public from harm, will act flexibly and in proportion to the risks and benefits to individuals

**Flexibility**

Means:

• those making individual healthcare plans will take into account new information and changing circumstances, and adapt plans accordingly
• people will have as much chance as possible to express concerns about, or disagreement with, decisions about their healthcare that affect them
• people who disagree with a decision about their healthcare are given access to a prompt, independent second opinion

**Good decision-making**

Means:

• those making decisions about healthcare act with openness and transparency, in line with professional and legal responsibilities, and;
  o consult people as much as possible in the time available and provide adequate time for their decision making (with an advocate if wished), especially around end of life care and do not attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions
  o involve people as much as possible in aspects of care planning that affect them, taking into account their individual needs and preferences
  o promote equity by assessing and responding to individual need, avoiding blanket policies based on protected characteristics especially disability or age
  o take into account all relevant views expressed and be open to challenge
- be clear about what decisions need to be made, and the model of care or analysis being applied
- be open about what decisions have been made, and why, and who is responsible for making them
- try to ensure that no person or group is excluded from being involved in decision making that affects them
- be accountable for the decisions taken or not taken
- take decisions reasonably, rationally, based on evidence, with a clear, practical process
- record decisions and actions along with the justification or reasons for them
AIM OF THE DOCUMENT

This document aims to provide support for people, particularly leaders in health and social care, during the COVID-19 crisis. It looks at some likely key decision points on the patient pathway in Wales, recognising that healthcare professionals are making very difficult decisions under unprecedented pressure. It does not attempt to be prescriptive.

It should have value to busy clinicians, managers, volunteer co-ordinators and carers, but it does not give strong guidance on the resolution of ethical dilemmas. Instead it provides links to practical, authoritative information and guidance issued by respected organisations and where relevant, legal sources.
The document should be read in conjunction with guidance issued by the UK Moral Ethics Advisory Group (MEAG), and its Welsh equivalent, C-MEAG, and guidance issued by professional bodies, all of which can easily be accessed by using links provided in the text. The UK Clinical Ethics Network is a particularly useful site.

Note that advice for clinicians in Wales on ethics can be accessed by applying to Clinical Ethics Committees in Health Boards.

Guidance can also be found in documents issued by organisations supporting social care, and it is important for NHS and social care staff in Wales to work collaboratively, as required by the Social Services and Well-being (Wales) Act 2014 and the Well-being of Future Generations (Wales) Act 2015.

**DECISION MAKING FRAMEWORK**

The Ethical Framework for Adult Social Care issued by England and adopted by Wales, which is of relevance to NHS staff working in the community, lists a number of useful guiding principles as follows: Respect, Reasonableness, Minimising harm, Inclusiveness, Accountability, Flexibility, Proportionality, and Community. The same principles are identified in the work of MEAG and C-MEAG and by NHS Scotland, which issued its ethical guidance on 3rd April 2020.

While the principles identified can be taken to reflect current thinking on medical ethics, they should not necessarily be treated as being of equal value. For example, in other scenarios involving applied ethics, such as decisions made by judges about end of life treatment, one would not value “flexibility” in itself, because that could

---

7. [Coronavirus (COVID-19): ethical advice and support framework - gov.scot](https://www.gov.scot)
produce uncertainty and result in inadvertent widening of scope – sometimes referred to as the “slippery slope” issue.

In the present crisis the pre-eminence of individual autonomy as an overriding principle has given way to a realisation of the importance of relational autonomy across society. Our interdependence on each other and the integrated functioning of society has come to the fore, with a heightened emphasis on fair distribution. This is seen in the way leaders at all levels have become aware of their reliance on others.

Within the concepts of ‘avoiding harm’ and ‘doing good’ has emerged a meticulous attention to detail, and to the importance of accurate data and scientific analysis to inform decision making. This is seen in the frameworks for difficult decision making that recognise the complexity of the individual and the need to provide care to a population whose needs outstrip the resources available to meet those needs. In this crisis, a commitment to care must be a core value at every level, which supports better decision making when demonstrated by compassionate leadership.

This re-balancing of priorities and values has resulted in much of the high-quality guidance available, some but not all of which is cross-referenced in this paper.

With the passage of time, when the world reflects on the COVID-19 crisis and seeks to identify lessons that can be learned from the way in which governments handled it, ethicists may conclude that the predominant emphasis on individual autonomy became less dominant in the extreme circumstances of a pandemic, or that at least the ethical principles required substantial modification to recognise the interconnectedness of human relationships.

For many years clinicians have been taught the principles as originally described by Beauchamp and Childress. In this situation they continue to pertain and can be stated as follows:

- Autonomy - The importance of considering and respecting as much as possible a person’s wishes and feelings, while ensuring they do not adversely impact on the rights of others
- Beneficence and non-maleficence – Weighing up the need for an intervention or support against the ability of the person to benefit from it. And in the process the person should not suffer disproportionate harm from whatever is offered.
- Justice - The just allocation of scarce resources must be assessed in proportion to the needs of all. For the individual, justice requires that the person receives the best care possible within the resources available. A useful article on Guidelines for institutional ethics services responding to

---

9 King's Fund: Why Compassionate Leadership Matters in Times of Crisis
COVID-19 was published by the Hastings Center\textsuperscript{12} on the 16th March 2020.

\textsuperscript{12} https://www.thehastingscenter.org/ethicalframeworkcovid19/
1. SOURCES OF INFORMATION

A bewildering array of ethical guidance now exists in respect of COVID-19. Many organisations are issuing updates to their guidance on a regular basis – among them Welsh Government, Public Health Wales, NHS Organisations, Royal Colleges, Local Authorities and voluntary organisations.

Links are included to selected guidance documents at various points along the patient pathway.

