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Chief Executives & Directors of Nursing (Trusts)
Chief Executives of Hospices

Date: 5 November 2020

Dear Colleagues

UPDATE TO END OF LIFE CARE VISITING GUIDANCE WITHIN HOSPITALS AND HOSPICES DURING THE COVID-19 CRISIS

As a result of the Northern Ireland Executive's decision to invoke limited additional restrictions across Northern Ireland in response to increasing COVID-19 transmissions, updated visiting guidance covering all Health Care settings was published and took effect from 23 September 2020. This guidance is written in such a way as to require different levels of restriction based on the regional position in terms of surge assessment, and is kept under constant review, to permit changes or additions as necessary.

It has consistently recognised end of life care as being an exceptional circumstance in which restricted visitation to a patient will be permitted regardless of the Regional Alert Level Position at that time. Every effort has been made to support visiting by those who are important to the person who is approaching end of life, with due regard to risks and responsibilities regarding COVID-19. However, visiting restrictions to prevent the transmission of COVID-19 have rightfully still been applied.

This is a very emotive and sometimes difficult issue and therefore to reduce the distress for families and support decision making for staff dealing with circumstances in which end of life care is being provided, an update to the guidance has been published.

The **“Principles for visiting people (adults) with life limiting or progressive conditions, including visiting at the patient’s time of death**”, has been added as an appendix to the regional guidance. This will take immediate effect in hospices and hospitals. This update is located at ‘*Appendix 7*’ of the full guidance, available at: https://www.health-ni.gov.uk/Covid-19-visiting-guidance

The appendix has been informed by colleagues across the sector with expertise in this area and reflects the ‘COVID-19 Ethical Advice and Support Framework’, enclosed for information. Further work will be done in the near future in partnership with care homes and families of residents to consider the implementation of equivalent guidance within this setting.

I ask that this updated guidance be appropriately circulated to facilities and staff.

Yours sincerely

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COVID-19 Guidance: Ethical Advice and Support Framework

COVID-19 HSC Clinical Ethics Forum

21 September 2020

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PART 1

The Framework and Ethical Principles

1 Foreword

The four Chief Medical Officers of Northern Ireland, England, Scotland and Wales are working to ensuring a collective approach to managing the COVID-19 outbreak across the four nations, and guidance developed specifically for Northern Ireland is closely aligned with that of the rest of the UK.

Under normal circumstances, those using health and social care services, as well as those working in the service, expect fairness and equity in access to treatment and care with openness and transparency in how decisions are made, supported by an ethical and compassionate approach to how care is received and delivered. This is enshrined in the Health and Social Care services values of: excellence, working together, openness and compassion.

The COVID-19 pandemic presents particular ethical challenges at all levels of health and social care. This framework document is designed to support decision-makers by establishing agreed broad parameters that must be considered in the process of decision-making to ensure that such processes are fair, open and compassionate.

The principles of equality of concern and respect should apply to all individuals, their families and carers, professionals and communities and will underpin all decision making. The harm that might be suffered by every person matters regardless of age, health condition or disability, gender, ethnicity, sexuality, religion or mental health. As a health and social care system, our decisions and actions will seek to minimise the harm to individuals as well as the overall harm that this pandemic may cause. The safety of every patient is the constant concern of everyone working in health and social care at every level and we recognise that the involvement of people in decisions about their own care is critical to the delivery of safe, effective, accountable and compassionate care and treatment.

This guidance will be continuously reviewed and updated as the evidence and our experience of COVID-19 grows. Any comments you may have on the content of this document and how it can be improved will be considered in the next version of the guidance.[1]

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[1] **Please send feedback to:** Stephanie.Jones@health-ni.gov.uk

2 Executive Summary

Core principles

The COVID-19 pandemic presents ethical challenges at all levels of health and social care, including for those patients with non-COVID conditions whose care and treatment has been affected. A framework to support ethical decision-making has been developed which includes general principles (part 1) and guidance (part 2) on the application of ethical principles in practice.

- This guidance on ethical advice and support should be read alongside (regional and national) clinical decision-making and escalation **guidance.** It applies at all levels of health and social care delivery in hospitals, care homes and the community.

- There are multiple levels of decision-making and clinical decisions should continue to be guided by the **codes of professional practice** as well as available evidence. Clinical teams have responsibility for decisions about their patients.

- This guidance and framework must be interpreted using a **rights based approach** taking into account as a minimum the principles of: respect; fairness; minimising harm; working together; flexibility; keeping things in proportion; reciprocity and good decision-making.

- Whilst the overarching ethical aim is to provide the greatest good for the greatest number, in situations where demands are high and resources finite, each **individual case should be weighed on its merits**. There are no blanket exclusions.

- The important underlying principle of **compassion** should be applied**.** In every instance, the desire to maximise the benefits to the population must be balanced with the duty to care for each individual and to treat others as we would wish to be treated.

- While the approach to assessing, supporting and recording decisions about **capacity and consent** remains unchanged during the COVID-19 pandemic as it does under normal circumstances, the limitations imposed by patient isolation and PPE mean extra effort will be required to ensure that such discussions take place with patients and their families in a timely and sensitive way. The guidance sets out the underpinning legal framework, including information on consent and capacity.

- Patients will continue to be offered **treatment in all care settings appropriate to their need**. A review of the placement of the individual in the care setting should be prompted if this is not possible.

- The importance of respecting people's personal choices about their care and treatment is highlighted, through the encouragement of **advance care planning.** These ensure that people have an opportunity to say in advance how they wish to be treated, as well as when and where such care should be provided, so that clinical decisions can, where possible, take into account their expressed wishes.

- In all care settings it is important to have a **consistency of approach** between individual clinicians, units and Trusts. This is only possible through the adherence to Regional guidance for ethical decision-making that then informs guidance and processes for those delivering services in HSC Trusts and commissioned services.

- It is recognised that at these times, when difficult decisions must be made, care-givers will be faced with ethical dilemmas, or even moral distress, and it is recognised that making such decisions in these circumstances requires **moral courage.** It is at these times, especially, that care-givers needs moral, psychological and pastoral support.

- In the anticipated small number of situations where **ethical advice and support** is needed, this must be available to aid decisions at individual, group or population level. HSC Trust Clinical Ethics Committees will provide such advice and support, including through the creation of panels or sub-groups where necessary.

- Clinicians should be assured that **decisions taken in good faith**, in accordance with national actions and guidance to counter COVID-19, will not be held against them.[2]

Access to Critical Care

- It is necessary and correct for critical care specialists, as part of their usual work, to make **rapid decisions regarding admission** to critical care units, and this remains the norm at this time. Not all patients will benefit from critical care services which is reflected in the decision-making process at all times.

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[2] GMC statement set out in appendix 2 (i) and BMA Guidance in 2 (ii)

- In the context of finite critical care resources, there is a possibility that some patients who would normally benefit from critical care may not be able to avail of it due to unusually high demand therefore **agreed principles around decision-making processes**, and agreed clinical criteria, are needed to ensure a consistent approach[3].

- Health and social care staff may need **psychological and pastoral support** during and after making difficult, complex or challenging decisions. Clinicians working outside their normal area of practice should not be making such finely balanced decisions. However, doctors making decisions within their normal scope of practice will be doing these in an unusually difficult and demanding environment. In unprecedented circumstances this may result in psychological distress; support should be made available within individual Trusts as required.

Clinical Ethics Committees

- Local **ethics decision support groups** within Trusts may help clinicians to make difficult decisions. The advice and support available through Trust Clinical Ethics Committees should also assist by virtue of advice being objective, agreed by consensus and based on ethical principles.

- The **roles of the regional COVID-19 HSC Clinical Ethics Forum** and HSC Clinical Ethics Committees may need to evolve as the clinical context changes. Advice and guidance may change to reflect the evolving situation and the emergence of new issues. All such changes will be communicated clearly.

- This guidance aligns with the work of the **UK Moral and Ethical Advisory Group**, which was established to provide advice to the four Chief Medical Officers of Northern Ireland, England, Scotland and Wales taking a coherent approach across the UK.

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[3] BMJ Journals: Journal of medical ethics:
Revisiting the equity debate in COVID-19: ICU is no panacea ...jme.bmj.com › 2020/06/22 › medethics-2020-106460

3. Context

The COVID-19 pandemic is impacting on the lives of everyone in Northern Ireland. We each have a responsibility to take care of ourselves and others for the benefit of all, accepting restrictions in our lives which are unprecedented. It is important that ethical consideration is given to the implementation of public health measures introduced to reduce and mitigate risk. All such measures must be proportional, reasonable, and equitable.

Some individuals are more at risk from the serious adverse effects of COVID-19 infection than others, and while everyone matters equally, the needs of individuals differ. This is reflected in the great number of older and more vulnerable individuals being shielded in such a way that severely restricts their access to family and friends. Health and social care staff and those in essential services are at higher personal risk to the exposure and effects of COVID-19 infection than the general population. This must be reduced by the provision and rational use of protection from infection and support in the exercise of their crucial roles, and by the exercise of collective and collaborative responsibility by all.

As with ethical deliberations in non-COVID times, sometimes there may be tension both within and between principles – in balancing different sorts of harm to individuals and groups, and in trying both to minimise risk of harm and to be fair. There are often no absolute right answers, and a judgement may have to be made on the priority to be given to each element of a principle (such as the potential impact of different types of harm) and to the principles themselves in the context of particular circumstances.

The COVID-19 pandemic presents ethical challenges at all levels of health and social care with increased patient demand for Health and Social Care services in Northern Ireland, along with a high level of staff absence. This may impact on the entirety of the health and social care system, including its capacity to meet the increase in demand in the community and in secondary care as well as the limited critical care service. This framework document is necessary to establish agreed broad parameters that must be considered in the process of decision-making. This is especially the case in the context of finite critical care resources that may be outstripped by demand over the course of the pandemic situation.

The treatment of non-COVID patients at a time of pandemic

Delivering care to patients seriously ill with non-COVID conditions during the COVID-19 crisis is challenging given the competing risks of death from the original illness versus death or serious complications from infection, and the likely higher risks of COVID-19 disease in immunocompromised patients, particularly those with cancer. Other challenges include postponement or cancellation of diagnostic imaging and procedures, surgery and face-to-face hospital appointments. This is particularly relevant to (but not confined to) treatment of major cancers.

There is no ‘one size fits all’ approach to delivering cancer care during the COVID-19 pandemic, and treatment decisions must be made on a case-by-case basis, which recognises the increased risk of infection associated with receiving care in any healthcare facility, as none can be entirely COVID-free. The approach to decision-making should balance the risk of progression with delay of cancer care versus the risk for significant morbidity from COVID-19. A very high risk of progression would ideally result in no delay in treatments for the individuals most likely to benefit; however benefits of immediate treatment must be balanced against the risks, particularly if critical care facilities are anticipated to be required following surgery.

For some cancers, alternative treatment or active surveillance may be considered, but these are difficult decisions, and should also take into account specific patient comorbidities as well as values and preferences. Care should be taken as far as is possible to ensure that patients with serious non-COVID disease are not disproportionately disadvantaged, and as the threat of pandemic situation lessens in severity, consideration is given to resumption of services as soon as is practically possible, in line with professional guidance.

