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Good communication with patients waiting for care

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This guidance outlines core principles for providers to help deliver personalised, patient-centred communications to patients who are waiting for care. It has been produced by NHS England and NHS Improvement with support from Healthwatch, National Voices, the Patient's Association, The Richmond Group of Charities and Versus Arthritis.

This document is primarily aimed at acute trusts but may also be of interest to the wider system.

Introduction

The [third phase of the NHS response to COVID-19 letter](#) explains trusts should ensure that “every patient whose planned care has been disrupted by COVID receives clear communication about how they will be looked after, and who to contact in the event that their clinical circumstances change.”

This is further supported in the [2021/22 operational planning guidance](#) which states that systems should “maintain effective communication with patients including proactively reaching out to those who are clinically vulnerable”.

This guidance outlines core principles for providers to help deliver personalised, patient-centred communications to patients who are waiting for care. It is primarily aimed at acute trusts but may also be of interest to the wider system.

Whilst the NHS has managed the immediate challenge of dealing with COVID-19, many patients waiting for elective care have experienced longer waiting times and changes to their treatment plans at short notice. Constitutional rights around elective care have not changed (eg referral to treatment time and patient choice), and there are additional requirements for trusts to undertake validation and clinical prioritisation of waiting lists. These factors combined mean it is now more important than ever to maintain frequent and honest contact with patients who are waiting for care.

You may need to communicate difficult messages to patients, such as delays or changes to treatments, and collate specific information from them in order to jointly plan and manage ongoing care.

The National Voices report [Patient Noun Adjective: understanding the experience of waiting for care](#) (October 2020) highlights patients’ lived experiences of provider communications while waiting for care.

The report reveals inequalities in experiences of waiting for elective care according to the nature of the condition, regional variations, socioeconomic factors and ‘protected-characteristics’. It also shows a range of communication barriers may exist for those who have:

- no or limited proficiency in the English language
- sensory impairment
- long-term conditions
- physical or mobility impairment

- learning disability
- mental health conditions
- autism
- or who are older/frail.

To improve communications with patients, you should seek to:

- 1) Understand the importance of improving the experience of waiting.
- 2) Invest in developing patient-centred information and communication.
- 3) Support people while they wait, by:
 - a. providing and supporting self-management and shared decision-making
 - b. monitoring routinely and providing clear pathways to specialist advice
 - c. exploring potential for carefully delivered virtual healthcare
 - d. partnering with and signposting to voluntary, community and peer support.

To build on the National Voices report, this document lays out the core principles to support the standardisation of clear, person-centred communication with patients across the health service. This is essential to improve patient experience and understanding when waiting for treatment in these uncertain times.

Communication strategies must be focused on two areas:

- the individual patient
- engaging with the local population

Your strategies must consider the needs of local communities and health inequalities and make reasonable adjustments to ensure communications are inclusive.

Local strategies should make use of accessible and inclusive media to inform and engage with patients – such as social media, letters, on-site posters and one-to-one clinical discussion. Upon request, information should be made available in alternative formats, such as easy read or large print, and should be available in alternative languages.

Principles

The principles below should be applied to all communication with patients in relation to their ongoing care. Providers and their boards must ensure these are applied consistently and equitably across their services and populations. Example resources are provided in Appendix A.

Personalised

Your communications should give clarity on the next steps of a patient's care pathway including likely and honest timescales, and what they can expect. This will enable the patient to participate in an informed discussion about their treatment.

Patients must fully understand the process and the implications of their decisions; and providers must welcome and encourage questions and queries from patients. To this end, it is crucial that when communicating with patients, you consider and are mindful of:

- health inequalities
- protected characteristics
- the accessibility of information for patients
- literacy levels
- language translation
- wider communication
- reasonable adjustment requirements.

You should consider providing patients with additional information or signposting them to resources that will help prepare them for conversations about their care – eg information that is sent out with appointment letters, posters in clinics and general waiting areas – as well as using a range of local media. Information should be made available in alternative formats and in alternative languages upon request.

Information and communications must comply with the [Equality Act 2010](#) and reflect the [accessible information standard](#). This includes making sure that advice for patients on preparing for appointments/treatment is accessible in several different formats, and that it is understandable for people at all levels of health literacy.

Patient safety

All your communications with patients should reinforce the message that it is safe to use NHS services. Significant steps have been taken to minimise the risk of COVID-19 transmission while in hospitals; however, local communication should reflect conditions in the locality.

You should ensure that patients can contact you with concerns in this regard. Clinicians should discuss with patients the balance between their need for treatment versus the risk of coming into hospital.

Clear language

Language should be clear, accessible and easy to understand. This should apply to written and verbal communication with patients. A simple tool like the Flesch Reading Ease Score, [available on Microsoft Word](#), can help guide the development of good written communications that are easy to understand. Sometimes, technical terms are needed but these should be explained, or avoided when possible. Try to avoid language that may deter patient involvement in discussions about their care or reduce their choice.

Shared decision-making (SDM)

The concept of shared decision-making should be communicated to patients – and their selected advocate if required – so they can prepare for their conversation/appointment. The process of SDM should be outlined and patients informed of its importance. Patients should then be supported to make decisions that are right for them with an understanding of the risks and benefits of going ahead with, cancelling or delaying their procedure.

