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Clinical validation of surgical waiting lists: framework and support tools

1 October 2020 Version 1

Most long-waiting patients on the surgical waiting list will have agreed to undergo operative treatment before the coronavirus pandemic started. Many people's circumstances may have changed as a result of the pandemic or other factors since then, and some patients may now have changed their minds about having surgery or wish to defer this until the pandemic is over. Similarly, some people's condition may have changed, which they may not have wanted to inform their GP or specialist about.

The clinical validation of surgical waiting lists project will produce a clinically validated waiting list that allows operating lists to run effectively, by:

- checking on a patient's condition and establishing any additional risk factors
- establishing the patient's wishes regarding treatment
- providing good communication with patient and carer and GP
- introducing the P5 and P6 categories that allows patients to postpone surgery but remain on the waiting lists

This project is supported by the Academy of Medical Royal Colleges (AoMRC) as well as relevant medical royal colleges and specialist societies. It has been reviewed by the NHS England and NHS Improvement legal cell.

1. Principles

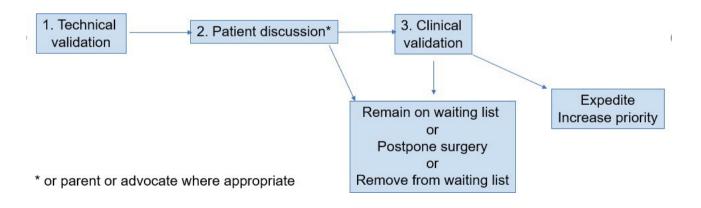
The principles are:

- Times have changed: patients now face different risks and their social and economic circumstances may have changed.
- Local design and delivery of the validation process: core standards but locally interpreted. No patient's care should be delayed by the validation process: those trusts that have started to clinically validate their surgical waiting lists should continue.
- Arrangements to support patients who change their mind about surgery after the initial conversation must be in place.
- Appropriate consultation to meet a patient's needs: remote or face to face.
- Narrowing of health inequalities: e.g. support for people with communication difficulties, 11 including those whose first language is not English; appropriate arrangements for those with a learning or behavioural difficulty or a mental health problem that may impact on their capacity to make an informed decision.

The project is about making the best mutually agreed decisions with patients and is not an exercise to reduce numbers on waiting lists.

Waiting lists should be validated in two or three stages:

- 1. Technical validation: ensure the waiting list is accurate and up to date.
- 2. Patient discussion: patients are contacted by a locally determined competent team to establish their wishes.
- 3. Remote clinical consultation: for patients who wish to discuss their situation in more detail using shared decision making (SDM).



¹ Follow the Accessible Information Standard – format must be accessible for the individual, e.g. BSL, audio or those with visual impairments using screen readers.

2. Use of the P5 and P6 categories

Since 2015, patients have been able to remain on the waiting list for treatment, even if this extends their RTT pathway beyond 52 weeks, but until now there has been no systematic way of capturing that a patient has chosen to defer treatment because of their concerns about COVID-19 and for the NHS to profile its impact on the waiting list.

The P5 category identifies a patient as having requested to remain on the waiting list but to defer treatment because of their concerns about COVID-19 and should only be used if this is the reason treatment is being deferred. Its introduction will allow NHSE, regions and trusts to view the waiting list including and excluding those patients listed as a P5.

Patients who fit the P5 category will remain on the appropriate active waiting list(s) and therefore remain visible. In line with current waiting list rules, waiting times will not be 'paused' and clocks will continue to tick through the period that the patient chooses not to attend. Where patients decline appointments for 'other' reasons, they will not be assigned to the P5 category and will be treated in line with existing access policies.

As patients in the P5 category have deferred rather than declined treatment, they must not be discharged back to their GP, unless this is in their clinical interest and has been agreed by them following a conversation with their clinician.

Patients will be given a review date to make sure their condition or preference has not changed. The maximum time before a review date is six months. Where a patient has been clinically prioritised for treatment in less than six months' time, the review date and clinical prioritisation will be aligned.