Patients with acute medical or surgical conditions should continue to be managed in line with best clinical practice. Decision-making should not be disease-specific – i.e. the presence or absence of COVID-19 should not be a limiting factor in treatment decisions. At a time of increased demand, where care between a COVID-19 patient and another patient in need of care is in question, care should be prioritised based on national guidance, as well as the individual circumstances, clinical opinion and a second opinion if necessary, with involvement of ethics committees if deemed necessary. Professional accountability remains unchanged and the basis for decisions should be robustly documented.

4. The Framework

4.1 Purpose

The purpose of this Framework is to support the fair access to all levels of health and social care services and the effective use of critical care capacity in the event of exceptional demand. The Framework is based on published national guidance, taking account of the requirements under local legislation, such as Section 75 of the Northern Ireland Act 1998[4] and the overarching HSC values of excellence, working together, openness and compassion.

4.2 Process

This Framework, which has been developed by the regional COVID-19 HSC Clinical Ethics Forum,[5] has taken cognisance of advice from other organisations including the British Medical Association (BMA, 2020), the National Institute for Health & Care Excellence (NICE, 2020), the Royal College of Physicians (RCP, 2020), and the British Board of Scholars and Imams (2020) (see references in section 9). These are based upon specific ethical principles and evidence-based guidelines. They inform decision-making and can enhance trust and solidarity and strengthen the legitimacy and acceptability of the measures put in place. However, clinicians should remain mindful of the obligations and responsibilities set out in professional codes of conduct and continue to use their professional judgment.

4.3 Application

This Framework will be adopted by all HSC organisations and those contracted to provide services, in the first instance for the duration of the period during which special arrangements are in place to address the COVID-19 pandemic.

The general application of principles will apply at all times in determining access to health and social treatment and care with clear decision-making guidance to assess individual cases, and advice on appropriate management and escalation, to assist clinicians and clinical teams make difficult decisions. Detailed decision-making criteria and processes, including the ability to review decisions and seek advice and support, should be put in place in each Trust.

Each HSC Trust providing critical care services should have a clear objective, evidence-based and transparent decision-making process to support ethical decision making in situations of exceptional

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[4] http://www.legislation.gov.uk/ukpga/1998/47/section/75

[5] COVID-19 HSC Clinical Ethics Committee Terms of Reference set out in Appendix 1

demand for services. This should inform individual HSC Trust plans. However, the decision making process for each Trust must be broadly similar and take account of the regional context in the availability of the Critical Care resource.

4.4 Application at a time of exceptional demand

By definition the sections of the Framework relating to situations of *exceptional demand (*for example in critical care) will only be applied in defined circumstances. Exceptional demand may occur due to a single catastrophic event with an overwhelming number of casualties who require intensive care or due to an ongoing “slow burn” event such as the COVID-19 pandemic, having occurred as a result of a novel infectious disease.

In the exceptional demand scenario, the available critical care resource may not be sufficient to be available for all patients with the ability to benefit. The threshold for access therefore rises.

4.5 Ethical support and advice

The Northern Ireland COVID-19 HSC Clinical Ethics Forum will act as the overarching group responsible for developing principles and practical guidance for the health and social care sector as well as considering and offering advice on regional ethical issues that emerge.

The support of existing clinical networks (such as the Critical Care Network for Northern Ireland) and other expert groups will allow access to collective advice around complex clinical, ethical and logistical challenges as they arise.

A process for ethical advice and support has been established in each HSC Trust, to deliver further pragmatic ethical support to clinical teams for complex or difficult cases, using where necessary a small panel which can respond in a timely manner.

Arrangements for support and advice are set out in detail in section 8 of this Framework.

5 Ethical principles

5.1 Introduction

In the rights based approach every human life, regardless of age, gender, race, ethnicity, religion, political affiliation, marital status, sexual orientation, disability, or persons with or without dependents is considered equal.[6] This also relates to social or economic status.

It is a core principle that individuals are treated independently of suspected or confirmed COVID-19 status, and that any **clinical decision guidance applies equally** to all individuals with or without COVID-related diseases.

An important underlying principle is that of **compassion.** In every instance, the desire to maximise the benefits to the population must be balanced with the duty to care for each individual and to treat others as we would wish to be treated.

All clinical staff should act in accordance with **professional guidance** and in accordance with their **legal obligations**. For doctors this includes the GMC's guidance *Good Medical Practice* (2013), *Consent: patients and doctors deciding together* (2008) and *Treatment and care towards the end of life* (2010). For nurses this includes the NMC guidance on the code of practice *Professional standards of practice and behaviour for nurse, midwives and nursing associates (2015)*. For Social workers this includes *NISCC Standards of Conduct and Practice for Social Care Workers and Social Workers in November 2015.* For AHPs, Biomedical and Clinical Scientists, and Practitioner Psychologists this includes HCPC Standards of Conduct, Performance and Ethics https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/

While there is a wish to **maximise the overall benefit** to the greatest number of individuals from the distribution of limited resources at a time of high demand, balancing potential benefit with risk of harm, it would be unethical to allocate health and social care resources to those who cannot realistically be expected to benefit from them. There are two key questions applicable whether or not resources are limited:

- Would the intervention benefit the individual? That is, will there be a realistic chance that the benefit will sufficiently outweigh any adverse effects?
- If the intervention is likely to be of benefit, outweighing any adverse effect, would the patient want it? That is, the standard issue of consent.

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[6] The Northern Ireland Act 1998 – Section 75 Appendix 3 (ii)

Each **individual case should be weighed on its merits**: there are no blanket exclusions. However, pre-existing health issues, including frailty, which impact on the likelihood of benefitting from a specific clinical intervention, must be taken into consideration.

5.2 Ethical principles particularly relevant at a time of high demand and finite resources

For the great majority of health and social care services provided during the COVID-19 pandemic, practice continues as usual, based on standard principles of good clinical practice. The following considerations apply to situations of high demand and finite resources:

- It is the overarching duty of all health and social care professionals to maximise quality of life and to minimise pain and suffering. This duty of care applies regardless of any decision concerning the allocation of health and social care resources.

- Whilst the overarching ethical aim is to provide the greatest good for the greatest number, in situations where demands are high and resources finite, each individual case should be weighed on its merits. There are no blanket exclusions.

- Access to care is determined by clinical assessment of the benefit to the individual, with the explicit understanding that the threshold for benefit will necessarily change as the demand increases.

- Individuals will continue to be offered appropriate treatment in all care settings. A review of the placement of the individual in the care setting should be prompted if this is not possible.

- If it is decided that resources (such as critical care) are to be allocated preferentially to an individual with a lower level of pre-existing healthcare need, this should only be because that individual is deemed to have a greater ability to benefit with a greater chance of recovering from the illness.

- Decisions regarding an appropriate plan for care must take account of the patient's wishes, ideally stated at a time when the patient is stable and not acutely unwell, in discussion with a GP or other clinician who has an on-going relationship with the patient (see Part 2 section 7). Where such advance care planning has occurred, this information should be documented and made readily available to clinicians involved in the patient's acute care via the Key Information Summary (KIS) of the Electronic Care Record (ECR), where this is available.

- An appropriate optimal level of care should ideally be considered on admission to hospital, when a hospital anticipatory care plan may be helpful (see Part 2 section 7). Clear communication is essential in treatment decisions with individuals and their relatives or those close to them.

- In situations of impaired capacity, all measures should be taken to maximise capacity. If capacity remains impaired, then decisions should be made on the basis of the best interests of the individual, and should take account of any previously expressed wishes and preferences. Communication with family to those close to the patient remains paramount.

- Clear explanations, for individuals and family members, regarding the institution of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders are of critical importance to avoid misunderstandings. DNACPR orders exist to prevent the inappropriate, potentially harmful or futile intervention of cardio-pulmonary resuscitation on a person who is in the terminal phase of their illness or who is unlikely to survive such an intervention. It does not refer to any other clinical intervention. GMC guidance[7] describes when CPR may be successful in restarting a patient's heart and breathing and restoring circulation, the benefit of prolonging life must be weighed against the potential burdens and risks.

5.3 General ethical principles in a COVID-19 pandemic

The ethical framework developed by the Committee on Ethical Aspects of Pandemic Influenza was first published in 2007, revised by the Department of Health and Social Care in 2017 and adapted in March 2020 in guidance for the COVID-19 pandemic.[8] This framework outlined the fundamental principles that all people should be treated with equal concern, respect and compassion.

- Everyone matters.
- Everyone matters equally – although 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.
- Where there are high demands on finite resources, individuals should receive the best care possible, while recognising that there may be a competing obligation to the wider population with each individual case being weighed on its merits.

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[7] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/cardiopulmonary-resuscitation-cpr

[8] Department of Health and Social Care: Responding to COVID-19: the ethical framework for adult social care 19 March 2020

This guidance and framework must be interpreted taking a rights based approach reflecting the obligations under human rights,[9] equality legislation[10] and disability discrimination.[11]

Respect

Every individual should be offered good quality and compassionate care:

- Holding a view of the person as a whole, taking into account their rights, wishes and feelings as a unique individual.
- Keeping individuals as informed as possible, ensuring that communications are available in accessible formats.
- Giving individuals the opportunity to express their views and take part in decisions on matters that affect them and responding to a person's personal preferences about their treatment and care.
- When an individual is not able to make a decision, those who have to decide for them take such decisions based on the best interests of the person.
- Maintaining confidentiality.

Fairness

Every person should be treated justly as an individual so that decisions are rational, fair, practical, and grounded in appropriate processes, available evidence and a clear justification:

- Everyone matters equally, so people with an equal chance of benefiting from health and social care resources should have an equal chance of receiving them.
- Any assessments of potential benefits and harms from a health or social care intervention or its timing must respect individual rights.

Minimising harm

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[9] The Human Rights Act 1998 http://www.legislation.gov.uk/ukpga/1998/47/part/VII/crossheading/human-rights
[10] The Northern Ireland Act 1998 http://www.legislation.gov.uk/ukpga/1998/47/section/75
[11] The Disability Discrimination Act 1995

Striving to reduce the amount of physical, psychological, social and economic harm that the outbreak might cause to individuals and communities.

- Any assessments of potential benefits and harms from a healthcare intervention or its timing must respect individual rights in the avoidance of harm by inappropriately giving or omitting a treatment or intervention.
- Learn from experience about the best way to provide optimal health and social care to people who are ill in a pandemic situation, 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 and social care services needed for people's survival and wellbeing.

Working together

All those working in health and care services should collaborate in the planning and delivery of services. Individuals using health and social care services should expect to work in partnership with health and social are staff in any decision making around their treatment and care.

- The present and past wishes and feelings of individuals should be taken into account so far as they can be ascertained by any means of communication with those directly involved or knowledgeable about such wishes and preferences.

- Clinicians should act with honesty and integrity in their communication with individuals, carers and families and should communicate clinical decisions and the reasoning behind them transparently, being honest and clear where there is uncertainty and avoiding predictions (both positive and negative). This should be documented appropriately.

- All health and social care staff should co-operate to limit infection spread, especially to more vulnerable groups and to minimise the risk of complications if someone is ill.

- Health and social care services must work together with other services, statutory agencies and third sector, to plan for, and respond to, the pandemic; cooperating to help one another.

- Health and social care services should be prepared to share information (for example, on the effects of treatment, or particular risks to some) that will help others.