Patients and their advocates should be informed of the impact that the COVID-19 pandemic may have on their appointment and should be given the opportunity to ask questions about this.

Managing appointments, delays and cancellations

Provide a clear and honest message with a compassionate tone about upcoming appointments, delays or hospital cancellations. If cancellation is required, be clear about why and what happens next. If a patient is going to experience a long delay, open and honest communications will help manage expectations. This should be supported by a realistic timescale as to when the patient can expect to hear further information. If next steps are uncertain, explain that to the patient.

Contact point for patients

Trusts must ensure that it is easy for patients to get information about their upcoming care and to raise any questions. This should ideally be by telephone, but reasonable adjustments and inequalities should be considered, including alternative options for any patients with specific language or communication needs.

Trusts may approach this using a number of solutions, but patient groups strongly support the creation of a Single Point of Contact (SPOC) and would like to see every trust working towards this.

The opening hours for this service and number should be clear and easily available and

patients should be able to leave a message out of hours. An email alternative should be offered, ensuring this inbox is checked regularly and someone is assigned to respond. The local Patient Advice and Liaison Service (PALS) team must be aware of the SPOC process and there will be an opportunity for some overlap in training for the PALS and SPOC teams.

Interim information and services

As part of the shared decision-making process, if treatment is subject to delay, withdrawn or the patient decides not to go ahead, then alternative options should be discussed.

Supporting information should also be provided to the patient to help them manage their condition whilst waiting for care. It should be clear to patients who they should contact if their condition deteriorates. In the first instance this should be through the SPOC.

Cancellation policy

Provide clear instructions to set out how a patient can cancel their care if required. This should be via their SPOC. Additionally, where providers need to cancel patient care this should be done in line with the trust's access policy and national rules. There should be supporting, standard operating procedures that detail this process to ensure consistency.

Communication strategy

There should be wider, generalised communication with local populations to explain that delays to care are likely, due to the impact of COVID-19 and what to expect in the future. This will cover timeframes for when they should expect to be contacted and next steps, along with how patients can contact their providers for more specific information.

Information should be made available in alternative formats and in alternative languages, depending on the needs of the local communities.

Appendix A: Resources

Listed for the topics below are a series of resources and examples of their use. Please also see:

- [Good communication with patients waiting for care: core principles](#) (NHS England and NHS Improvement) – a visual aide memoire to support delivery of this guidance.
- Letter templates:
 - [postponing an appointment](#)
 - [rescheduling an outpatient appointment](#)
 - [postponing](#) a planned operation
 - previously delayed or cancelled appointments

Model Access Policy Addendum following COVID-19

- Policy (via FutureNHS platform):
<https://future.nhs.uk/connect.ti/ElecCareISt/view?objectID=76671365>

Personalised and shared decision-making

- Guidance and resources (NHS England and NHS Improvement):
 - <https://www.england.nhs.uk/shared-decision-making/guidance-and-resources/>
- Patient and carer info (Choosing Wisely):
 - <https://www.choosingwisely.co.uk/i-am-a-patient-carer/>
- ‘Getting ready to talk about your health’ (Academy of Medical Royal Colleges):
 - <https://www.aomrc.org.uk/wp-content/uploads/2021/01/Getting-Ready-to-Talk-About-your-Health-Interactive-Infographic-FINAL.pdf>
- [Shared decision making infographic \(NHS England and NHS Improvement\)](#):
 - <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/10/Shared-decision-making-infographic.pdf>

Patient information on what to expect when visiting hospital

- Elective surgery – What do I need to know during the COVID-19 pandemic? (East Lancashire Hospitals NHS Trust):
 - <https://elht.nhs.uk/about-us/coronavirus-covid-19-guidance/guidance-patients-attending-surgical-procedures/elective-surgery-what-do-i-need-know-during-covid-19>

[19-pandemic](#)

Wider population communication to explain impact of waits due to COVID-19

- Cambridge University Hospitals NHS Foundation Trust:
 - Facebook post: <https://www.facebook.com/247200598685107/posts/4809137109158077/?vh=e&d=n#>
 - Patient leaflet: https://bucket-cuh-production.s3.amazonaws.com/documents/Advice_for_patients_waiting_to_be_seen_at_CUH.pdf

Preparing for surgery and what to expect

- Guidance for adult patients having an operation during COVID-19 (Centre for Perioperative Care):
 - <https://cpoc.org.uk/patients/guidance-adult-patients-having-operation-during-covid-19>

Support for patients waiting

- Improving our understanding of the experience of waiting for care (National Voices):
 - https://www.nationalvoices.org.uk/sites/default/files/public/publications/patient_no_un_adjective_october_2020.pdf
- 15 ways to move more at home (Active Notts):
 - <https://www.activenotts.org.uk/uploads/15-ways-to-move-more-at-home.pdf?v=1599739436>

Accessible information standard

- NHS England and NHS Improvement:
 - Information: <https://www.england.nhs.uk/ourwork/accessibleinfo/>
 - Resources: <https://www.england.nhs.uk/ourwork/accessibleinfo/resources/>