Patients who have been offered two dates for treatment and have declined to accept for non-Covid reasons, but still wish to remain on the waiting list will be coded as P6. This is if the reason given to continue to wait is not COVID-19 related. This is in line with current patient choice guidance but enables us to quantify the number of patients who fall into this category.

To note:

- The clinician and provider retain responsibility for any changes to the patient's pathway.
- The patient's GP must be notified of the outcome of the discussion. Patient initiated follow-up should be considered where appropriate: https://www.england.nhs.uk/outpatient-transformation-programme/patient-initiatedfollow-up-giving-patients-greater-control-over-their-hospital-follow-up-care/

- Patients are free to change their minds. Trusts must provide a contact telephone number and/or email for patients to contact should they change their mind within 28 days.. Beyond that date, the patient will need to be re-referred by their GP.
- The local patient advice and liaison service (PALS) should be made aware of the project
- Local teams should design their own system for waiting list validation.
- **Implementation:** the Elective Care Recovery and Transformation team will support implementation, initially with a soft launch at pilot sites in the North West to identify any specific training issues.
- This framework includes tools and other resources that local teams might consider adapting for local use:
 - a shared decision-making tool for use when a patient requests a clinical review (Appendix A)
 - frequently asked questions, both for trusts and patients (Appendix B)
 - supporting distressed patients (Appendix C)
 - clinical prioritisation (Appendix D)
 - pre-habilitation options (weight loss, activity, mental health, diabetes, smoking). These provide generic national resources but local options should be substituted when available
 - template pre-habilitation advice sheet and list of national resources
 - template letters to patients published in word to allow easy local adaptation (published separately).

Appendix A: Shared decision-making (SDM) tool

- Within the context of waiting list support for patients, the SDM tool may be used by clinicians for planning for patient care and delivery.
- SDM is the process whereby patients and clinicians work together to make evidence-based decisions centred on patient values and preferences - The example provided has been adapted for the clinical validation of waiting lists.
- Senior clinicians should have increased ownership of waiting list management, particularly for patients with the highest clinical need or length of wait. This is in line with surgical and medical prioritisation guidelines.

Overview (for patients on surgical waiting lists)

GETTING READY

INTRODUCTION

THE PATIENT

How are they coping with their condition? Check for changes in symptoms, medications, general health and support circle. Explore patient concerns regarding COVID-19 in a clinical environment. Check expectations of the patient regarding the surgery (do they want to proceed or postpone or defer decision). Communicate self-isolation and testing quidance. Consider wider risks to the patient's household.



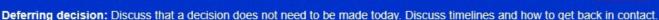
OPTIONS TALK

Discuss appropriate input at this stage; surgical, medical, therapies, non-surgical options. Discuss the outcomes of delaying treatment. Decision support tools. Discuss risk if they catch COVID-19 considering patient's wider background/concerns.



DECISION TALK

Going ahead with surgical / medical input: Discuss self-isolation and testing before surgery. Reduced immunity during recovery. from public transport and risk from contracting illness from other household members. Check understanding of current guidelines. active, healthy diet, smoking cessation, reduce alcohol. Signpost to resources to support preparing for surgery (pre-habilitation).





FINAL STEPS

Summarise your and patient's next steps. Signpost patient to further options if required. Offer any leaflets/material in easy read format if appropriate. Draft letter as per template with a copy to GP and medical records.



Appendix B: Frequently asked questions

Patient questions

1. How long will I have to wait for my operation?

Unfortunately, at the moment we can't be certain. The pandemic has had a big impact on the NHS and we are trying to resume services and keep patients safe at the same time as we continue to treat COVID-19 cases. We are reviewing all patients to see what they want and prioritise those in most urgent need. We are doing our utmost to ensure you get the treatment you require as soon as possible.

2. I have breached the 18 week wait. What are my options?

As per the NHS constitution, you have the right to access certain NHS services within maximum waiting times or, if this is not possible, for the NHS to take all reasonable steps to offer you a range of suitable alternative providers. However, the pandemic may be limiting these alternative services.

3. What if I get worse?

If your symptoms get worse, please contact us on [insert contact number]. Alternatively, you can contact your GP or call NHS 111 for advice.