Flexibility

As the clinical situation evolves both at the individual and population level, decisions require regular review with clear guidance at both national and regional level:

- Those making individual healthcare plans should take into account new information and changing circumstances, and adapt plans accordingly, in light of revised advice and guidance which has developed to address emerging issues.

- Individuals will have as much chance as possible to express concerns about, or disagreement with, decisions about health and social care that affect them and be given access to advocacy services and/ or prompt independent second opinion.

Keeping things in proportion

Those responsible for providing information will neither exaggerate nor minimise the situation and will give people the most accurate information that they can, being honest and clear where there is uncertainty and in such circumstances avoiding firm predictions (either positive or negative):

- 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.

- Support should be provided proportional to needs and abilities of individuals, communities and staff, and the benefits and risks that are identified through decision-making processes.

Reciprocity

The ethical principal of reciprocity requires that society supports those who face a disproportionate burden in protecting the public good and takes steps to minimise the risks and burdens as far as possible. In the case of health and social care workers this includes taking all reasonable precautions to prevent illness:

- Health and social care workers should be provided with the necessary personal protective equipment (PPE) required to facilitate the completion of their tasks safely, as well as training in its use.

- Health and social care workers may need to be prioritised when and if a vaccine becomes available. This is equitable and proportionate, given the heightened risks they are exposed to and the vital role they play in mitigating the effects of a pandemic.

- NHS staff of black, Asian and minority ethnic (BAME) backgrounds may be given roles away from the frontline in recognition of the disproportionately high death rate for those staff.[12] This may also apply to retired health and social care workers who return to the service.

- Decisions may be taken to expedite the testing and treatment of health and social care workers, through priority access to anti-viral medicines or other interventions.

The necessity for psychosocial and pastoral support for staff is also an issue of reciprocity:

- Service leaders should ensure that risks and burdens are minimised as far as possible, responding proportionately to the risk. Illness among staff and their resultant absence from work, as well as increased demand in specific clinical areas, may require the redeployment of other staff to roles outside their normal remit. Where possible, staff should be redeployed according to their relevant skills and experience.

- Where staff must be redeployed to areas outside their normal scope of practice or working environment, some induction and training should be provided, and any decisions or actions taken by such staff must be assessed in the context of challenging contemporaneous circumstances rather than with the benefit of hindsight.

- It is recognised that when difficult decisions must be made, caregivers will be faced with moral dilemmas in choosing between incompatible courses of action, each of which has ethical justification. *Moral distress* (Rorty et al) may be experienced when the caregiver is clear about the ethical course of action but other constraints make it difficult to implement. Both situations can lead to burnout and it is recognised that repeatedly making such decisions requires moral **courage**.

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[12] BAME groups are over-represented by 27% in the overall death rate in the UK from COVID-19 and 63% of the first 106 health and social care staff known to have died from the virus were black or Asian (the Health Service Journal)

- Any person asked to face increased risks or burdens during the pandemic should be supported in doing so by proportionate and effective physical, moral, psychological, and pastoral support.

Good decision-making

Decisions about the care, treatment and intervention are underpinned by the principles of:

- **Rights-based** to promote and respect the rights of all people to equality of treatment.
- **Holistic and Person-Centred** to be assisted to make informed choices and decisions about treatment and care.
- **Open, Honest and Collaborative** to act with honesty and integrity in communication with patients, service users, carers and families.
- **Consent-Driven** to recognise that adults have the right to give or withhold consent and to expect care givers to act in their best interests where they lack capacity.
- **Accountable and Transparent** to act with openness and transparency and to the best standards of practice, professional codes and ethics.

Those delivering health and social care services should:

- Promote equity by assessing and responding to individual need, avoiding blanket policies based on protected characteristics especially disability or age.

- Consult and involve individuals as much as possible, in the time available, in all aspects of care planning that affect them including end of life care, taking into account their individual needs and preferences. All efforts should be made to maximise an individual’s capacity to participate in such decision-making, with an advocate if wished)

- Take decisions reasonably, rationally, based on evidence, with a clear, practical process to that accountability is clear and decisions and the reasons for them are recorded.

- Take into account all relevant expressed views, wishes and preferences, which may be previously document in advance care planning discussions, and any legally binding (validate and applicable) advance decision to refuse treatment (ADRT) and be open to challenge a when discussing with patients and those important to them, clinician decisions such as do not attempt Cardio-Pulmonary Resuscitation (DNACPR) notices.

6 The legal context for ethical decision-making

6.1 Rights based legislation

The **Human Rights Act 1998**[13] sets out the fundamental rights and freedoms that everyone in the UK is entitled to. It incorporates the rights set out in the European Convention on Human Rights (ECHR) into domestic law. The rights are set out in a series of articles, with those particularly relevant to the ethics of clinical decision-making are summarised in Appendix 3 (i).

The **Northern Ireland Act 1998 (the Act)**[14] set out to change the practices of government and public bodies so that equality of opportunity and good relations are central to policy making and service delivery, summarised in Appendix 3 (ii).

The statutory duty to involve and consult, Sections 19-20 of the Health and Social Care Reform Act (2009), sets out a requirement for Health and Social Care to involve and consult service users and their carer's on matters relating to:

(a) the planning of the provision care.

(b) the development and consideration of proposals for changes in the way that care is provided.

(c) decisions to be made by the body affecting the provision of that care.

This means HSC organisations are accountable for ensuring that the necessary steps have been taken to involve and consult service users and carers in all major decisions regarding the planning, development and delivery of HSC services.

The Equality Commission has responsibility for enforcing the **Disability Discrimination Act 1995** (DDA), as amended, in Northern Ireland. It also has a legal duty to work towards the elimination of discrimination against disabled people, to promote the equalisation of opportunities for disabled people, and to keep under review the working of the Disability Discrimination Act 1995 (DDA). A summary of guidance as it relates to the provision of services and employment is set out in Appendix 3 (iii).

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[13] From the NI Equality and Human Rights Commission https://www.equalityhumanrights.com

[14] https://www.equalityni.org

During the COVID-19 pandemic this means that decisions about treatment or care of individuals are **ONLY** made on the basis of whether (as per section 5 of the Framework)

1. Would the intervention be of benefit to the individual? That is, will there be a realistic chance that the benefit will outweigh any adverse effects?
2. If the intervention is likely to be of benefit, would the individual want it? That is, the standard issue of consent.

Where the individual lacks the capacity to consent, or by virtue of circumstances where the ability to understand or communicate their wishes is difficult, all practicable steps should be taken to communicate appropriately. The use of personal protective equipment (PPE) is necessary to reduce cross-infection, wearing masks and eyewear may further disorientate a confused individual in an unfamiliar environment. In these circumstances support or assistance may be required from those more expert in such communication. This may include a learning disability/mental health nurse (as appropriate), family members or carers.

Under the DDA, discrimination in employment occurs when a reasonable adjustment is not made for a disabled person.

During the COVID-19 pandemic this means that disabled staff who may be more vulnerable to the impact of the coronavirus should be shielded appropriately, either through home isolation or protection from high exposure roles (as per section 5.3 of the Framework) and be provided with the required adjustments to ensure their continued protection; this includes, but is not limited to the provision of appropriate PPE.

6.2 Capacity and consent[15]

Principles for consent

While the approach to assessing, supporting and recording decisions about capacity and consent remains the same during the Covid-19 pandemic as it does under normal circumstances, the limitations imposed by patient isolation and PPE mean extra effort will be required to ensure that such discussions take place with patients and their families in a timely and sensitive way.

Clinicians should continue to apply the ethical, professional and legal frameworks set out below to all interactions with patients as set out under common law.[16] This is set out in more detail in Appendix 4 and summarised below:

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[15] http://www.legislation.gov.uk/nia/2016/18/contents

[16] The Mental Capacity Act (NI) 2016 has not commenced for the purposes of medical treatment. The Act is only commenced for the purposes of deprivation of liberty and research

- Respect for patients' autonomy; to impose care or treatment on people without respecting their wishes and right to self-determination is not only unethical, but illegal.
- The approach to consent in Northern Ireland is currently governed by common law with all over the age of 16 years assumed to have capacity to consent. All practical steps should be taken to support patients in being able to input into decision-making.
- Assessments of capacity should follow the principles outlined by the General Medical Council in guidance "Consent: doctors and patients making decisions together and 0-18 years: guidance for all doctors", which provide context on the law in Northern Ireland.

6.3 Consent in children and young people

The capacity to consent depends more on the patient's ability to understand and consider their decision than on their age. Below the age of 16 years individuals have the capacity to consent to medical treatment where, in the opinion of a qualified medical practitioner attending them, they are capable of understanding the nature and possible consequences of the procedure or treatment.

In Northern Ireland, a child is defined as a person under the age of 18 years, although the presumed age of capacity is 16 years and over. The Age of Majority Act (NI) provides that a person over the age of 16 years can consent to certain things (medical and dental treatment) if competent to do so.

- As with any patient, a young person or child may have the capacity to consent to some services or treatments but not to others. Therefore it is important to assess maturity and understanding individually, bearing in mind the complexity and importance of the decision to be made.

- If a young person or child does not have the capacity to consent, consent must be provided by a person with **parental responsibility** as defined in the Children (Northern Ireland) Order 1995:[17]
  - *Where a child's father and mother were married to each other at the time of his birth, they shall each have parental responsibility for the child.*
  - *Where a child's father and mother were not married to each other at the time of his birth—*
    (a) the mother shall have parental responsibility for the child.

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[17] http://www.legislation.gov.uk/nisi/1995/755/contents

    (b) the father shall not have parental responsibility for the child, unless he acquires it in accordance with the provisions of this Order.
  - *More than one person may have parental responsibility for the same child at the same time.*

- Legal advice may be sought if:
  - There is any doubt about who has parental responsibility for the individual; or
  - The views of those that have parental responsibility differ.

- Children should be involved as much as possible in decisions about their care, even when they are not able to make decisions on their own.

COVID-19 Guidance:
Ethical Advice and
Support Framework

COVID-19 HSC Clinical Ethics Forum

PART 2

The Framework and practical guidance

7 Ethical decision-making in practice - delivering the right care in the right setting

7.1 Ethical principles in practice

The following practical principles emerge from this ethical framework. These principles **do not represent a series of rules**, to be applied rigidly. They are simply principles, to be considered and applied flexibly, humanely and sensitively in the particular context of each patient and their family.

Patients with COVID-19 disease will be cared for in a variety of settings. Decision-making will occur specifically around:

- Decisions to admit to hospital for active treatment.
- Decisions to admit to critical care facilities.
- Decisions to admit to hospital settings for palliative care.
- Decisions to admit for palliative care to other facilities, both statutory and non-statutory (including nursing homes, residential homes).
- Decisions to arrange palliative care at home.

Some patients who are COVID-19 positive will have a mild illness, or indeed may be asymptomatic; these will not require admission to specialist care settings and will remain in their own homes, or in other care settings where they currently reside, such as residential and nursing homes.

However it is recognised that a significant proportion of patients who are COVID-19 positive may benefit from specialist hospital care, and a proportion of those will develop life-threatening illness, for which admission to critical care may be beneficial. Decisions on appropriate levels of care are ideally made before a patient becomes acutely ill, and at a time when they have capacity to participate in the decision-making with a clinician (e.g. GP, district nurse, palliative care team) with whom they have built up a trusting relationship, as part of Advance Care Planning discussions.