A selection of useful guidance is listed below:

- **For healthcare professionals**  
  - [GMC Ethical Guidance for doctors on COVID-19](#)  
  - [Joint Statement by Chief Medical Officers for England, Wales, Scotland and Northern Ireland](#)  
  - [RCN Clinical Guidance for managing COVID-19](#) (contains many useful links)  
  - [Ethical Guidance on COVID-19 and Primary Care](#)  
  - [BMA Ethics FAQs](#)

- **Guidance on practical matters**  
  - [UK Government Guidance on COVID-19](#) (updated regularly)  
  - [Public Health Wales Advice on COVID-19](#) (very useful updates for wide readership)

- **For managers**  
  - [Welsh NHS Confederation updates](#)

- **Daily statistics**  
  - [Regular information on the data](#)

- **Information about equality and human rights concerns**  
  - [Royal College of Physicians on COVID-19 and Health Inequalities](#)  
  - [Human Rights and COVID-19](#)

- **The wider world**  
  - [World Health Organisation](#)

- **Faith Communities**  
  - [Connections with Faith Communities](#)

- **Workforce support**  
  - [Up-skilling support](#)  
  - [Guidance for Trade Unions](#)

- **Excellent advice for Community Social Care and Ambulance Services**  
  - [NHS England practical guidance](#)
• Managing Capacity and Demand in Community Mental Health, Learning Disabilities and Autism Services  
  o NHS England Advice for Community Services

• MHRA Guidance  
  o MHRA Guidance on flexible approach to regulation during COVID-19 crisis
2. THE PATIENT JOURNEY: KEY DECISION POINTS

This is an attempt to identify the key points when decisions may need to be made with and for patients. There are several points on the patient pathway when other organisations and partners such as local authorities and voluntary organisations are involved.

2.1. Asymptomatic people in the community

People who are feeling well are urged to follow Welsh Government’s instructions about social distancing\(^\text{13}\). The Coronavirus Act 2020\(^\text{14}\), which became law at the end of March, aims to reduce the spread of the infection and consequently save lives, and it has far-reaching implications for the lives of the entire population. The Act introduces temporary measures which either amend existing legislation or create new statutory powers to enable the Government to respond quickly to deal with issues as they arise on many aspects of life, including the NHS, social care, the workforce, personal finance, the wider economy, the courts, prisons, transport services and the everyday freedoms which people have taken for granted for so long. In broad terms, the Act aims to:

- increase the size of the health and social care workforce in various ways, including the removal of barriers in order to allow recently retired NHS staff and social workers to return to work, and speeding up registration of newly qualified staff
- ease the burden on frontline staff by introducing measures to reduce administrative tasks, enabling local authorities to prioritise care for those with the most need, allowing staff to perform more tasks remotely, and having power to suspend individual port operations
- contain the spread of the virus by reducing unnecessary social contacts and strengthening the powers of police and immigration officers
- enable death services to manage the bodies of the deceased with respect and dignity during increased demand
- support people by allowing them to claim Statutory Sick Pay from day one, and by supporting the food industry to maintain supplies.

Some provisions of the Care Act 2014 (in England)\(^\text{15}\) which involve \textit{duties} to assess and meet eligible needs of adults and carers are downgraded to \textit{powers} unless failure to provide care and / or support would result in a breach of an individual’s human rights. In Wales a duty only arises where failure to do so would mean that the person may be experiencing or at risk of abuse or neglect.

\(\text{\textsuperscript{13} Statement from First Minister}\)
\(\text{\textsuperscript{14} The Coronavirus Act 2020}\)
\(\text{\textsuperscript{15} http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted}\)
Regulations made under the Act provide wide-ranging powers designed to curtail the movement of people with the aim of limiting the spread of COVID-19 in the UK, and they are believed by some to be the most restrictive powers ever created in peacetime. Not everyone in the community will be infected with the COVID-19 virus, and there is a need to balance the concept of freedom of movement with the need to protect the lives of people living in the community. Families are separated, friends are unable to meet, theatres and churches are closed and many businesses cannot function effectively.

**Balancing Risks and Benefits of Social Distancing and Self Isolation**

The police have the difficult task of rapidly becoming the enforcement agents for these restrictions, tasked with achieving an appropriate balance between safeguarding the community and the freedom of the individual\(^16\). Any breach of the Government advice issued under the Act requires a justifiable reason that must also be defensible on ethical grounds\(^17\).

**The role of GPs**

GPs have an important role when their patients are seeking advice about how strictly particularly vulnerable people with known frailty should adhere to the guidance. Letters have been sent to this group of patients by GPs, and it might be necessary for them to have difficult conversations with patients and relatives by telephone to discuss the option of setting up a Lasting Power of Attorney or less formal ways of enabling people to express their wishes. Guidance for GPs and patients on COVID19 has recently issued by the Royal College of General Practitioners (RCGP)\(^17\), the National Institute for Health and Care Excellence (NICE)\(^18\) and Public Health Wales\(^20\).

**The right of every person to express their wishes**

A public information campaign of support is needed to explain in clear language what choices are open to people. ‘My life my wishes’\(^19\) is a booklet which explains the importance of advance care planning. This has been through trials in the community and has been well accepted and used extensively for more than two years.

---


\(^{19}\) [http://www.powysthb.wales.nhs.uk/mylifemywishes](http://www.powysthb.wales.nhs.uk/mylifemywishes)
Age UK\textsuperscript{20} has produced web-based guidance on expressing wishes. For those wishing to appoint a representative with Lasting Powers of Attorney (LPA), links to the Office of the Public Guardian explain how LPA can be generated \textsuperscript{21}.

