

# ETHICAL MANAGEMENT OF PATIENT CHOICE:

## HOW SHOULD PATIENT CHOICE BE MANAGED DURING THE SERVICE RECOVERY PHASE OF THE COVID-19 RESPONSE?

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REFERENCE GROUP

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## Executive Summary

This paper describes an approach to dealing with patients who request deferral of treatment during the pandemic. These are expressed in the form of do's and don'ts and can be found at page [8](#) . They are based on:

- An ethical analysis using Beauchamp & Childress' Four Principles Approach
- A brief description of legal and ethical issues relating to mental capacity and safeguarding
- Themes identified by analysis of systems and processes developed by services and clinical networks in the South West

## Introduction

South West system leaders asked the South West Health & Social Care Ethics Reference Group (SWERG) to advise on this issue from an ethical perspective. The problem arises when patients on the waiting list are offered appointments for their procedures or investigations and decline, requesting that their treatment be further delayed. The context is the long wait times, limited capacity and lengthy waiting lists for elective care which are due to the disruption caused by the Covid-19 pandemic. The phase 3 letter from Sir Simon Stephens sets an expectation that rapid progress be made to offer treatment as soon as possible to those waiting.

This document represents SWERG's advice on the development of appropriate, ethical policy or guidance under which patients refusing treatment on the grounds of choice can have their position on the waiting list reassessed.

## Scope

This document is intended to cover all non-emergency care pathways (including cancer) from the point of referral to secondary services. The patients covered by this document are individuals on waiting lists for treatment who request deferral of treatment on one or more occasions. It only covers patients who have the capacity to make autonomous decisions about their own treatment; although this may in some cases need to be assessed.

Out of scope are emergency admissions, trauma, emergency surgery, treatments for immediate life or limb threatening conditions; and situations where capacitous patients have clearly requested removal from the waiting list. Where patients are judged to lack capacity to make autonomous decisions about their own treatment, they are out of scope of this document and a safeguarding or best interests' pathway will need to be followed.

## Terms of reference

1. To produce a document for consideration by South West System Leaders by September 30<sup>th</sup>, 2020
2. To outline ethical considerations relevant to the management of patients experiencing lengthy waits for elective care
3. To make recommendations for fair and ethical management of patients which will balance:
  - The rights of patients to have choice regarding their treatment
  - The need to reduce harm caused by delayed access to care

- The duty of commissioners and providers to optimise the use of resources to provide care for as many people as possible
  - The risk of worsening health inequalities
  - The needs and rights of specific vulnerable groups including the legal requirement to make reasonable adjustments
  - The legal duties of health care providers and commissioners relating to finance, public health and clinical quality
4. To highlight where interventions to maximise throughput of cases and reduce the number of patients on the waiting list may raise safeguarding or clinical concerns

## Why do patients wish to defer treatment?

A brief literature search (PubMed) failed to identify any research relating to this question. Anecdotally, healthcare workers (HCWs) in the South West who have been trying to encourage patients to accept treatment have identified the following factors:

1. General sense of wanting to “wait until the pandemic is over”
2. Fear of catching Covid in hospital
3. Living with or caring for someone who is shielding or vulnerable
4. Reluctance to have a swab test
5. Difficulties with public transport – including infection risk and reduced services
6. Precarious employment causing difficulty with planned sickness absence including loss of income
7. Caring for children where there is inadequate childcare available to the family

This is clearly a question which should be further explored in order to understand patient and public perspectives and identify possible interventions which would support better access to healthcare in line with the intentions and targets set out in the phase 3 letter.

## Method

A sub-group of SWERG will undertake a first draft of the document which comprises:

1. A short description of the important ethical considerations
2. A list of themes derived from approaches being taken by providers and clinical groups which could be applied to managing long waits
3. Recommendations for next steps

The sub-group contacted clinicians in regional networks and clinical leadership positions to gather as much information as possible regarding how this issue was already being addressed. Contributors are listed in Acknowledgements; and sources are included in the Appendices. These approaches were analysed to draw out common themes which were consistent with the ethical principles.

## Ethical considerations

*How should patient choice be managed during the service recovery phase of the Covid-19 response?*

### SWERG’s approach to ethical analysis

We use “the four principles approach” for ethical analysis. A fuller account of our interpretation of the four principles approach to ethics in the context of the Covid-19 pandemic and why the SWERG has adopted this approach has been developed and will be published by the end of October 2020.