If it is felt that admission to hospital is not appropriate for an individual patient with life-threatening illness, or if the patient has expressed a wish not to be taken to hospital, they will be cared for in other settings where care will be guided by palliative care principles.

7.2 Advance care planning in healthcare

[18]Advance care planning is an umbrella term covering legal, personal and clinical planning to prepare for a person's future care.

Advance care planning is an on-going process of discussion between the person, those close to them and their health care professionals focusing on the person's wishes and preferences for their care as they approach the end of their life.

Advance Care Planning is **a voluntary process** which gives a person the opportunity to consider their end of life care, and to discuss and record their wishes with the health care professionals who will be responsible for providing that care.

Advance care planning is relevant to everyone but particularly important for key groups such as people with progressive life limiting conditions, people with multiple comorbidities and people with early cognitive impairment or functional decline. Advance care planning can represent an important opportunity to explore a patient's wishes and preferences for care before they become too unwell or lose the capacity to do so.

Advance care planning conversations should be sensitive, informative and present the advantages and disadvantages of relevant treatment options. These conversations should allow the patient to have realistic and practical discussions regarding how and where they would wish to be cared for at the end of their life. This process should be underpinned by operational guidance, training and policy.

The result of the advance care planning discussions may be a documented **Advance Care Planning Summary,** which can be used to communicate their preferences and decisions across care settings if inputted on a Key information summary (KIS) on NIECR.

The Public Health Agency through Palliative Care in Partnership has carried extensive work with the public to promote conversations around the important if advance care planning and about thinking, discussing and documenting their wishes and preference, including their care. Together with Macmillan they have developed a Northern Ireland-specific booklet “Your life and your choices: plan ahead”. The publication is aimed at all members of the public not just those towards the end of life . People (public / patients) can record their preferences , including those relating to health care in the **'Record of My Wishes'** which is part of this publication.

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[18] Advance Care Planning Operational Guidance (Draft 2017) HSCNI

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Advance Decisions to Refuse Treatment (ADRT)

An Advance Decision to Refuse Treatment is a set of instructions from a person to the health and social care team caring for them. It sets out specific circumstances in which the person would not want certain treatments or would want a particular treatment to be stopped.
In Northern Ireland an ADRT is legally binding, it is governed by common law instead of an Act. This means health and social care professionals must follow an ADRT providing that they know about it.

An ADRT recorded in advance of loss of capacity will only become relevant when a person loses the capacity to make decisions.

7.3 Anticipatory Care Planning

To meet the principles of a rights-based, holistic and person-centred approach that is transparent, collaborative and driven by the consent of the individual (as set out in section 1 of the Framework), an integrated approach across all the settings of care which is used consistently across HSC services would ensure the equity, fairness and proportionate treatment of all patients. Consistency of approach throughout primary care and secondary care and between Trusts, through adoption of common guidance and documentation, would facilitate delivery of appropriate care in all settings.

An **Anticipatory Care Plan (ACP**) is a documentation of appropriate treatment options for an individual patient. Development of anticipatory care plans can be supported by advance care planning with patients. Advance care planning (ACP) is a dynamic process which should be developed over time through an evolving conversation, collaborative interactions and shared decision-making. It is a summary of discussions between the person, those close to them and the practitioner.

Currently GPs in NI have proactive discussions with patients who may be perceived to be approaching the end of their lives, reviewing aspects of planned care, as part of a care planning Local Enhanced Service. This discussion (which may be recorded as an Advance Care Plan Summary) could form the basis for a **Community Anticipatory Care Plan (CACP**) which is uploaded to the Key Information Summary (KIS) section of the NIECR. Here it is accessible for colleagues in the acute sector, as well as GP out of hours services and NIAS staff, so that appropriate care can be delivered, taking into account any previously expressed wishes. CACPs should ideally inform discussions and decision-making with regards to the process of management within primary care, admission to acute settings, critical care settings and at the end of life, if appropriate.

This is already happening to some extent: GPs are encouraged to complete CACPs (also called Medical Care Plans) particularly with patients perceived to be approaching the end of their lives, in order that the patient may have an input in deciding what care is appropriate. Where the patient lacks capacity to engage in discussion, despite efforts to maximise capacity, the GP will act in the best interest of the patient to decide the most appropriate treatment. This information should be made available on the ECR to facilitate best care for an individual. A paper copy of the CACP should be kept in nursing home notes, as NIECR is not yet available in nursing homes.

Hospital Anticipatory Care Plans (HAnCP) similarly signpost appropriate treatment following admission to hospital. These are variably used throughout NI at present but usage is increasing and becoming more consistent. Any information on the NIECR relating to previously expressed wishes should be used to inform the HAnCP. Unlike the CACP, the HAnCP relates only to a particular admission, although reference to it in a hospital discharge letter could be used to inform the CACP.

A HAnCP is particularly indicated when one or more of the following applies to a hospital inpatient:

- The patient is unstable with the possibility of deterioration.
- The patient has specific wishes regarding medical interventions.
- The patient has severe frailty / is completely dependent for activities of daily living (ADL) / has progressive end stage organ failure / multiple co-morbidities / advanced cancer.
- Treatment limitation in the event of a crisis/deterioration would be in the patient’s best interests and would avoid harm.
- Agreed clinical tools/scales will assist in the determination of decisions.

7.4 Decisions around appropriateness of critical care[19]

Decisions regarding admission to Critical Care will be made by the acute care admissions teams and critical care specialists who are highly experienced in making decisions regarding access to highly specialist intensive hospital care and in end of life decision-making and care.

The intensive care society has set out operational and ethical principles for decision-making during a pandemic that makes explicit reference to the different phases of a pandemic and introduces a revised CRITCON-PANDEMIC framework. Key elements include:

- Usual legal and ethical frameworks should continue to apply while capacity and NHS mutual aid are available (CRITCON-PANDEMIC levels 0-3), as is the case at time of writing.

- However by recognising the possibility of future conditions of resource limitation (CRITCON-PANDEMIC 4) and providing a structured approach, the guidance lays a responsibility on all NHS organisations to work together to avoid such conditions arising.

- Clinicians should focus on current clinical needs and should not treat patients differently because of anticipated future pressures. In making decisions they should work collectively with each other and with their organisations, and take into account all possible routes of escalation and mutual aid.

- It is emphasised that all patients must be treated with respect and without discrimination, because everyone is of equal value.

- COVID-19 is a new disease with a partial and evolving knowledge based where an objective clinical decision-making framework based on the best available information should be the objective.

- Factual assessment of likely benefit may take into account age, frailty and comorbidities, but the guidance emphasises that every assessment must be individualised, balanced, and may inform clinical judgment but not replace it.

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[19] BMJ Journals: Journal of medical ethics:
Revisiting the equity debate in COVID-19: ICU is no panacea ...jme.bmj.com › 2020/06/22 › medethics-2020-106460

- The effects of a comorbidity on someone’s ability to benefit from critical care should be individually assessed. Measures of frailty should be used with care and should not disadvantage those with stable disability.

7.5 Do Not Attempt Cardiopulmonary Resuscitation order (DNACPR)

Cardiopulmonary resuscitation (CPR) is a treatment that could be attempted on any individual in whom cardiac or respiratory function ceases. This principle applies to CPR as to any other treatment. A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order is an explicit statement exist to prevent the inappropriate, potentially harmful or futile intervention of cardiopulmonary resuscitation on a person who is in the terminal phase of their illness or who is unlikely to survive such an intervention or if it is deemed that the risk of CPR would outweigh the benefit to an individual.

A DNACPR order does not refer to any other clinical intervention.

The responsibility for making a DNACPR order rests with the senior clinician who has clinical responsibility for the patient during that episode of care.

DNACPR decision should be made in conjunction with other members of the multidisciplinary team including the GP.

DNACPR decision is made on clear clinical grounds that CPR would not be successful there should be a presumption in favour of informing the patient of the decision and explaining the reason for it.

The process for putting in place such DNACPR orders are sensitive and complex and should include considerations of:

- Whether an advance decision to refuse treatment (ADRT) for the individual is in place.

- Whether the wishes of the person are known for the circumstances that now arise (‘ Record of my wishes’ or Advance Care Planning Summary) .

- What treatment interventions might be appropriate - DNACPR orders only relate to cardiopulmonary resuscitation, and do NOT mean that no other treatment or support will be provided.

A DNACPR decision may be made and recorded to guide those present if a person subsequently suffers sudden cardiac arrest or dies:[20]

- By the health and social care team, because CPR should not be offered to a person who is dying from an advanced and irreversible condition where CPR will not prevent their death.
- By the health and social care team because the person themselves is not able to contribute to a shared decision and a decision must therefore be made in their best interests.
- As a shared decision (made by the person themselves and their clinician and/or other health and social care team members) that the likelihood of CPR being beneficial in their current situation would not outweigh the potential burdens and risks of receiving attempted CPR (eg loss of dignity, lack of family presence at end of life).
- At the request of the person themselves as documented in an advance decision to refuse treatment (ADRT) .

The decision is recorded on a specific 'DNACPR' form, so that it can be recognised and its content assessed very quickly by those who may need it to guide their decisions and actions in an emergency situation.

7.6 Palliative care

Some patients will be cared for in contexts where recovery is not expected. This may be in designated hospital settings or in other facilities, both statutory and non-statutory (including nursing homes, residential homes or hospices) or in the patient's own home. Care should be informed as far as possible by any expressed patient's wishes (e.g. verbally to the care team if the patient retains capacity, or previously expressed in a "Record of My Wishes "document, held by the patient, as part of the "Your life and your choices: plan ahead"[21] booklet, on Advance Care Planning Summary). In all circumstances each individual should receive personalised and compassionate care, including appropriate palliative treatment. Upskilling of the interdisciplinary team in all settings regarding basic principles of palliative care may be required.

The pandemic situation further exacerbates difficulty in palliative care situations due to physical distancing regulations that prevent or limit family visiting and the necessity of having difficult

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[20] Resuscitation Council UK

[21] https://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx

conversations behind masks and over phones. No visiting is currently possible in critical care, but all efforts should be made to allow one family member to be present with their dying relative in all care settings, where possible, to facilitate the striving for peace, meaning and connection.

Bereavement support for families, and also support for healthcare staff, should be considered a priority.

7.7 Ethical considerations in the care of residents in care homes during COVID-19 pandemic

Many ethical challenges in the care of residents in care homes have been reported in the literature. These include, autonomy in decision-making, challenges in end-of-life care, use of restraints, lack of resources, consent and capacity, communication and cooperation between health and social care organisations and individuals and the residents' family members, as well as an individual's privacy and behaviour**.**

Achieving a balance between risk, protection and human rights

The impact of COVID-19 pandemic on care home residents has highlighted these and other key ethical issues. At the start of the pandemic the strict infection control measures introduced included a reduction in footfall into care homes with an aim of reducing to **essential visiting only**. The unintended but necessary consequence of this was loss of family connection and relationships experienced by individual residents and their families. The measures put in place are appropriate in that they are a proportionate response to achieve a legitimate aim which is the preservation of life. As the pandemic progresses, these measures must be reviewed to ensure that the balance is appropriately considered, in light of the age, frailty and wishes of individuals in the remaining years or months of their lives. There is, therefore, an obligation to consider and explore alternative means of communication and a controlled means of contact with friends and family members.