Identifying vulnerable groups during “lockdown”

In addition to those identified as extra vulnerable who have received letters from their GP, there are other groups who are particularly vulnerable when normal human contact is suspended. These include the following groups to whom advice is available as indicated:

- Victims of domestic violence:
  - Advice for Victims of Domestic Violence
  - Domestic abuse statement from UK Government
  - Advice from Women's Aid

- Children who would usually have free school meals at school:
  - Advice on free meals

- People with learning disabilities:
  - Advice: Learning Disabilities
  - Learning Disabilities Easy Read

- People with physical disabilities:
  - WHO guidance for people with disabilities

- People receiving domiciliary care:
  - Government advice on Domiciliary Care

- People living in care homes:
  - PHW Advice for Care Homes

- People with mental health problems in hospital and community settings:
  - Royal College of Psychiatrists Guidance

- Street sleepers and homeless people:
  - Advice for Homeless People from Shelter

\textsuperscript{20} https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/power-of-attorney/what-happens-if-you-dont-have-a-power-of-attorney/

\textsuperscript{21} https://www.lastingpowerofattorney.service.gov.uk/guide#topic-what-is-an-lpa
• People with substance abuse problems: 
  o UK Government Advice for people with Substance Abuse Problems

• The prison population:
  o UK Government Advice for Prisons

2.2. Early symptoms
People experiencing symptoms, or living with someone who develops symptoms, are required to self-isolate. Self-isolation differs from social distancing. It involves staying at home, only going out alone in the garden. It also means staying away from other people living in the same house, keeping at least 2 metres away from them especially people over 70 or with a long-term condition; sleeping alone if possible; and asking people to leave food deliveries outside the door.

Information for households
Not every household has internet access by which to obtain information about important decisions such as the care of children and vulnerable family members. However, all households should have received information by post about social distancing and self-isolation, management of symptoms and practical matters such as disposal of personal waste.

Members of the public require information explaining what to expect and how to act if they develop symptoms, when to call the GP, participation in testing when it becomes widely available and information about data collection to identify as clearly as possible the number of potential infections in the population.

Early symptoms could include loss of taste and smell, sore throat and dry cough, but symptoms can vary widely and people are encouraged by the government to share information about their symptoms so that a national database can be maintained. For legal and ethical reasons it should be made clear that such information is anonymised and that it will remain confidential.

The First Minister for Wales has put in place a specific site offering advice on what people can expect and how they can help one another during the present crisis.

Clinical trials
Clinical trials are essential in the community and more widely, to collect information about the COVID-19 virus and the most effective treatments. Clinical staff are ideal subjects for prevention and early treatment studies, using the Kings data-base App to collect data.

22 King's College London Symptom Reporting App Database
23 Sources of information in Wales
For rapid studies, it is easier to consent healthcare workers for data collection than it would be if the general public were to be involved. They can provide blood and swab samples more easily than the rest of the population, but drive-through swab sites may also be used to collect blood samples from them.

It is considered to be ethically sound to enter NHS staff into such trials because they are among those at the greatest risk of contracting COVID-19. However, it is important from an ethical perspective to enable other groups to access some clinical trials in order to afford them the opportunity to derive some benefit from new treatments for the virus and to contribute to the knowledge base\textsuperscript{24}. Resources already developed must be rapidly shared. Symptoms monitored on the Kings App can be collated with blood results data, which must be freely available to the patient in a trial.

There is a need for collaboration in COVID-19 research across the whole of the UK and internationally in order to ensure that the best possible care is delivered to patients on the basis of sound evidence. “Silo” working must be avoided and appropriate ethical standards of research must be met in the interests of the safety of patients and the population as a whole. This includes compliance with ethical standards and requirements.

The Medicines and Healthcare Regulatory Authority (MHRA) has a framework\textsuperscript{25} for prioritising research submissions relating to COVID-19\textsuperscript{26}. The Health Research Authority (HRA)\textsuperscript{29} is also working to expedite Research Ethics Committee Reviews and has produced an expedited standard operating procedure to help submissions by researchers. A comprehensive list of potential opportunities for funding COVID-19 research can be found on the Medical Research Council (MRC) website\textsuperscript{27}.

\textbf{2.3. If symptoms progress.}

People who are worried about their deteriorating condition are advised to ring the 111 ‘phone number for advice. Some practical problems have been reported with this service due to the extreme pressure of telephone calls.

The algorithms used have had to focus on identifying and advising on COVID-19, although non-specific symptoms that could be suggestive other serious illnesses make advice algorithms difficult to develop. Research is required into the outcomes of 111 advice and should explore whether people who need treatment in A&E were not directed there.

\textsuperscript{24} https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3894239/
\textsuperscript{25} https://www.gov.uk/government/collections/mhra-guidance-on-coronavirus-covid-19
\textsuperscript{26} https://www.hra.nhs.uk/covid-19-research/covid-19-guidance-sponsors-sites-and-researchers/
\textsuperscript{29} https://www.hra.nhs.uk/
\textsuperscript{27} https://mrc.ukri.org/funding/browse/
There could be a case for issuing clearer information to the public about conditions than can be confused with COVID-19 but NHS Direct Wales already offers a self-help guide for COVID-19 and advises patients experiencing life-threatening symptoms of any kind to dial 999 and not to visit a GP surgery, hospital or pharmacy.

Patients who are unable to use the internet - among them people with learning disabilities, some elderly people, those living in areas with no internet access in rural Wales and street sleepers - are likely to be disadvantaged in these circumstances.

It should also be noted that in addition to the Equality Act 2010, Welsh Government has made a number of commitments to paying due regard to equality of opportunity for all people.

**The potential for unintended consequences**

While it is understandable that the key focus is on treating people who are suffering the severest symptoms of COVID-19, it has been claimed that other people who need medical care are suffering as a consequence partly because of staff absences caused by movement of key clinicians to areas treating COVID-19 patients, and partly as a result of self-isolation of some staff members with symptoms of the virus.

Much elective surgery had to be cancelled, except in emergencies. Surgery for cancer patients is being postponed, that there is suboptimal management of chronic wounds in some areas, that fewer renal transplants are taking place and that children with mental health problems are not attending CAMHS appointments.