4. What if I change my mind?

You are always free to change your mind. If we agreed that you would come in for surgery/treatment and you decide you no longer wish to have this, or you now decide you would like it when previously you chose not to, please contact us on [insert contact number] or email us on [insert email] and we can discuss your options with you.

5. Will my family/carer have to isolate with me before I have surgery?

Before you come in for surgery, we will give you clear instructions on the COVID-19 test and how to self-isolate after the test until you come into hospital. Those who live with you do not have to self-isolate and are free to come and go, but they must follow social distancing and face covering rules when not at homeplus wash their hands frequently.

6. How will I be tested for COVID-19?

The test involves taking a swab of your nose or throat. We will send you clear instructions on how, where and when the test will take place.

New tests are being developed and within a few months we may be able to test your spit (saliva) instead.

7. What about my right to choose?

We are contacting all patients on our surgical waiting list to find out what their symptoms and needs are now, rather than at the time their surgery was booked. This will allow you and your clinician together to agree what is best for you now. If you still require surgery, you can choose between going ahead or postponing it. You may be offered treatments other than surgery, where these are appropriate for you. You don't need to decide what you want to do when speaking to your clinician on the telephone; you can let us know within [x] weeks following your consultation by contacting us on [insert contact number].

8. Do I need to have a laptop or smart device to have a consultation?

We're most likely to ring you. Where we can run video consultations, we can use this if you have the right electronic equipment [adapt as locally appropriate].

9. Is it safe to go ahead with my surgery? Will I catch COVID-19 in hospital?

Our hospital follows very strict rules for preventing all types of infection, including COVID-19. You will be cared for in a low risk area and all patients who are admitted to this area will have had a negative swab test, like you. No staff who have COVID-19 symptoms or come into contact with someone with symptoms are allowed to work in the hospital.

10. Can I have a cancellation slot?

It's impossible to give one answer to this question as it will depend on how our local services are organised and whether this is appropriate for you. However, cancellations do occur and we may consider introducing a system to allow patients to be called in at a late stage (allowing for pre-operative screening and testing) [adapt as locally appropriate].

Trust questions

1. What about the patient's right to choose?

Clinical validation enables clinicians to gain up to date understanding of a patient's conditions and by talking to their patients, joint decision-making between clinician and patient. Patients will be given the choice between having surgery/treatment (where required) and postponing this, if they prefer to wait. Patients will also be offered the option of alternative treatments where appropriate.

2. How will clinical validation be applied?

Validation will be undertaken by the clinician responsible for the patient's care. Patients can then be prioritised for treatment, in line with the FSSA guide https://fssa.org.uk/ userfiles/pages/files/covid19/prioritisation master 240720.pdf

3. What happens if there is a second spike of COVID-19?

There is always a risk that COVID-19 will again severely reduce capacity and that a lockdown may prevents patients from coming in for treatment. The validation will give you an up-to-date picture of the patient's symptoms, If patients experience a further long delay, further validation may be required as we have a duty of care to our patients.

4. We have previously done clinical validation. What will be different this time?

If you have already completed or have commenced clinical validation, including direct contact with patients, since the pandemic commenced, there is no need to repeat if you are confident that the current waiting list is an accurate reflection of the patient's wishes.

For those that have not started this process, the current status of patients needs to be validated. This clinical validation is based on joint decision-making and also allows patients to be prioritised using the FSSA prioritisation system. Patients should be contacted to explain that they will have a remote appointment to discuss their current symptoms and situation. At a review held with the patient either online or using the telephone, a joint decision should be made and confirmed in writing to the patient, with a copy sent to their GP. The patient will then be prioritised based on this review.

5. Is additional funding available for clinical review?

You will need to discuss this with your local line manager. Remote consultations are most efficient if they are organised like a clinic and performed in a session. 'Cold calling' patients does not work. These remote clinics are part of direct clinical care.

6. Does the consultation have to be done face-to-face, by video or by telephone?

Face-to-face consultations should be avoided if possible but for some groups of patients, this will be the only way to ensure good communication and to prevent them from being

disadvantaged. We anticipate that most consultations will be by telephone, but video consultation can be used where both the trust and the patient have this facility

7. What if the patient does not want treatment?

Patients can choose to delay or decline treatment. We advise that the patient is informed of any alternatives to surgery (if available) and any risks associated with delays in treatment. A clinical decision should be made on whether the patient should be discharged back to primary care or remain under review. Patient initiated follow up may be a good option for some.