Care homes have an obligation to protect, through effective infection prevention and control measures, the vulnerable populations under their care. Apart from the limitations placed on visiting, the use of **personal protection measures** and **restriction on movement of individuals** can have a detrimental effect, particularly for those confused or alarmed by such changes and restrictions, such as those with dementia or learning disabilities. Consideration should therefore be given to how this might be sensitively done, while balancing the risk and harm to the individuals and population as a whole.

Individual care workers, through their personal behaviours and professional codes of conduct, have **obligations to protect** all residents under their care, balancing the wishes of individuals against the overarching needs to protect the resident community. Care staff, in turn, have a reciprocal right to be **supported and protected** in the exercise of those duties, as set out in section 5.3.

A rights-based, holistic and person-centred approach which is transparent, collaborative and driven by the consent of the individual is important to ensure that the needs and wishes of the individual are acknowledged and respected. Information on **Advance Care Plan** is set out in section 7.2/ 7.3/ 7.5.

An integrated approach across all the settings of care that is used consistently across HSC services would ensure the **equity, fairness and proportionate** treatment of all individuals in care homes. Individuals will continue to be offered appropriate treatment even if they are not admitted to hospital or critical care. Appropriate supportive and palliative care must be available whenever and wherever the individual is being cared for. A review of care setting should be prompted if this is not possible.

The importance of respecting an individual's **personal choices** about their care and treatment is highlighted in an ethical approach, through the encouragement of advance care planning process. These ensure that people have an opportunity to say in advance how they wish to be treated, as well as when and where such care should be provided, so that clinical decisions can, where possible, take into account their expressed wishes.

All people should be offered high quality and compassionate care, recognising that every person and their human rights, personal choices, safety and dignity matters.

7.8 Visiting in end of life situations:[22] Ethical Framework to determine the appropriateness of face-to-face visiting during the COVID-19 major incident period

All patients who are judged to be dying from COVID-19 or other conditions within hours or days are entitled to receive visitors. That entitlement is however qualified by a number of factors; these are set out in more detail in Appendix 5 to reflect the extant guidance.

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[22] Taken from the Royal College of Physicians Edinburgh - Scottish Academy April 2020 https://www.rcpe.ac.uk/sites/default/files/sa_statement patients_and_family_at_end_of_life_care_final_0.pdf

The Scottish Academy of Medical Royal Colleges (the ‘Scottish Academy’), the Royal College of Physicians of Edinburgh (the ‘College’), Marie Curie and Scottish Care have devised an ethical framework to guide the decisions being made by clinicians and care givers when determining the appropriateness for face to face visiting. This framework, based on a number of broad principles has been adapted to fit the Northern Ireland context and is outlined below:

- **Respect**

A patient’s current or previously known wishes about their own end of life care should be taken into account. Clinicians should act with honesty and integrity in their communication with patients and should communicate and document decisions regarding visiting and the reasons behind them transparently. Organisations have a responsibility to ensure that staff are aware of and engaged with the rationale for the local guidance. There must be transparency in how the competing factors of social responsibility, PPE resource, and direct and indirect risk of infection and of psychological harm are being balanced.

- **Family/Loved One presence** (Suggest ‘those important to them’ as opposed to loved one)

Family and loved ones should be considered and where practically and humanly possible be accommodated across all care settings. Travel for the purpose of visiting relatives receiving end of life care should be identified as essential and therefore within the purposes accepted as being permitted.

- **Minimising Harm**

Harm from visiting can occur to the visitor, to those they subsequently come in contact with, or to others in the care facility. The patient themselves may experience harm if they feel guilt about exposing family visitors to the infection. That harm must however be balanced against harm to the dying person occasioned by absence of family, harm to family who are unable to be present (both immediate and longer term in bereavement), and harm caused to care staff who substitute themselves for absent family and undertake difficult telephone communication.

- **Reciprocity**

Where there are resource constraints, particularly during high surge periods, patients should receive the best care possible when nearing the end of life, while recognising that there may be a competing obligation to the wider population. In this situation visiting, even at time of death, may be refused on the basis of the need to protect others and share finite resources.

- **Capacity and Consent**

The capacity of family to provide informed consent relating to the risks associated with visiting should be taken into account as should the capacity of the patient to receive visitors.

- **Flexibility**

As the clinical situation evolves both at the individual and population level, decisions will need to be kept under review with clear guidance at national level.

The particular circumstances of the COVID-19 pandemic mean that direct contact with family members by the clinical team is very limited. However, particular care should be taken to use all possible means to have face-to-face contact (such as the use of video phones etc.) or contact by phone to discuss implementing a DNACPR order.

Ethical advice can be sought by clinicians and clinical teams as necessary from trust Clinical Ethics Committees or the Regional Ethics Forum.

7.9 Handling of patient remains

The transfer of deceased patients from the place of death to the care of the funeral director must take into consideration the needs and requirements of the individual, which includes a recognition of their faith and cultural needs such as the removal (or not) of jewellery, sacred threads or significant religious items of clothing. For some faiths and culture this can also include the gender of the healthcare staff member accompanying the individual being transferred. Useful advice is set out in the ‘Multi Cultural and Beliefs Handbook’.[23] In practice many faith communities have arrangements in place with specific funeral directors who are aware and sensitive to their particular requirements.

In the pandemic escalation it is expected that all efforts are made to continue to respect traditions and requirements around death; however it is recognised that this may not always be possible due to safety considerations for both health and social care staff and family members.

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[23] The Handbook was developed by Belfast HSC Trust but now available as a regional resource

7.10 Ethical guidelines on the transfer of critically ill patients between or within trusts[24]

The decision to transfer a patient is the joint responsibility of both referring and receiving clinicians. The medical staff at the receiving unit may offer specialist advice on patient management, however primary responsibility for the patient lies with the clinician in attendance who may, if circumstances change, decide not to transfer the patient.

A contentious issue, which sometimes arises when a transfer is necessary because of lack of availability of critical care beds, is whether to transfer the new and potentially unstable patient, or an existing more stable patient who is less likely to deteriorate. In general, no patient should be subjected to an intervention that is not in their best interest, and it could be considered unethical to transfer one patient out of a critical care unit for the sole purpose of making room for another. This may on occasion, however, be the most pragmatic approach, particularly where the transfer is required to generate capacity in a tertiary centre for a patient requiring specialist care.

More detailed guidance on the transfer of patients is set out in Appendix 6.

7.11 Care of COVID-19 positive residents in mental health and learning disability hospitals and wards, and those who require admission to general hospitals

Some patients will be in-patients in psychiatric hospitals, mental health or residents in other care facilities at the time of a positive COVID-19 test or will require admission or transfer between a home or care facilities to a psychiatric hospital whilst already known to be COVID-19 positive.

A series of inter-related and difficult decisions will be necessary with regards to the care of patients who are acutely mentally ill or who are long-stay patients in psychiatric care; these include, but are not limited to:

- Decisions related to the care of COVID-19 positive patients who are in-patients in psychiatric hospitals and psychiatric wards in general hospitals (either voluntary or detained) because of acute mental illness.
- Decisions related to the care of COVID-19 positive patients in psychiatric hospitals and psychiatric wards in general hospitals (either voluntary or detained) because of chronic mental illness (long-stay patients).

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[24] Facility of Intensive Care Medicine and The Intensive Care Society- Guidelines May 2019

- Decisions related to the care of COVID-19 positive patients who are under the care of Crisis Response or Home Treatment Teams (that is, who remain in their own homes or in residential facilities whilst receiving care and treatment for an acute episode of mental illness).

Some of these patients will be distressed or agitated, and many will be detained under the Mental Health Order. The care of such patients if physically deteriorating and requiring transfer to a general hospital for acute medical care or critical care is likely to prove especially challenging.

Specific issues will arise with regards to the care of patients who have moderate or severe learning disability/intellectual disability and who reside in their own homes, residential care homes, long-stay hospital settings or in a range of settings in the community. Therefore provision should be made for the needs of this group, where necessary, via the identification and assistance of a trained learning disability/mental health nurse (as appropriate) and the provision of a designated physical ward space should it be needed. It is recognised that in a period of exceptional demand this may not be readily available in all situations.

It is important that all decisions are made after careful consideration of the impact of current psychiatric symptoms and behaviour, and that there is no indirect discrimination on the basis of mental illness.

Decisions related to the care of COVID-19 positive patients in residential care homes or psychiatric hospitals because of chronic mental illness (long-stay patients), including dementia and other organic or neurological disorders, present particular difficulties. Some of these patients will meet criteria for palliative care and this may be provided in settings that would not normally be considered. In all circumstances each individual should receive personalised and compassionate care, including appropriate palliative treatment.

Decisions related to the care of COVID-19 positive patients who are under the care of Crisis Response or Home Treatment Teams (and who are acutely ill, requiring active and on-going treatment) are also likely to prove especially challenging, but should follow the overarching principles set out for the care of all patients.

8 Regional and HC Trust structures and processes for ethical support

8.1 HSC Trust Clinical Ethics Committee (CEC)

Clinical Ethics Committees (CECs) have been established in each HSC Trust to support useful, timely and pragmatic ethical support to clinical teams for decision making in complex or difficult cases. The CEC will usually provide a written summary report of its activity:

- The CEC should be **broadly independent** of senior decision-makers within the Trust senior management team, to ensure that it is able to offer independent advice.

- The **membership** of each Trust CEC will be appointed locally, with efforts taken to ensure a diverse range of backgrounds and expertise. Membership should include lay representation, as well as experienced clinical, public health and social care members and religious group representation. A multi-disciplinary and multi-professional membership and perspective is essential.

- Many **crucial decisions** around clinical care may need to be made quickly, without recourse to a broader discussion, and would not be practical to involve a full CEC discussion, although a panel or sub-group may be helpful in difficult decisions. In the critical care setting it will not usually be necessary to involve the CEC in decision-making as clinicians are not departing from usual practice, including the usual practice of withdrawal of care due to non-response to treatment within a reasonable clinical timeframe.

- In the main the Clinical Ethics Committee will seek to **support clinical staff** in decision-making, including ensuring adherence to national guidance around admission criteria when relevant.

- It is important that Trust CECs have a **flexible approach**, are readily available and able to offer timely support.

- The CEC **should meet formally as frequently** as is required but the timing of meetings will depend on the pressures within health and social care system, including the time pressures on individual members.

- Additional CEC processes should be put in place, which are **responsive** to the needs of all staff including critical care staff. There should be provision for members of the CEC to be in contact on a daily basis, including on weekends, utilising various means of communication.

- Where necessary, sub-group of the CEC will form a **panel** (each Trust to determine the exact composition and working arrangements of such a panel) which will be available to meet “ad hoc” at short notice to address individual issues, responding to requests triggered from any member of staff.

Where **immediate advice** is needed to aid urgent or critical decisions, it is important that this is available and accessible. A senior member of the CEC should be available for telephone consultation at all times. Examples where the CEC may usefully offer insight include:

- Complex decisions around the withdrawal or withholding of treatment(s)
- Situations where clinical decision makers feel uncomfortable with the application of regional or national guidance.
- Challenging decisions around escalation planning and ceilings of treatment.
- Complex decisions related to patient discharge due to high clinical demand.
- Challenges related to reduced ability to provide normal standards of care, in particular in the community or for patients at the end of their lives.
- Challenges related to demand outweighing availability of resources.