These reports reveal a number of ethical issues concerning treatment priorities which are perhaps not being adequately addressed during the present crisis in which time is short and the media is driving information to the public. If resources are being re-allocated to treat COVID-19 patients this would have been anticipated at an earlier point during annual pandemic planning on the basis of ethical considerations, not necessarily with public consultation, but informed by evidence and supported by explicit and well-reasoned justifications.
Access to PPE (personal protective equipment), ventilators, oxygen, medication and other resources

Our health and social care staff are our most important resource and they need to be properly cared for at a time when a large number of people may be risking their health and even their lives. Many resources necessary to maintain the safety of staff and provide essential care for patients are scarce in the current crisis, and every effort is made across the UK to ensure that these are allocated fairly according to formulae which are calculated in a transparent manner, ensuring security of supplies, avoiding waste and exploring ways to re-use items, including unused medication, clean equipment and PPE^{40}.

NHS and other employers owe a duty of care to their staff in the law of negligence and also under the Health and Safety at Work Act 1974^{41} and Regulations made under it - The Personal Protective Equipment Regulations 2002^{42} and the Personal Protective Equipment at Work Regulations 1992 (as amended)^{43}. The duty under the Act subsists despite the present emergency situation. The Health and Safety Executive^{44} and several professional bodies have issued advice for reference purposes during the COVID-19 crisis^{45, 46, 47}.

The Health and Safety at Work Act places general duties on employers in relation to their employees:

“2. (1) It shall be the duty of every employer to ensure, so far as is reasonably practicable, the health, safety and welfare at work of all his employees.

(2) Without prejudice to the generality of an employer’s duty under the preceding subsection, the matters to which that duty extends include in particular:-

(a) the provision and maintenance of plant and systems of work that are, so far as is reasonably practicable, safe and without risks to health;

(b) arrangements for ensuring, so far as is reasonably practicable, safety and absence of risks to health in connection with the use, handling, storage and transport of articles and substances;

(c) the provision of such information, instruction, training and supervision as is necessary to ensure, so far as is reasonably practicable, the health and safety at work of his employees;

(d) so far as is reasonably practicable as regards any place of work under the employer’s control, the maintenance of it in a condition that is safe and without

---

^{40} HMG PPE guidance 12 April 2020
^{41} Health and Safety at Work etc. Act 1974
^{42} PPE Regulations
^{43} The Personal Protective Equipment at Work Regulations 1992
^{44} Health and Safety Executive Guidance
^{45} Government guidance on PPE
^{46} RCP Guidance on use of PPE
^{47} RCN position statement on PPE
risks to health and the provision and maintenance of means of access to and egress from it that are safe and without such risks;

(e) the provision and maintenance of a working environment for his employees that is, so far as is reasonably practicable, safe, without risks to health, and adequate as regards facilities and arrangements for their welfare at work”.

Clearly, what is reasonably practicable in the present crisis may not be the same as it would be in normal workplace settings. There is a large body of case law detailing claims made by injured employees and defences available to employers, and the Health and Safety Executive has recently published a report analysing compensation claims made by employees. This is no place for a detailed exposition of this complex area of law, which involves both civil and criminal liability, but details can be found in an accessible form.

Some organisations, including the Royal College of Nursing, have been very concerned about the risks for staff if appropriate protective equipment is not provided.

The BMA has issued a detailed statement after repeatedly seeking assurances from the UK government that there are sufficient safeguards in place dealing with the safety of doctors and seeking fresh guidance for the UK on PPE to match international safety standards. Concerns are heightened by reports of deaths of clinical staff who have tested positive for COVID-19.

In response, Public Health England have published updated guidance on PPE, which has been issued jointly by the Department of Health and Social Care, Public Health Wales, Public Health Agency Northern Ireland, Health Protection Scotland, and NHS England as official guidance.

The legal position is that an employer must do everything that is “reasonably practicable” to safeguard their employees and those affected by their operations. This means that employers must assess the risks of being infected by COVID-19 in the workplace and take appropriate measures to reduce the risk, taking into account any vulnerable employees such as those with underlying health problems.

Under the Regulations dealing with Personal Protective Equipment, if there are unavoidable occupational risks to health and safety that cannot adequately be controlled in other ways, PPE must be supplied, depending on the type of work and

---

48 HSE Analysis of Claims 2019
49 Health and Safety Law. All you Need to Know: NHS Executive
50 RCN Views on PPE
51 BMA approach to PPE problems
52 Joint guidance on PPE
The same Regulations require proper assessment of PPE before use, to confirm its fitness for purpose in terms of whether it affords adequate protection for its intended use, and adequate training for staff using it. There must also be compliance with storage, lifecycle and disposal standards relating to PPE.

Employers are required to give employees clear and accurate guidance on all these matters, and it is important for the supply chain to ensure that other essential equipment and medication is allocated fairly and according to predetermined and agreed criteria53.

2.4. The need to go to hospital

A single official source of information is essential for the public, giving clear information about when to dial for an ambulance54 or go to hospital, especially for people living alone with progressing COVID-19 symptoms, and for relatives caring for patients at home. For some patients there is a sudden deterioration in condition which can be very frightening.

The advice can be different according to the location of the patient:

- In main cities
- In rural areas
- Note the particular difficulties in remote areas of Wales close to the border with England
- When the local ICTU is full.

Note the difficulties that can be experienced by rough sleepers55, substance users, people with learning disabilities, people with mental illness and other vulnerable people suffering from serious COVID-19 and non-COVID medical conditions.56

2.5. Death at home or in care homes.

Advice for carers and relatives is essential and members of the public need to know what is involved and what to expect.

Care Inspectorate Wales has also issued specific advice to care homes62.