In brief outline, recognising the wide diversity of often mutually incompatible overarching moral theories and approaches to moral reasoning, we adopt the **four principles** (or the “four pillars”) approach to health care ethics. This approach is familiar to many health care professionals and is now usually called “principlism”.<sup>1</sup> The approach was designed by Beauchamp and Childress in the 1970s precisely to help doctors and other health care workers to deal with the ethical issues they regularly faced, usually in contexts where neither the health care workers themselves nor their patients or clients shared a common “overarching” ethical theory, whether religious, secular, political or philosophical. Simply summarised, the four principles *in no order of precedence* are:

- **Beneficence:** the prima facie moral obligation to benefit (at least some) others. All of us in health care are committed to this principle!
- **Non-maleficence:** the prima facie moral obligation to avoid harming others. ‘Prima facie’ is especially important a qualification for anyone who is trying to benefit others since when one tries to help others one almost always risks harming them. So, if we’re intending to benefit, we must always think about the possible harms and always aim for **net** benefit; i.e. “benefit-over-harm”. Even when we don’t have an obligation to benefit others, we should still strive to avoid harming others (hence the need for four rather than three principles!). “Prima facie” is also needed because, like the other principles, non-maleficence may conflict not only with beneficence but also with respect for autonomy and with justice.
- **Respect for autonomy:** roughly speaking this is the prima facie moral obligation to respect people’s thought-out choices for themselves. Note that this principle requires the often-forgotten qualification “insofar as this is compatible with respect for the autonomy of all potentially affected”. Note too that it is people’s **self**-rule (autonomy literally means self-rule), not their rule of others, that is to be respected, no matter how autonomous is their desire to rule others!
- **Justice/fairness:** the prima facie moral obligation to treat people as equals unless it is morally justified to treat them as unequal, in which case they *should* be treated unequally in relation to the morally relevant inequality. Note that this may involve treating them better or worse than others depending on the morally relevant inequality. The most obviously relevant inequalities in the context of health and social care concern people’s health needs. The NHS was founded on the basis of treating people **both** as equals (when there are no morally relevant inequalities) but also as unequals (when their **needs** are unequal).

#### Principlism carries some “health warnings”

- These principles may conflict with each other – hence they are ‘prima facie’ rather than absolute moral obligations.
- They are very high level and general principles; very often in practice they need, singly or more usually in combination, to be made more specific for application to particular circumstances or types of circumstance – so-called specification. Many legal and professional obligations are specifications of conflicts between these four prima facie principles or indeed between conflicting specifications!
- The four principles approach itself does not incorporate a method for dealing with conflicts between the principles or their specifications. All such methods require the mysterious and undefinable capacity of moral judgment; principlism does not produce an algorithm for moral judgment

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<sup>1</sup> Beauchamp T, Childress J. Principles of Biomedical Ethics (2019 - 8<sup>th</sup> ed). New York, Oxford: Oxford University Press

- Nor does the four principles approach incorporate a method for addressing the scope of these principles (to whom or to what do they apply and to what extent?). All of the prima facie principles create disagreements about their scope.

#### Then why use the four principles approach?

Given these “health warnings”, why, it may be asked, does SWERG choose to use the four principles approach?

First because it provides a set of four universalizable – very widely acceptable – high level prima facie **moral commitments** to which all (or almost all?) moral agents (whatever their overarching moral theory) can commit themselves. So fundamental moral disagreements about for instance religion or politics or moral theory can be bypassed by acceptance of these four prima facie commitments. We invite all who consult SWERG to ask themselves if they can personally accept these four prima facie moral commitments (and to feed back to us rejection of any one of them and the reasons). Given such acceptance, they provide a mutually agreed basic set of moral commitments, a basic moral language and a basic moral framework for addressing, analysing and sometimes helping to resolve real life moral issues, including those arising in the context of the Covid-19 pandemic.

Finally, within that context these principles, understood as shared prima facie moral commitments and objectives, help us make sense of all the *additional* moral principles and requirements to be found in the many and ever proliferating Covid-19 ethics guidelines. We see these additional requirements as aids towards achieving one or some combination of these four prima facie moral commitments/objectives.

#### Application of the four principles approach to the specific question:

##### *How should patient choice be managed during the service recovery phase of the Covid-19 response?*

Patient choice is highly prized in contemporary NHS practice. As an aspect of respect for autonomy the notion itself needs analysis, as does its potential conflict with both beneficence and non-maleficence (aka net benefit over harm, aka the patient’s best interests) both as perceived by health care providers and as perceived by the patient. Then there is the potential conflict of patient choice with justice/fairness, whether distributive (fair allocation of scarce resources), legal (obligations to obey morally acceptable law) or rights-based (especially human rights, now incorporated into UK legal systems).