8.2 The role of HSC Trusts Clinical Ethics Committees during COVID-19

HSC Trust CECs should be considered as a **point of contact** for ethical advice, and not an alternative to existing clinical national guidance or to replace team-based clinical decision-making for the provision of good clinical care. The number of cases referred may change during different phases of the COVID-19 pandemic, and CECs may need to adapt their ways of working. It is expected that only a small minority of cases will need to be referred to and discussed by the CECs.

Given the rapidly evolving and unpredictable nature of the COVID-19 pandemic it is important that clinical teams should apply appropriate judgement as to whether they should review patient care in the light of any developments. Where these changes happen, these should be clearly communicated to patients and their families.

It is strongly advised that no decision to refuse or discontinue treatment should be taken by a lone clinician but should be discussed with the wider clinical team[25] and where necessary seek advice from the Trust Clinical Ethics Committee.

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[25] Advice from Intensive Care Society 2020

There must be immediate access to ethical advice if this occurs, to offer an independent view and support in difficult circumstances. This may include discussion of the risks and benefits related to the transfer or escalation of care of patients. Access to advice or support for clinical decisions in urgent or emergency situations, from the relevant clinical experts is occasionally necessary.

Specially convened panels or sub-groups of the Trust CECs will offer access to immediate support and advice which will allow access to independent advice around complex clinical, ethical and logistical challenges as they arise.

8.3 COVID-19 HSC Clinical Ethics Forum[26]

The regional COVID-19 HSC Clinical Ethics Forum (the ‘Forum’) has been established by the CMO to develop a regional support Framework for ethical advice and guidance, to consider regional and national ethical issues and offer advice and support to HSC Trust CECs as needed.

The regional COVID-19 HSC Clinical Ethics Forum (the Forum) will be available as a point for escalation for Trust CECs. The Forum will meet to review system-based challenges or complex individual cases that have already been discussed at the local level, to review the common challenges that are being encountered and to consider whether review of existing guidance or additional guidance would be useful.

The Forum will include representatives of each Trust CEC in addition to other health and social care professionals, academics, legal professionals, religious group representatives and lay representation; terms of reference are set out in Appendix 1.

The Forum will meet on a regular basis and will report to the Chief Medical Officer or to a delegated responsible officer. A written summary of items discussed, and any recommendations made by the Forum, should be reported to the CMO or the delegated responsible officer after each meeting.

8.4 Support for staff involved in clinical decision-making

All health and social care practitioners face the possibility of making difficult and unexpected decisions during the COVID-19 pandemic. No member of staff should be expected to make such decisions in isolation or without consulting the wider clinical team. Psychological and pastoral

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[26] The NI Clinical Ethics Forum was established under the sponsorship of the COVID-19 Gold Command Professional/ Clinical Advisory Group

support should be available for all staff in each Trust[27] as well as access to ethical advice and support when appropriate.

Moral injury is the psychological distress that results from actions, or lack of them, which violate someone's moral or ethical code. Moral distress or injury may occur when staff are forced to make important decisions which have 'no right answer' and feel that they have been placed in an 'impossible' situation. The concept is particularly relevant to the psychological impact of healthcare workers having to take certain decisions or actions due to the circumstances of the COVID-19 pandemic. The negative feelings, which may be generated, can contribute to the development of mental health problems, including depression, post-traumatic stress disorder (PTSD) and anxiety.

In April 2020 the Staff Health and Wellbeing framework was launched to ensure that staff and volunteers, irrespective of where they work, have access to the information and support. The 5 key messages for staff has been: connect (you are not alone); be active (look after yourself); take notice (you are stronger than you think); keep learning (embrace the challenge); and give (kindness will help you through).

A framework for leaders and managers to support the wellbeing of staff during the pandemic captures and builds on existing initiatives and signposts leaders, managers and staff to the next health and wellbeing resources and ideas. Psychological helplines have been established that are available to Trusts, GP practices and independent care providers.

There must be a clear route and process in each HSC Trust for clinicians and clinical teams to access advice from the CEC and a clear process by which discussions with the CEC are documented and fed back to the responsible clinical team.

It is important that conversations are clearly documented and communicated with the rest of the clinical team to enable ongoing learning and review.

Clinicians should be assured that decisions taken in good faith, in accordance with national actions and guidance to counter COVID-19, will not be held against them.[28]

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[27] As per the Ministerial announcement 16 April 2020 " Staff Wellbeing Framework"

[28] See Appendix 2 (i) GMC statement and 2 (ii) BMA statement

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APPENDIX 1 (i)

Department of Health
An Roinn Sláinte
Mãnnystrie O Poustie
www.health-ni.gov.uk

COVID-19 HSC Clinical Ethics Forum

1. TITLE

1.1. The Forum shall be known as the COVID-19 Health and Social Care (HSC) Clinical Ethics Forum (hereafter referred to as the "Forum" or CEF).

2. PURPOSE

The purpose of the Forum is:

2.1. To advise HSC Trusts in matters relating to ethical issues in clinical decision making

2.2. To promote and maintain ethical standards relating to clinical practice across HSC Trusts

2.3. To assist in the resolution of ethical dilemmas in clinical decision-making during the COVID-19 pandemic escalation, in particular when demand outstrips access to resources.

2.4. To give consideration to the needs of everyone requiring access to health and care services during such a period of escalation

3. TERMS OF REFERENCE

3.1. To develop a Framework for the management of ethical dilemmas in clinical practice.

3.2. To provide an overarching set of principles for the HSC in clinical decision-making for everyone seeking or requiring access to health and social care services.

3.3. To develop a regional process for access to ethical advice and support when needed, including standards for such advice within individual Trusts.

3.4. To consider the ethical implications of clinical decision making as arise during the COVID-19 escalation period and review the Framework and process of support as necessary.

3.5. To consider the use of 'Clinical Prioritisation Decision Aids', for use during a period of exceptional demand that puts pressure on finite resources.

3.6. To liaise with other bodies concerned with ethical issues, on a four nations basis.

4 MEMBERSHIP[29]

4.1 The NI Clinical Ethics Forum will be drawn from a wide range of clinical staff, individuals with expertise in ethics, faith representatives, as well as wider community interests.

4.2 Members will be nominated or identified by HSC Trusts, Public Health Agency (PHA)/ Health and Social Care Board from existing, or former staff members as well as members of Clinical Ethics Committees. Other members will be co-opted as required.

4.3 Although drawn from across representative bodies, members contribute in their own right with no formal representational role.

5 STANDING ORDERS

5.1 The Forum will exist under the sponsorship of the COVID-19 Gold strategic cell of the Professional/ Clinical Advisory Group who will approve the terms of reference and membership

5.2 The Forum will be supported to meet 'virtually' during the COVID-19 period of escalation; to be reviewed and amended as necessary.

5.3 Meetings shall be chaired by an appointed convenor or designated deputy.

5.4 Meetings shall have an agenda and action note recorded.

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[29] Current membership is set out in Appendix 1 (ii)

APPENDIX 1 (ii) COVID-19 HSC Clinical Ethics Forum

Current Membership:

Dr Ciaran Mulholland	Psychiatrist	Northern HSC Trust
Dr Clodagh Loughrey	Chair of Division of Laboratories and Pharmacy	Belfast HSC Trust
Dr Phillip Gardiner	Rheumatologist	Western HSC Trust
Dr Paddy Donnelly	Cardiologist	South Eastern HSC Trust
Dr Angela Garvey	Palliative Care	Former Western HSC Trust
Dr Damian Scullion	Anaesthetist	Southern HSC Trust
Dr Chris Clarke	Intensivist	CCaNNI
Dr Neal Beckett	Anaesthetics	Belfast HSC Trust
Bronagh Scott	Nursing	Former Director of Nursing
Dr Dale Spence	Midwifery Officer	Department of Health
Prof Hugh McKenna	Nursing	University of Ulster
Dr Niall Collum	Emergency Medicine	South Eastern HSC Trust
Dr Terence McManus	Respiratory	Western HSC Trust
Dr Jennifer Doherty	Palliative Medicine	Marie Curie and South Eastern HSC Trust
Rev Norman Harrison	Chaplain	NI Hospital Chaplains Association
Father Robert Sloan	Chaplain	NI Hospital Chaplains Association
Peter McBride	Chair	IHRD Openness Subgroup
Aine Lockhart	Lay member	Belfast HSC Trust
Marie Lynch	Lay member	Belfast HSC Trust
Dr Siobhan McEntee	GP	General Practice
Dr Michael Trimble	Physician	Belfast HSC Trust
Prof Hugo van Woerden	Public Health	Public Health Agency
Sandra Aitcheson	Frailty Network	Public Health Agency
Miriam McCarthy	Director of Commissioning	Health and Social Care Board
Rodney Morton	Director of Nursing	Public Health Agency

Convenor

Patricia Donnelly	Former acute director	HSC Leadership Centre

Interested parties:

Michael Bloomfield	Chief Executive	NIAS
Vivian McConvey	Chief Executive	Patient and Client Council (PCC)
Palliative Care in Partnership group (PCiP)		PHA

Reference groups:

IHRD
Palliative Care in Partnership
Alzheimer’s Society
Disability Action
Independent Health Care Providers
User, carer and family reference group
User forum

Sponsored by:

Dr Julian Johnston Dr Paddy Woods	Profession/ Clinical Advisory Group	DoH COVID-19 Gold command

Approved by:

Dr Michael McBride	Chief Medical Officer	Department of Health

APPENDIX 2 (i) GMC

General Medical Council statement

Whenever a concern is raised with us, we always consider it on the specific facts of the case, taking into account the factors relevant to the environment in which the doctor is working. We know that health services are under intense pressure, and managers and clinicians are making difficult decisions about how to provide care to patients often in extremely challenging circumstances. The scale of the challenges to delivering safe care would be relevant to a question about the clinical care provided by a doctor.

In addition, we'd consider the resources available to the doctor, the problems of working in unfamiliar areas of practice and the stress and tiredness that may affect judgment or behaviour. We would also take account of any relevant information about resource, guidelines or protocols in place at the time.

APPENDIX 2 (ii) BMA

Guidance note: COVID-19 Ethical Issues

This guidance note addresses some of the main ethical challenges likely to arise during this pandemic. Wherever possible, links to other sources of advice are provided. From an ethical and professional regulatory perspective – which is also likely to govern the approach of the Courts if there are legal challenges – doctors should be reassured that they are extremely unlikely to be criticised for the care they provide during the pandemic 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.

Should decisions be called into question at a later day, they will be judged by the facts available at the time of the decision, not with the benefit of hindsight.

APPENDIX 3 (i) Summary of the Human Rights Act 1998

Article 2 Right to life

For health and social care this means that nobody, including the Government, can act to end a life and must take steps to protect it if an individual’s life is at risk. Public bodies have to consider an individual’s right to life when making decisions that might put them in danger or that affect their life expectancy.