---

54 https://www.ambulance.wales.nhs.uk/
55 https://sheltercymru.org.uk/get-advice/homelessness/sleeping-on-the-streets/
56 WLGA Guidance for councils on rough sleepers and homeless
During the COVID-19 emergency, local hubs have been established in some areas to ensure rapid access to medicines needed for palliative care in care homes and in the community. Such hubs could be community pharmacies, GP practices, community hospitals, acute or other settings where palliative medicines (including controlled drugs) can be safely and legally stored and rapidly released when needed. Senior pharmacists in Health Boards and their teams will have an important role in this, and Health Boards need to ensure that they have rapid access to end of life medicines for patients.

See also ‘Care for patients in Care Homes during the COVID-19 crisis NHS England’\(^{57}\). Note that this guidance recognises (page 21) that in exceptional circumstances, such as when a person is dying, excluding a relative may be inappropriate.

### 2.6. Referral to hospital.

Evidence-based decisions need to be made to assist clinicians in reaching the initial decision about whether a patient should be referred to hospital and possibly to critical care. These must be based on the needs and informed wishes of the individual patient. Crucial decisions need to be made by staff at various points in hospitals, depending on the condition of the patient on arrival, and patients and/or relatives need to be kept informed about the options. Not every patient suffering serious COVID-19 symptoms when entering hospital will require treatment in Intensive Care. Many need oxygen on a ward, perhaps recovering relatively quickly, but a small percentage will require supportive ventilation in critical care; data available from Italy suggests that a relatively small percentage of those will survive\(^{58}\).

The decision to admit the patient to critical care is likely to be based on information about the patient’s general health and any underlying medical conditions, and after arrival in critical care a decision may need to be made about whether to provide organ support. Experience suggests that the time spent by patients on a ventilator could well amount to weeks, at a time when other patients may well be waiting for admission, so it is necessary to weigh the potential risks and benefits of admission to critical care for the individual patient. That process has been in place in the normal course of clinical practice for many years and clinicians will be familiar with applying it.

Some assistance for clinicians can be found in the use of objective decision tools, such as decision trees, and clinical frailty scoring, taken together with factors such as age. The importance of this approach is to facilitate defensible decision-making, and there are national guidelines to support this\(^{59}\). It is important to record carefully the basis for decisions and also to record the involvement of the patient, and if

---


\(^{58}\) https://jamanetwork.com/journals/jama/fullarticle/2764365

\(^{59}\) NICE Guideline on COVID-19 Decision Chart
necessary, family members. Second opinions may be sought, and where possible within the time available, an opinion could be sought from a Health Board Ethics Committee.

As far as patients are concerned, the pathway in hospitals may lead to concerns about

a. Red /Green areas  
b. PPE  
c. Oxygen supplies  
d. Other drug supplies  
e. Considerations about an upgrade to ICU

The Royal College of Nursing has produced comprehensive information on nursing in the COVID-19 pandemic\textsuperscript{60}.

\textit{Learning from experience}

Some of the problems experienced by front-line clinicians in Italy are explained in an article written to illustrate the ethical dilemmas they faced there and the tension between different ethical principles\textsuperscript{61}, although by definition there is no “right” answer to ethical dilemmas. A study was carried out when elective surgery had been cancelled, all beds were occupied and it was impossible to meet the needs of so many critically ill patients. Although the participating clinicians appeared to favour first those patients with the greatest chance of surviving in the short term, followed by those who had the fewest co-existing conditions and the best chance of longer term survival, the article continues:

\begin{quotation}
\textit{Although the participants’ input suggested that age should not be the primary or sole criterion for resource allocation, people recognised that there were circumstances under which it may be appropriate to consider stage of life in decision-making.} \\
\end{quotation}

The author concludes that whatever the ethical guidance, if such resource-scarcity were to arise, there would be a large number of scenarios that might feel morally untenable, particularly in the face of “prognostic uncertainty”.

The paper concludes with the recommendation that it is most important to separate clinicians providing the care from those making triage decisions. The idea would be to have a triage officer, with the backing of a team with particular expertise in nursing and respiratory therapy, to make decisions about allocation of treatment resources, and then communicate them to clinicians, the patient and the family or supporter of

\textsuperscript{60} RCN Guidance for nursing staff  
the patient (with the permission of the patient, if competent or a person with an LPA for medical decisions or Deputy if not).

If there were time available for such a system to be trialled in Wales, this could be a sensible route to consider for providing support for clinical teams on the front line.

The Hastings Centre has produced an informative paper on the same issue, entitled “Ethical Framework for Health Care Institutions Responding to COVID-19: Guidelines for Institutional Ethics Service Responding to COVID-19”\(^62\).

This paper, which covers responsibilities of leaders for staff as well as patients, covers a number of important issues, identifying 3 essential ethical duties of Healthcare Leaders responding to COVID-19:

- Duty to plan
- Duty to safeguard
- Duty to guide

The paper begins as follows:

> “An ethically sound framework for health care during public health emergencies must balance the patient-centred duty of care—the focus of clinical ethics under normal conditions—with public-focused duties to promote equality of persons and equity in distribution of risks and benefits in society—the focus of public health ethics. Because physicians, nurses, and other clinicians are trained to care for individuals, the shift from patient-centred practice to patient care guided by public health considerations creates great tension, especially for clinicians unaccustomed to working under emergency conditions with scarce resources”.

This paper, which has thirteen highly qualified contributors, contains a large number of useful references and recommendations together with guidelines for ethics services responding to COVID-19. It is worth reading.

Another article based on the overwhelming recent experiences in Italy offers some guidance on ethical decision-making when it might become necessary to establish criteria for access to and discharge from Intensive Care\(^63\), based not only on clinical appropriateness and proportionality of care, but also inspired also by a criterion, agreed upon as widely as possible, of distributive justice and the appropriate allocation of limited health resources.