8. What happens to the PTL position on the waiting list?

The patient continues to wait for treatment and is therefore visible and reported as part of national weekly and monthly returns. This does not alter current reporting for patients who have chosen to defer treatment.

Appendix C: Supporting distressed patients

Understandably some patients may become distressed or angry when contacted about their surgery.

Trusts can give their patients support via PALS, and should ensure this team understands the validation process.

Ensure you have information leaflets outlining the complaints process, and can post these to patients if required.

Make sure that junior staff have someone to escalate any concerns to.

These are useful resources:

- https://www.bmj.com/content/333/7563/s64
- https://www.bma.org.uk/advice-and-support/your-wellbeing/insight-and-advice/firsttimes/managing-angry-patients

Appendix D: Waiting list prioritisation*

<1 month	P2
<3 months	P3
>3 months Delay 3 months possible	P4
Patient wishes to postpone surgery because of COVID-19 concerns**	P5
Patient wishes to postpone surgery due to non-COVID-19 concerns**	P6

^{*} Based on the prioritisation tool produced by the Federation of Surgical Specialty Associations and endorsed by all surgical colleges: https://fssa.org.uk/ userfiles/pages/files/covid19/prioritisation master 240720.pdf

^{**} This decision needs to be discussed with the patient within six months.

Appendix E: Resources for trusts and patients

For providers	
Shared decision-	Shared decision making infographic
making	Shared decision making infographic https://www.personalisedcareinstitute.org.uk
3	https://www.e-lfh.org.uk/programmes/shared-decision-making/
Clinical prioritisation	Surgical prioritisation guidance
Cirrical prioritisation	Evidence-based interventions guidance
Templates	Standard letter to patient following waiting list review (to be copied
Templates	to GP)
	Standard letter inviting patient to consultation
	Standard letter inviting patient to consultation Standard letter advising patients how to get ready for surgery
Proporing for	
Preparing for	https://www.nationalvoices.org.uk/sites/default/files/public/publicat
consultation	<pre>ions/the_doctor_will_zoom_you_nowtop_tips.pdf https://www.nationalvoices.org.uk/publications/our-publications/dr-</pre>
For notice to	will-zoom-you-now-getting-most-out-virtual-health-and-care
For patients	https://www.php.uk/panditions/aboutty/
Obesity	https://www.nhs.uk/conditions/obesity/
Diabetes	https://www.nhs.uk/conditions/diabetes/
Smoking	https://www.nhs.uk/conditions/stop-smoking-treatments/
Alcohol	https://www.nhs.uk/conditions/alcohol-misuse/
Physical activity	https://www.nhs.uk/live-well/exercise/
	https://cpoc.org.uk/patients/fitter-better-sooner-toolkit
	https://www.nhs.uk/better-health/
Self-management	https://www.nhs.uk/conditions/stress-anxiety-depression/improve-
	mental-wellbeing/
	https://www.csp.org.uk/conditions/managing-pain-home
Mental health	https://www.nhs.uk/conditions/stress-anxiety-depression/improve-
	mental-wellbeing/
Learning disability	https://www.nhs.uk/conditions/learning-disabilities/
Older people and those	https://www.cqc.org.uk/guidance-providers/adult-social-
with a disability	care/access-hospital-care-treatment-older-disabled-people-living
Pre-operative guide for	https://cpoc.org.uk/patients/guidance-adult-patients-having-
patients (adults)	operation-during-covid-19
Pre-operative guide for	https://cpoc.org.uk/my-operation-and-coronavirus-guidance-
patients (young people)	young-people-undergoing-surgery-during-covid-19-pandemic
Preparing for surgery	https://cpoc.org.uk/patients/fitter-better-sooner-toolkit
NICE guide on	https://www.nice.org.uk/guidance/ng180
perioperative care (Aug	
2020)	
Shared decision	https://www.choosingwisely.co.uk/about-choosing-wisely-uk/
making	