Article 3 Freedom from torture and inhuman or degrading treatment

For health and social care this means that no individual should be subject to inhuman or degrading treatment or punishment. Public bodies must not inflict such treatment and must act to protect the individual if others are treating the individual in this way. Inhuman treatment is defined as treatment that causes intense physical or mental suffering.

Article 6 – Right to a fair trial

For health and social care this relates to a public authority making a decision that has an impact on an individual’s civil rights or freedoms. Although not directly relevant it has been argued that decisions in health care should also follow the requirements for impartiality, openness and transparency and that the consent process allows for the individual to be given sufficient information to make an autonomous decision.

Article 8 – Respect for your private and family life, home and correspondence

For health and social care this relates to the confidentiality and privacy of family life and has been interpreted by the court as covering sexual orientation, lifestyle and how an individual dresses. It also includes who sees and touches another person’s body, so that permission (through the consent process as required) is needed for such activities. Article 8 also covers the right to enjoy family relationships without interference, including the right to live with your family and to have regular contact.

Article 14 Protection from discrimination in respect of these rights and freedoms

For health and social care this means when a person is treated less favourably than others in a similar situation and this treatment cannot be objectively and reasonably justified. Discrimination can also occur if an individual is disadvantaged by being treated the same as another person when the circumstances are different. These rights are also covered by the Northern Ireland (equality) Act 1998.

APPENDIX 3 (ii) Equality Legislation

The Northern Ireland Act 1998 (the Act)[30] is set out to change the practices of government and public bodies so that equality of opportunity and good relations are central to policy making and service delivery.

Section 75 of the Act requires public bodies (including Health and Social Care organisations) to comply with the *Equality of Opportunity duty* in promoting equality of opportunity between nine equality categories*:*

- Religious beliefs
- Political opinion
- Racial group
- Age
- Marital status
- Sexual orientation
- Gender
- Disability
- Persons with dependents and persons without

A second *Good Relations duty* requires public bodies to promote good relations between persons of different religious belief, political opinion and racial group.

For health and social care this means that every HSC organisation has to have an *Equality Scheme* in place as public statement of the organisation's commitment to fulfilling its Section 75 responsibilities including procedures for measuring performance which is scrutinised by the Equality Commission (now the Equality and Human Rights Commission).

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[30] https://www.equalityni.org

APPENDIX 3 (ii) Disability Discrimination Act 1995[31]

The Equality Commission has responsibility for enforcing the Disability Discrimination Act 1995 (DDA), as amended, in Northern Ireland. It also has a legal duty to work towards the elimination of discrimination against disabled people, to promote the equalisation of opportunities for disabled people, and to keep under review the working of the Disability Discrimination Act 1995 (DDA).

Disability discrimination law in Northern Ireland – a short guide

The following is an extract from the short form guidance provided by the Equality Commission for NI as it relates to the **provision of services and employment.** Further information is available from the Commission's Enquiry line and on the website.

The Equality Commission for Northern Ireland

The Equality Commission has responsibility for enforcing the Disability Discrimination Act 1995 (DDA), as amended, in Northern Ireland. It also has a legal duty to work towards the elimination of discrimination against disabled people, to promote the equalisation of opportunities for disabled people, and to keep under review the working of the Disability Discrimination Act 1995 (DDA).

The law

The Disability Discrimination Act (DDA) introduced, over a period of time, new laws and measures aimed at ending the discrimination faced by many disabled people. It gives disabled people rights in:

- employment
- access to goods, facilities and services, including transport
- the management, buying or renting of property
- education.

The DDA only protects people who meet its definition of disability.

The DDA defines disability as "a **physical** or **mental** impairment which has a **substantial** and **long-term adverse effect** on a person's ability to carry out **normal day-to-day activities**".

Physical impairment - this includes, for instance, a weakening of part of the body (eyes, ears, limbs, internal organs) caused through illness, by accident or from birth. Examples are blindness, deafness, paralysis of a leg or heart disease.

Mental impairment - this includes mental ill health and what is commonly known as learning disability.

Substantial - put simply, this means that the effect of the physical or mental impairment on ability to carry out normal day-to-day activities is more than minor or trivial. It does not have to be a severe effect.

Long-term adverse effect - the effect has to have lasted, or be likely to last, overall for at least twelve months and the effect must be a detrimental one.

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[31] Equality Commission Short form guidance on the Disability Discrimination Act 1995

People who are diagnosed with cancer, HIV and multiple sclerosis are deemed to be disabled from the point of diagnosis rather than from the point when the condition has some adverse effect on their ability to carry out normal day-to-day activities.

A **normal day-to-day activity** is something which is carried out by most people on a fairly regular and frequent basis, such as washing, eating, catching a bus or turning on a television. It does not mean something as individual as playing a musical instrument to a professional standard or doing everything involved in a particular job.

To meet the definition, a person must be affected in at least one of the respects listed in the DDA:

- mobility;
- manual dexterity;
- physical coordination;
- continence;
- ability to lift, carry or otherwise move everyday objects;
- speech, hearing or eyesight;
- memory or ability to concentrate, learn or understand; or
- perception of risk of physical danger.

People who satisfy the definition of ‘disability’ are covered by the DDA. This includes people who have had a disability in the past.

Discrimination in Employment

Under the DDA, discrimination in employment occurs when:

- a disabled person is **treated less favourably** than someone else on the grounds of his/her disability (direct discrimination)
- a disabled person is **treated less favourably** than someone else and the treatment is for a **reason relating to the person’s disability**, and this treatment **cannot be justified** (disability related discrimination)
- there is a **failure to make a reasonable adjustment** for a disabled person
- **victimisation** occurs if a disabled person is subjected to **harassment** for a reason which relates to their disability.

Provision of goods, facilities and services

Those who provide goods, facilities and services to the public, or a section of the public, cannot discriminate against a disabled person.

Under the DDA, discrimination in the provision of goods, facilities and services occurs when:

- a disabled person is **treated less favourably** than someone else and the treatment is for a **reason relating to the person’s disability**, and this treatment **cannot be justified**
- there is a **failure to make a reasonable adjustment** for a disabled person.

Education

A separate piece of legislation deals with disability discrimination in education. Under the Special Educational Needs and Disability (NI) Order, discrimination in education occurs when:

- a disabled pupil or student or prospective pupil or student is **treated less favourably** than someone else and the treatment is for a **reason relating to the pupil’s or student’s disability**; and this treatment **cannot be justified.**
- there is a failure to make a **reasonable adjustment** for a disabled pupil or student.

- **victimisation** or **harassment** occurs.

Reasonable adjustments by service providers

Service providers who offer services to the public must make reasonable adjustments. In order to make a reasonable adjustment, a service provider may have to:

- change a **practice, policy or procedure** which makes it impossible or unreasonably difficult for disabled people to use their services, for example, amending a “no dogs” policy to allow a disabled person accompanied by a guide dog to enter their premises.
- provide an **auxiliary** aid or service if it would make it easier for disabled people to make use of their services, for example, the provision of information in alternative formats such as audio tape, Braille or large print.
- provide a reasonable **alternative method** of making services available to disabled people where a **physical feature** makes it impossible or unreasonably difficult for disabled people to make use of them, for example, providing staff assistance to disabled customers who cannot access goods due to their disability when shopping.

Service providers have to make reasonable adjustments to the physical features of their premises to overcome physical barriers to access. A physical feature includes:

- any feature arising from the design or construction of a building on the premises occupied by the service provider.
- any feature on those premises or any approach to, exit from or access to such a building.
- any fixtures, fittings, furnishings, furniture, equipment or materials on such premises, including steps, kerbs, internal and external doors, toilet and washing facilities, lighting, signs and furniture.
- all features are covered whether temporary or permanent. A building means an erection or structure of any kind.

Can a service provider treat a disabled customer less favourably or not make reasonable adjustments?

A service provider can justify treating a disabled customer less favourably or refusing to make reasonable adjustments:

- where the treatment is necessary in order to avoid endangering the health and safety of any person.
- where the disabled person is incapable of entering into a legally enforceable agreement or of giving informed consent.
- if they would otherwise be unable to provide the service to the disabled person or other members of the public.
- when greater expense is involved in providing a special service for a disabled customer.
- when an adjustment would fundamentally alter the nature of a business or service.

The service provider must believe that one or more of the above conditions exist and it must be reasonable to hold that belief.

Is there anything to stop a disabled person being given more favourable treatment?

A service provider may treat a disabled person more favourably than others. For example, a theatre manager can offer people who are hard of hearing front stall seats at rear stall prices; football clubs can reserve pitch-side places for wheelchair users; and historic houses can offer concessionary prices for disabled people.

APPENDIX 4 Consent and Capacity in Northern Ireland

Summary

Respect for patients' autonomy is expressed in consent law; to impose care or treatment on people without respecting their wishes and right to self-determination is not only unethical, but illegal.

The approach to consent in Northern Ireland is currently governed by common law with all over the age of 16 years assumed to have capacity to consent. This assumption must be based on interaction and must include consideration that the person may not be able to consent.

Key principles

For consent to be valid:

1 The patient must be competent – mental capacity is decision-specific. Assessment of a person's capacity should be based on his/her ability to understand, retain and weigh the information relevant to a particular decision.[32] The person must also be able to communicate the decision. A patient who is unable to make a decision about a complex proposal is not necessarily incapable of making any decisions at all, and may be perfectly able to consent where the issues are simpler.[33] The starting point in the case of adults over 16 years of age is always to presume that they have capacity until it is shown otherwise.

2 The patient must have sufficient information to make a choice – without adequate information, patients are unable to make decisions about their treatment. The information provided should, for example, include: an explanation of the investigation, diagnosis or treatment; an explanation of the probabilities of success, or the risk of failure or harm associated with options for treatment. The patient should be given time to ask questions.

> ***Montgomery V Lanarkshire Health Board.*** The law on informed consent has changed following this recent Supreme Court judgment. Doctors must now ensure that patient are aware of any "material risks" involved in a proposed treatment, and of reasonable alternatives. This is a significant change to the previous "Bolam test" which asks whether a doctor's conduct would be supported by a responsible body of medical opinion. This test will no longer apply to the issue of

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[32] **Current common law notes:** Understand the information required; Retain it long enough to make a decision; Use and weigh the information; Communicate a decision

[33] Capacity discussions do not distinguish between complex and simple decisions as there are many other factors. A complex decision to one, may be simple to someone else.

consent. This is a move towards the "reasonable patient" standard of consent which is already prescribed in the GMC consent guidelines. Patients should be informed of any risks that a reasonable person in the same position would attach significance to. This includes rare but potentially serious complications. It is only appropriate to withhold information if you believe that giving it would cause the patient 'serious harm'. In this context, 'serious harm' means more than the patient may become upset or decide to refuse treatment.

3 The patient must be able to give his/her consent freely – pressuring patients into consenting to treatment invalidates the consent. To ensure that consent is freely given, patients should, where possible, be given time to consider their options before deciding to proceed with a proposed treatment. Be aware, too, that patients' friends and relatives may also try to exert their influence and that this can be subtle but, nevertheless, powerful.

4 When treating patients under 18, consent must be obtained from:

- Someone with parental responsibility for them
- A person aged 16 or 17 if they are deemed capable of making informed decisions, or
- Someone under 16 if they are deemed Gillick competent.[34] That is, they have the maturity and intelligence to fully understand the nature of the treatment, the options, the risks involved and the benefits. While there is no statute in Northern Ireland setting out the general principles of consent, common law dictates that touching a patient without valid consent may constitute the civil or criminal offence of battery.