---

\(^62\) [https://www.thehastingscenter.org/ethicalframeworkcovid19/](https://www.thehastingscenter.org/ethicalframeworkcovid19/)

The authors point out that this type of scenario is similar to what happens in the context of “disaster medicine,” on which ethical reflection has been necessary for some time. In that context practical guidance has been developed for physicians and nurses who have to make difficult choices.

The authors recommend, controversially, that clinicians should aim at guaranteeing intensive care treatment for patients who have the best chance of therapeutic success, pointing out that:

“We are therefore dealing with privileging those who have the “greatest life expectancy.” As an extension of the principle of proportionality of care, the need for intensive care must therefore be integrated with other elements of “clinical suitability” for intensive care, thus taking into account the type and severity of the disease, the presence of comorbidities, and the impairment of other organs and systems and their reversibility. This entails that there is not necessarily a need to follow a criterion for access to intensive care, such as “first-come, first-served”.

Articles in the UK media have expressed some alarm about an approach that scores people according to frailty and age64.

The need for transparency in decision-making

It is vital that decisions are made fairly, transparently and consistently on the basis of the best available evidence. A BMA publication which offers guidance for doctors during the present crisis explains that the clinical demands created by the pandemic will require doctors to make extremely difficult choices about how they provide care and to whom. The advice highlights how demands at the height of the pandemic will make it difficult for doctors to resolve the ethical dilemmas they will inevitably be required to face.

The ethical guidance issued by the BMA65 echoes the elements identified widely in other UK guidance including C-MEAG. The BMA statement of the essential elements of an ethical framework for doctors66, refers to the underpinning principles as:

- "**Equal respect:** everyone matters and everyone matters equally, but this does not mean that everyone will be treated the same
- **Respect:** keep people as informed as possible; give people the chance to express their views on matters that affect them; respect people’s personal choices about care and treatment

---

64 The Times April 13th 2020 comment on use of scores for over people 65
65 BMA COVID Guidance Ethical Issues
66 BMA Ethical Guidance issued April 2nd 2020 for doctors during COVID-19
- **Minimise the harm of the pandemic**: reduce spread, minimise disruption, learn what works
- **Fairness**: everyone matters equally. People with an equal chance of benefiting from a resource should have an equal chance of receiving it – although it is not unfair to ask people to wait if they could get the same benefit later
- **Working together**: we need to support each other, take responsibility for our own behaviour and share information appropriately
- **Reciprocity**: those who take on increased burdens should be supported in doing so
- **Keeping things in proportion**: information communicated must be proportionate to the risks; restrictions on rights must be proportionate to the goals
- **Flexibility**: plans must be adaptable to changing circumstances
- **Open and transparent decision-making**: good decisions will be as inclusive, transparent and reasonable as possible. They should be rational, evidence-based, the result of a reasonable process and practical in the circumstances.”

The guidance is the product of careful deliberations by an experienced team of clinicians and ethicists. It deals with issues of prioritising scarce resources and the following statement is made:

“All decisions concerning resource allocation must be: – reasonable in the circumstances
- based on the best available clinical data and opinion
- based on coherent ethical principles and reasoning
- agreed on in advance where practicable, while recognising that decisions may need to be rapidly revised in changing circumstances
- consistent between different professionals as far as possible – communicated openly and transparently
- subject to modification and review as the situation develops”.

**Recording the reasons for decisions**

The principle of accountability identified in the ethical guidance issued by the UK and Welsh Governments[^67] means that people making decisions need to be:

“transparent about how and which decisions need to be made and on what basis; and prepared to justify which decisions are made and why, ensuring that appropriate records are being kept.”

[^67]: Adult Social Care: Ethical guidance
It would be dangerous to use the term “rationing” in the context of decisions that need to be made about admission to critical care. Evidence must always be carefully considered and based on a detailed assessment of the available evidence.

The strength of arguments in favour of prioritising a particular patient can depend on the quality of evidence available to clinical decision-makers, but as COVID-19 is a new disease, there is considerable uncertainty in the evidence in view of the sudden appearance of the virus which has left little time for research to be validated.

Although this complicates matters greatly, it is important for clinicians to be able to justify their decisions, and they will no doubt be aware of the need for meticulous recording of the reasons for their decisions, demonstrating that they have weighed in the balance the various risks and benefits to each patient of any proposed treatment, with consideration of the resources available at the time.

The term “futility” is not generally mentioned in conversations with patients and their relatives. What are described as “futile medical interventions” are treatments and procedures from which the patient is likely to derive no benefit or where the risk of harms greatly outweighs any possible small or transient benefit. More commonly discussed is the concept of non-maleficence which becomes relevant when considering whether the proposed treatment is likely to cause more harm than good.

Other considerations that need to be weighed in the balance are respect for the autonomy of the patient and how it relates to the interests of other people, as well as other patients, society, and the country as a whole. These issues are discussed in the context of COVID-19 in an article recently published in Australia.68

2.7. Progression to ICU

Conversations with patients and/or relatives need to take place when a patient is sick enough to be admitted to ICU, but preferably before that. If the patient lacks decision-making capacity and is over the age of 16, the Mental Capacity Act 2005 (MCA) applies.

Consent to the proposed treatment

Treatment should not commence without consent, if the patient has mental capacity to consent to the intervention.

The Coronavirus Act has not altered the need to comply with the law in the Mental Capacity Act (MCA) and Deprivation of Liberty Safeguards (DoLS), which apply whenever a person lacks capacity for a particular decision at the time the decision must be taken. However, the processes around applications under DoLS have been

---

68 Australian Ethics Centre: Making difficult decisions in end of life care
69 The MCA and DoLS during the COVID-19 pandemic
made more proportionate in the Government’s updated guidance for England and Wales.