Our question represents a common example of such conflicts which arises when patients on a waiting list for diagnostic procedures or treatment do not attend appointments or refuse to accept offered appointments.

The following brief analysis considers patients who are considered to be “adequately autonomous” and “legally capacitous” to make the relevant decisions about their health care. Additional considerations, out of the scope of this paper, are needed for those who are not in this category; whether due to age, mental state, limited intellectual ability or undue influence of other individuals.

#### Respect for autonomy

Respect for people’s autonomy requires others (prima facie) to accept their “thought out choices *for themselves*” (note, autonomy = *self*-rule, not rule of others). Thus, autonomous refusal of treatment (including refusal of diagnostic opportunities) should be respected as an aspect of the patient’s “self-rule” and both professional and legal specifications (guidance) require such refusals to be respected. Nonetheless, if such refusals seem to the HCW to be against the patient’s best interests, discussion

and advice should be offered as part of the net benefit commitment. Perhaps, for example, this will involve reassurance about the low risks of accepting the intervention in comparison to the potential benefits; perhaps it will involve offers of help with transport; perhaps it will involve an offer to defer an appointment rather than cancel it. The bottom line is the patient's legal right (legal justice) to refuse intervention.

Requests or demands for treatments and investigations necessarily involve the autonomy of those asked to help the requester/demander. Issues to be considered here will include: the HCW's own assessment of likely benefit (e.g. doctors are not legally required to provide "futile" treatments); and the HCW's own professional and legal obligations which include restrictions on providing treatments that are in very short supply, very expensive, or unlawful.

#### Beneficence, non-maleficence and net benefit

Here the doctor or other HCW has first to decide what counts as the patient's net benefit, and who should decide if the HCW and patient disagree. As outlined above, when it comes to refusal of treatment or diagnosis the patient's view should prevail, though explanation and discussion should be offered.

If the patient is requesting a treatment or diagnostic procedure the HCW's own autonomy also requires respect. Thus, the HCW is not obliged to provide treatments or diagnostic procedures that reasonable professionals would regard as non-beneficial. On the other hand if the requested intervention might provide net benefit to the patient (even if not as much benefit as an alternative advised by the HCW) and if it would not unacceptably deprive others ("opportunity cost" and distributive justice) then the duty of beneficence will *prima facie* require provision of the requested intervention. However, even if the requested intervention would be mutually agreed by patient and HCW to be beneficial, the HCW will need to consider a possible conflict with justice to others in terms of fair distribution of scarce resources and any legal and human rights justice issues that may "trump" provision of the requested intervention.

#### Justice & fairness

In the context of restoring services halted by COVID-19 the requirement to "treat equals equally" arguably first requires existing waiting lists to be honoured, with exceptions based on good moral reasons justifying some "queue jumping" or prioritisation. Widely accepted justifications for such queue jumping include substantial and urgent clinical need. The "need for intervention X" can be understood as approximately equal to the probability of harm occurring without intervention X multiplied by the extent or severity of the harm which will be averted by intervention X. An important contribution to prioritisation in relation to stratification by risk of harm is provided by Takwale (Appendix (i)).

In relation to patient choice, justice and fairness may conflict with patients' positive requests for treatments and investigations. In responding to such positive requests, providers must balance their *prima facie* duties to meet the patient's individual needs with meeting the individual needs of as many as possible of their patients who have similar levels of need. Where the patient is requesting deferrals of treatment, there is a potential conflict between benefiting and respecting the autonomy of that individual patient (which may require additional resources) and meeting the needs of as many patients as possible.

Health service obligations to reduce health inequalities may (arguably) justify positive discrimination in favour of providing services to disadvantaged patients and populations.

These remarks about justice in relation to patient choice relate to distributive justice. Both rights-based justice and legal justice (the two often considered together since the incorporation of international human rights instruments into UK law) will also need consideration. Thus, both ethical and legal tensions arise in cases where a patient's choice of treatment is supported by the patient's physician but denied on grounds of fair allocation of scarce resources. Such tensions are not new but are particularly acute in relation to potentially lifesaving or life prolonging treatments where capacity is limited, as in the present phase of the pandemic.

A useful summary of relevant considerations is provided by Halpin D in an earlier SWERG document (Appendix (iv)).

## Consent, Mental Capacity & Safeguarding

It is important to note the legal limits on autonomy. In medical law the right to refuse treatment is well protected (*S v St George's NHS Trust*)<sup>2</sup>. Conversely, even though a patient may request treatment, that does not mean the doctor must provide it (*R (Burke) v GMC*)<sup>3</sup>. This could be explained on the basis that, if treatment is refused, no one apart from the patient is harmed. However, if a patient insists on a treatment which is not clinically justified provision of that treatment would affect the availability of resources for other patients. This is an additional legal support to the ethical support for clinicians refusing to treat as based on respect for the clinician's own autonomy.