Patients who withhold consent

There are certain circumstances where treatment may be administered to patients who refuse to provide consent:

- Part IV of the Mental Health (Northern Ireland) Order (1986) states that patients who are detained under the Order may receive treatment for their condition without their consent. Treatment for physical disorders unrelated to the mental condition remains subject to common law principles.
- The Public Health Act (Northern Ireland) (1967) says that a magistrate may order for patients suffering from certain infectious diseases to be medically examined and detained

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[34] As per Age of Majority Act (NI) this trumps parental responsibility.

in a hospital without their consent.

- However, the Order does not allow doctors to treat these patients without their consent, so treatment is dependent on common law principles.

Patients who lack capacity

Patients who lack capacity should not be denied necessary treatment simply because they are unable to consent to it.

However, in Northern Ireland there is no statutory provision to allow for someone to provide consent for medical examinations, care or treatment on behalf of an adult without capacity. Some exceptions to this, where health and social care professionals may intervene and provide care to patients without capacity, are listed above.

- Any decision that is taken on behalf of an incompetent patient must be taken in his or her best interests.

- Where there is doubt about whether a patient has capacity or what action would be in their best interests, the High Court can give a ruling on the lawfulness or unlawfulness of a proposed intervention.

- The Official Solicitor can advise on the appropriate procedure if

necessary. **Verbal or written consent?**

There are very few occasions where the law specifically requires written consent – for example, in relation to the storage and use of gametes and embryos in fertility treatment. But in the main, verbal consent is just as valid as written consent.

- Consent is a process – it results from open dialogue, not from getting a signature on a form.

- Completed consent forms provide some evidence that consent was obtained, but mean little beyond that – it is important to realise that they do not constitute proof that the consent was valid. If there is any dispute over whether valid consent was obtained, the key issue will not be whether the patient signed a form or not, but whether they were given all the information they needed to make a considered decision. It is, therefore, crucial that the essential elements of discussions with the patient are documented in the medical record.

- The notes do not need to be exhaustive, but should state the nature of the proposed procedure or treatment and itemise the risks, benefits and alternatives brought to the attention of the patient. Any particular fears or concerns raised by the patient should also be noted.

Failure to obtain valid consent

A significant proportion of clinical negligence claims are settled simply because valid consent was not obtained. In theory, where harm has befallen the patient and consent was not obtained, this could also give rise to claims for assault or battery and, in extreme cases, criminal charges, but fortunately this is exceptionally rare.

Disregarding the GMC's advice on consent can sometimes result in charges of professional misconduct and action by the GMC on the doctor's registration.

Further information

- GMC, *Consent: Patients and Doctors Making Decisions Together* – www.gmc-uk.org/guidance

- BMA, Consent Toolkit: 3rd edition (2007) – www.bma.org.uk

- Department of Health, Social Services and Public Safety - *Reference Guide to Consent for Examination, Treatment or Care* (2003) www.dhsspsni.gov.uk/consent-referenceguide.pdf

- Mental Health (Northern Ireland) Order 1986 Code of Practice, Chapter 5

APPENDIX 5 Ethical guidance on visiting

Visiting in end of life situations[35]

Summary of guidance from Chief Nursing Officer 30 April 2020

All patients who are judged to be dying from COVID-19 or other conditions within hours or days are entitled to receive visitors. That entitlement is however qualified by a number of factors. The COVID-19 pandemic and the ensuing government policy on social distancing and isolation has created concerns relating to visiting people either in hospitals, care homes, hospices or their own homes. While this can be accepted and adhered to by the majority of the population it becomes difficult, and one could argue inhumane, at the time of or the period leading to the death of family, friends and loved ones.

Deaths from COVID-19 and other diseases and illness occur across the entire range of care facilities. Patients die at home, in nursing and residential homes, in hospices, community hospitals, general wards of acute hospitals, emergency departments, and high dependency and intensive care units.

There is no argument with the logic of introducing processes for reducing the footfall through any of the above areas to reduce the risk of infection for staff, other patients and the general population.

People generally understand that they could contract infection from a patient dying of COVID-19 and thus come to physical harm themselves. They also understand that they could spread the infection to others outwith the care setting where the patient is dying. However when facing the prospect of losing a loved one it is conceivable that this logic could become immaterial and meaningless.

Practical Principles for facilitating Visits for Family Members/Loved Ones at end of Life

End of Life care constitutes a special circumstance and where feasible patients approaching the end of life should be afforded the opportunity to spend time with family members and/or loved ones. This is applicable to all areas of care including intensive care units.

The following practical principles adapted from the Scottish approach and outline the main considerations when determining the appropriateness or practicalities for accommodating face to face visits with dying patients.

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[35] Adapted from the Royal College of Physicians Edinburgh - Scottish Academy April 2020
https://www.rcpe.ac.uk/sites/default/files/sa_statement patients_and_family_at_end_of_life_care_final_0.pdf

1. People have the right to be with a loved one/family member/next of kin at the time of death and this should be respected and accommodated where possible. This is the expectation of the CMO/CNO and the health Minister for NI.
2. Family members and/or the loves ones of a patient dying from COVID-19 must be able to make an informed decision about whether visiting is the right thing for them or the patient in their particular circumstances.
3. Where possible, and as early as possible, staff caring for patients with COVID-19 should record the patient's wishes about their end of life care and should identify the person they wish to have with them during their dying moments.
4. Staff should, with the patient's permission, share this information with family members as early as possible in the patient's COVID-19 care journey.
5. Only in extreme cases should family members/ loved ones next of kin be denied the possibility to be with a patient at the time leading to or of death. Where this is the case the reasons should be clearly outlined to the patient and his/her family members and/or loved ones.
6. Care facilities are entitled to limit the frequency of visits, duration of visits, or numbers of visitors in accordance with the risk to other patients, other care staff, or other practical considerations in the care setting. However, the reasons for this must be documented and be in accordance with the framework outlined above.
7. Organisations especially those with limited space may limit the number of visitors to one at a time - when this is the case the situation should be explained clearly to those wishing to visit. In any case there should be no more than 2 people visiting at any one time.
8. Infection prevention and control requirements should not be so rigid as to prevent family members/loved ones from saying goodbye in as humanely a way as possible- this includes the ability for them to hold hands and touch the dying person.
9. When face to face visits are being accommodated visitors should be made aware of the PPE requirements and should be supported to adhere to these. Only where visitors are able and willing to comply with PPE requirements should the visit be facilitated/permitted.
10. In all cases, visitors must agree to undertake the subsequent isolation and quarantine restrictions appropriate to the contact that has occurred in association with their visits.
11. Where face to face visiting cannot be accommodated the reasons should be explained to the family and the patient and all efforts to accommodate virtual visiting should be made.
12. Each organisation should have a policy and guidelines for accommodating virtual visiting - these should be known by all staff and should be shared with family members and used as and when required.
13. In any case where there is increased risk to visitors due to the possibility or proximity of aerosol generating procedures then full PPE should be offered to the visitor and the visitor

should provide confirmation that he/she understands the risk posed to him/herself and others.

14. Where AGPs are being conducted during the time leading to death then visiting should as far as possible be limited to periods outside of these procedures (If possible there should be no visit until at least 1 hour after an AGP procedure).
15. Anyone who is unwell and/or exhibiting symptoms of COVID-19 - a new, persistent cough and fever or high temperature - should NOT visit any patients in a hospital or other care facility.
16. Clinical teams in more acute settings, particularly ICU and HDU, should receive support in family liaison from other staff members, including chaplaincy, bereavement and counselling services, thus enabling them to focus on direct patient care.

The particular circumstances of the COVID-19 pandemic mean that direct contact with family members by the clinical team is very limited. However, particular care should be taken to use all possible means to have face-to-face contact (such as the use of video phones etc) or contact by phone to discuss implementing a DNACPR order.

APPENDIX 6 Transfer of patients

Ethical guidelines on the transfer of critically ill patients between or within trusts[36]

The decision to transfer a patient is the joint responsibility of both referring and receiving clinicians. The medical staff at the receiving unit may offer specialist advice on patient management, however primary responsibility for the patient lies with the clinician in attendance who may, if circumstances change, decide not to transfer the patient.

A contentious issue, which sometimes arises when a transfer is necessary because of lack of availability of critical care beds, is whether to transfer the new and potentially unstable patient, or an existing more stable patient who is less likely to deteriorate. In general, no patient should be subjected to an intervention that is not in their best interest, and it could be considered unethical to transfer one patient out of a critical care unit for the sole purpose of making room for another. This may on occasion, however, be the most pragmatic approach, particularly where the transfer is required to generate capacity in a tertiary centre for a patient requiring specialist care.

When transfer to a specialist centre for immediate life-saving intervention is required (e.g. acute neurosurgery), this must not be delayed by lack of availability of an intensive care bed in the specialist centre. Transfer must occur to enable the required intervention, whilst arrangements are made to provide the subsequent on-going care.

This requirement clearly creates challenges for tertiary centres in ensuring capacity and equity of access to specialist services. Repatriation of patients from specialist centres back to their referring centres once they no longer require specialist care is entirely appropriate and should normally occur within 48 hours of the patient being identified as suitable for repatriation.

Once a patient has been accepted by a receiving unit, the bed must be kept available to receive the patient until the patient arrives or until the transfer is stood down. This is particularly relevant to repatriations (including those from overseas) when the patient may be travelling long distances and there may be logistical delays in the transfer process.

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[36] Facility of Intensive Care Medicine and The Intensive Care Society- Guidelines May 2019

- The decision to transfer and to accept a patient must be made by appropriate consultants in both the referring and receiving hospitals.

- Transfer for immediate lifesaving interventions must not be delayed by lack of availability of a critical care bed.

- Repatriation policies for patients who no longer require specialist care should be agreed across networks. Patients who require repatriation must be transferred within 48 hours of being identified as suitable for repatriation

APPENDIX 7 GLOSSARY

ACPS	Advance Care Plan Summary
ADL	Activities of Daily Living
ADRT	Advanced Decision to Refuse Treatment
AHP	Allied Health Professional
BAME	Black, Asian and Minority Ethnic
BMA	British Medical Association
CACP	The Nursing Home/ Community Hospital Community Anticipatory Care Plan
CEC	Clinical Ethics Committees
CEF	Clinical Ethics Forum
CMO	Chief Medical Officer
CPR	Cardiopulmonary Resuscitation
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
ECR	Electronic Care Record
ECHR	European Convention on Human Rights
GMC	General Medical Council
GP	General Practitioner
HAnCP	Hospital Anticipatory Care Plan
HSC	Health and Social Care
IHRD	Inquiry into Hyponatraemia Related Deaths
KIS	Key Information Summary of NIECR
NI	Northern Ireland
NIAS	Northern Ireland Ambulance Service
NICE	National Institute for Health and Care Excellence
NIECR	NI Electronic Care Record
NISCC	NI Social Care Council
NMC	Nursing and Midwifery Council
PPE	Personal Protection Equipment
PHA	Public Health Agency
PCiP	Palliative Care in Partnership
PTSD	Post-traumatic stress disorder
UK	United Kingdom