There is no need for a detailed analysis of the legal framework at this point, as clinicians working with patients in ICU are very experienced and well-acquainted with this area of law. The essential point is that in highly pressured circumstances there may be little time to consent the patient. It might well be more practical for the question of consent to be dealt with by appropriately qualified staff before patients enter ICU.

In order to obtain informed consent, clinicians would be required to explain the details of the treatment and answer any questions that the patient may have. A severely ill patient suffering the effects of advanced infection with COVID-19 may not have capacity, but would be assumed to have it unless, following an assessment, lack of capacity could be established. Communication is obviously very difficult if the patient is gasping for breath and in pain, the situation very urgent and the unit extremely busy.

The first two sections of the MCA are very important. Section 1 sets out the following principles:

- "A person must be assumed to have capacity unless it is established that he [or she] lacks capacity
- A person is not to be treated as unable to make a decision unless all practicable steps to help him [or her] to do so have been taken without success
- A person is not to be treated as unable to make a decision merely because he [or she] makes an unwise decision
- An act done, or decision made, under the Act for or on behalf of a person who lacks capacity must be done, or made, in his [or her] best interests
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action”.

Section 2 of the MCA defines situations in which a person may lack capacity. It states:

"For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time they are unable to make a decision for themselves in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain. It does not matter whether the impairment or disturbance is permanent or temporary.

A lack of capacity cannot be established merely by reference to:
• a person’s age or appearance, or
• a condition, or an aspect of their behaviour, which might lead others to make unjustified assumptions about their capacity."

It is important for patients to be given as much help as is practical before they are assessed as being unable to make their own decisions, and they should be supported as far as possible in making a specific decision for themselves.

The principle of respect means that if:

“a person may lack capacity as defined in the Mental Capacity Act, it is necessary to ensure that a person’s best interests and support needs are considered by those who are responsible or have relevant legal authority to decide on their behalf”.

In the case of people under the age of 16 a different set of legal rules applies, and it would be necessary to determine the question of capacity by applying the Gillick criteria, which will be familiar to clinicians working in PICU.

Clinicians should ascertain whether the patient had registered an advance decision to refuse treatment (ADRT), stating refusal of specific life-sustaining interventions, in compliance with the law, and whether there is a registered Power of Attorney for Health and Welfare decisions at an enhanced level for life-saving decisions. However, it must be noted that a person with capacity can change their mind at any time.

The Office of the Public Guardian which deals with matters arising in connection with the Mental Capacity Act 2005 and Deprivation of Liberty safeguards, has issued guidance supporting staff, some of whom are working in new roles during the COVID-19 crisis, to make urgent applications to discover whether patients have attorneys or deputies in place. Liaison with staff in social care is likely to be necessary in some circumstances.

Conversations with relatives usually have to take place over the telephone rather than in person, which can create difficulties for both clinicians and relatives. Important life and death matters such as decisions about the cessation of treatment and complex risks and benefits involved in treatment decisions, ventilation or DNACPR (do not attempt cardio-pulmonary resuscitation) would normally be best discussed in person. These major decision should be taken in advance wherever possible, preferably by generalist clinicians, as part of an advance care plan. Although ICU clinicians have considerable experience of breaking bad news to relatives in a sensitive way, at a distance this can be very difficult. It is also

---

70 NSPCC summary of Gillick and Fraser guidelines
71 Guidance by OPG on urgent applications in COVID-19 crisis
72 A letter on DNACPR in Wales from CMO/CNO will be publicly available shortly
necessary to keep in mind the need to comply with the legal framework on confidentiality and Data Protection.

In deciding to step-up care or step-down care it is suggested a few clear principles apply:

- The person’s wishes and feelings are very important and effort should always be made to discover what the patient wanted, consulting Advance Decisions to Refuse Treatment, Lasting Powers of Attorney, documented conversations and information from family and close friends about key conversations
- The clinical need of the patient should be assessed using objective agreed criteria
- The patient’s ability to benefit from the proposed treatment should be taken into account
- The resources available to meet the patient’s needs should be considered.

Whenever there is dispute over what to do next, an immediate panel should be available to assess the situation (if possible two expert clinicians and a suitably qualified lay person) at all times of the day or night – electronically or by phone if necessary. The clinicians should be very senior people who are aware of the frontline resources at the time, but independent of those with the clinical dilemma. These important roles are best fulfilled in a voluntary capacity and conflicts of interest must be avoided.

An application to a Court should not be ruled out.

2.8. Palliative Care.

Well tried and tested advice exists concerning palliative care. Patients may die:

a. At home
b. In a care home
c. In hospital
d. In transit.

The Association for Palliative Medicine has produced useful guidance that has been widely adopted. Although written for professionals caring for the dying in hospitals, it is easily adapted to other settings.

Presence of a relative when someone is dying

There has been considerable media comment on the inability of relatives in some areas to be present when their loved-one is dying.

Many hospitals have excluded all visitors, but there are policies to allow one relative to be at the bedside of a dying person, provided with appropriate PPE. This is a more humane response, better accords with the patient’s wishes, and may help
decrease long term psychological morbidity in the bereaved. It may also relieve staff of some pressure. At the time of admission, it may be that one family member can be identified as low-risk for COVID-19 and wishing to be called in.

This is particularly important for dying children and those with learning difficulties, but it is of great importance to every family. Relatives may want to say goodbye, albeit through another, and want to know that the person did not die alone.

The guidance in England specified that although visiting is suspended, the only exceptional circumstances where one visitor – an immediate family member or carer – is permitted to visit if the patient is receiving end-of-life care, a parent or appropriate adult visiting a sick child or to support someone with a mental health issue such as dementia, a learning disability or autism, where not being present would cause the patient to be distressed.

2.9. Step-down/leaving hospital

Some patients who still require care after leaving a District General Hospital will be discharged to convalesce in Community Hospitals. Others will return home without step-down care in a hospital setting.