A person who lacks capacity will be treated under the Mental Capacity Act 2005 and in line with best interest assessments. Those with parental responsibility for a child can make a decision on the child's behalf. Therefore, the autonomy principle is limited in scope where a patient lacks capacity to make a decision. Respect for autonomy where the patient lacks capacity or is a child can be upheld by ensuring that the patient is involved and informed in decisions in so far as they are able.

Where a deferral of treatment is requested and relates to an individual who is reliant on others to bring them e.g. child or adult with care and support needs, use of the organisation's "was not brought" policy should be considered or consultation with the organisation's named or designated safeguarding professional for advice.

## Themes

These themes emerged from analysis of approaches taken by providers, commissioners and services and discussions with clinical leaders and clinical networks. These are consistent with the ethical principles and should be considered in the development of any project to manage patient choice.

### Do....

1. Consider a prospective review of waiting lists to identify patients at risk of harm due to treatment delays. (Appendix (i))
2. Seek input from patient, public and carer groups when devising policies and processes for managing waiting lists generally and patient choice specifically
3. Develop a written policy for the management of patient choice and ensure it is implemented
4. Keep a record of all conversations with patients and follow-up arrangements
5. Carry out an overall non-clinical review of the patient's needs and concerns, using a remote or telephone consultation with a member of the team.
  - Establish the reason why the patient is reluctant to attend the offered appointment

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<sup>2</sup> *St George's Healthcare NHS Trust v SR v Collins and Others, ex parte S*; [1998] 2 FCR 685

<sup>3</sup> *R (Burke) v General Medical Council* [2004] EWHC 1879 (Admin)



- Explore what support or other intervention might be needed to facilitate attendance
6. Where a patient may lack capacity, ensure that this is assessed. Where the patient lacks capacity, seek advice regarding making a best interests' judgement
  7. Ensure that the patient is not being pressured or coerced by others to decline treatment. If in doubt, seek safeguarding advice
  8. Engage with the patient's carer or other supporter (with the patient's consent) to support the patient in making a decision about treatment
  9. Provide information about the risk of infection from attending the hospital and the steps being taken to reduce this.
  10. Seek to reduce non-clinical barriers to access
  11. Offer reasonable adjustments to support patient access: e.g. offering more notice of the appointment; offering alternative times of day
  12. Consider the role of the patient's GP in further discussion with the patient of their clinical condition and need for treatment including risk of delay
  13. Undertake a clinical review (this may require a consultation with a GP, specialist doctor, specialist nurse, allied health professional) to establish the current clinical condition of the patient and if necessary, review an earlier decision
  14. Consider whether any alternative investigation or treatment might be suitable and offer this to the patient
  15. Consider whether the patient could access care at an alternative provider
  16. Only remove a patient from the waiting list and offer no further appointments in consultation and in agreement with the patient and ideally their GP
  17. Communicate the outcome of any review, its rationale and the ongoing care plan to the patient's GP

#### Don't...

18. Set arbitrary numbers of appointment to be offered before removal from the waiting list: e.g. "two strikes and you're out".
19. Downgrade or reject referrals especially of suspected cancer
20. Block or prevent re-referral of patients where they have previously declined treatment or investigation
21. Offer interventions or alternatives that do not have a reasonable evidence base

### Further recommendations

Gather anonymised qualitative data on:

- The reasons why patients seek to defer treatment
- Which interventions improve acceptance of care
- Characteristics of the patient in terms of:
  - Needing or receiving care
  - Being a carer
  - Working age adult
  - Other lifestyle or demographic factors which have made accessing care difficult

Use this data to continually inform the development of new interventions and revisions to care pathways which will improve patient access and patient experience.

## Appendices

- (i) Proposal for clinical prioritisation and risk stratification



Proposal for clinical  
prioritisation and risk

- (ii) Supplementary Guidance – Patients on Cancer Pathways GHNHSFT



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Covid-19\_Action\_Card

- (iii) SWAG **DRAFT** Proposal to manage 2WW patients declining diagnostic tests



SWAG DRAFT  
Proposal to manage 2

- (iv) Restoration of Services: An Ethical Approach



SWERG notes on  
Ethical Issues D Halpin

- (v) SWERG ethics, professional guidance & law FAQ paper

To be included

## Acknowledgements

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