Advice will be needed for survivors, many of whom are likely to need support, particularly if they are suffering recognised physical and psychological symptoms following treatment in critical care.

A useful article in the Journal of the Intensive Care Society73 reviewed the evidence of the high levels of psychological and neuro-cognitive consequences of critical illness.

It will also be necessary to make arrangements for managing the physical, effects of critical care, cognitive dysfunction, neuropathies and myopathies after discharge.

2.10. Discharge home

Advice needs to be provided to relatives and carers of patients returning home, and arrangements will be necessary in collaboration with social services for discharge. Pre-discharge home support and longer term monitoring at home for long term sequelae will also be necessary.

Hospital Discharge Services Requirements for health, social care, third and independent sector partners in Wales, applicable from April 6th 202074 are clearly set out in guidance. Much of the content is familiar, following work already carried out to embed the ‘Every Day Counts; Home First’ policy and “Discharge to Recover then Assess” Pathways in Wales.

73 JICU Psychological impact of ICU
74 Welsh Government Advice on COVID-19 patients leaving hospital
People in need of particular support have been identified as pregnant women and families caring for elderly or disabled relatives.

2.11. Deaths

Advice has been issued by the Government on death certification, funerals and disposal\textsuperscript{75}. Guidance on nurse verification of death has been produced by Marie Curie\textsuperscript{76}.

Faith groups have been involved in discussions about these matters, as usual funeral arrangements will not normally be possible and the number of mourners will be restricted. The guidance is designed to assist coroners, mortuary operators, pathologists, other medical practitioners and funeral directors and their staff who are required to manage bodies of deceased persons infected with COVID-19.

The advice contains additional information for healthcare workers in both secondary and primary care, and first responders who come into contact with a body that may be infectious, as well as for members of the public who identify a death in the community.

The guidance also includes specific information for faith communities and the public to help them to take action to reduce the risk to mourners and the bereaved following a death from any cause in the community.

a. Handling of body
b. Death certification
c. Religious requirements
d. Burial grounds
e. Attendance at funerals.

The Muslim Council of Wales also issued a briefing and interim guidance regarding burials.

Muslim Council of Wales- Briefing and Interim Guidance Regarding Burials and COVID-19

2.12. Bereavement

Support during bereavement is already in place from trained counsellors, from faith groups and volunteers, but more help may be required. Advice has been issued by Chaplaincy services\textsuperscript{77}.

\textsuperscript{75} Government Guidance on COVID-19 Deaths
\textsuperscript{76} https://www.mariecurie.org.uk/help/support/bereaved-family-friends/practical-legal/verifying-and-certifying-death
\textsuperscript{77} Bereavement Advice
Many families will be unable to attend funerals, and memorial events are being planned to help in marking mass deaths.

A number of on-line memorial sites are helpful for grieving relatives.

2.13. Long term monitoring.

It is envisaged that there will be a need for long term follow-up of groups for sequelae - for example those who were pregnant during the pandemic and people who were ventilated in ICU.

2.14. Continuing protection and opportunities for staff

The lives of many people working in health and social care will be changed by the COVID-19 crisis and longer term repercussions will present challenges and/or opportunities for some.

Staff working in new roles

The opportunity for staff to step up to more challenging roles could provide opportunities to some for working in different and more interesting ways in the future. However, some more vulnerable people with a history of mental health problems may well need to be identified by occupational health services as needing additional support after their working lives return to normal.

There are have also been concerns that claims for compensation could be made by patients and families suffering loss or damage as a result of what they consider to be negligence in healthcare. This situation was anticipated when the Coronavirus Act 2020 was passed, and special provision was made for indemnity for health service activity in England and Wales. Section 11 states:

“(1) The appropriate authority may:
   (a) indemnify a person in respect of a qualifying liability incurred by the person, or
   (b) make arrangements for a person to be indemnified, in respect of a qualifying liability incurred by the person, by an authorised person.

(2) References in this section to a qualifying liability are to a liability in tort, in respect of or consequent on death, personal injury or loss, arising out of or in connection with a breach of a duty of care owed in connection with the provision, after the coming into force of this section, of a relevant service”.

2.15. Learning lessons

At the end of the pandemic, research will be needed into a number of matters, including planning the provision of services during the COVID-19 crisis, and in due
course consideration will doubtless be given to learning from the experiences of COVID-19 in the UK and also other countries on matters such as:

- Transport of sick patients – France has converted a TGV into a large intensive care unit. This allows it to be moved to anywhere that is at capacity to remove patients, care for them in transit even for many hours and take them to a city that has capacity. It has been used to transport patients from France to Germany. Could Wales learn from this idea?

- Prevention – the early trials of hydroxychloroquine to prevent viral load in infection are promising, but it is a drug with serious toxicity. Other work suggests vitamin D and prophylactic antivirals may play a role in decreasing viral burden and in decreasing the risk of cytokine storm. Wales should be an immediate adopter of pre-infection studies and work in collaboration with UK wide and international research groups. Is there a trials research register in Wales and are the relevant clinical research collaboratives being established in Wales?

- With the shortage of clinical PPE, coordination of volunteers across Wales could help to produce masks and scrubs and gowns for use in low-risk areas, reserving other PPE for high risk areas. Is such a network in action?

- Planning the exit strategy – plans for mobility, vaccination and other decision need to be developed now.

- Public information – Wales needs a really effective public information campaign for situations such as pandemics and some lessons could be learned from the way organ donation information was handled. There is also a need for public information to help the public avoid becoming victims of misinformation and fraud, as criminal groups have exploited the current emergency.

Authors

Vivienne Harpwood, Emerita Professor of Medical Law and Ethics, Cardiff University, Chair of Powys Health Board and Chair of Welsh NHS Confederation

Ilora Finlay, Honorary Professor of Palliative Medicine, Cardiff University, Chair of the National Mental Capacity Forum and Crossbench Peer