

Clinical Outcome Data Capture for patients with Inflammatory Bowel Disease

The Association of the Coloproctology of Great Britain & Ireland are delighted to be working in collaboration with Amplitude Clinical Outcomes.

As an association we are keen to implement a UK registry of patients with IBD to define, improve and maintain the quality of care for individuals having operations for their inflammatory bowel disease.

What are clinical outcome measures?

Clinical outcomes are a method of recording and comparing your physical progress and wellbeing, as well as your quality of life, before and after a clinical intervention/treatment.

Your experience as an IBD patient and the outcome of your treatment is important to us. We aim to collect standardised comparable data across the UK over a long period of time to improve the care we as clinicians offer you.

These outcomes inform us of what patients think of the long-term effectiveness of interventions, the best treatments to offer future patients and to allow us to generally improve the care we offer.

A note from your consultant and treating team

Your experience as my patient and the outcome of your treatment is important to me. It is important that we can demonstrate the quality of our treatment to you and others.

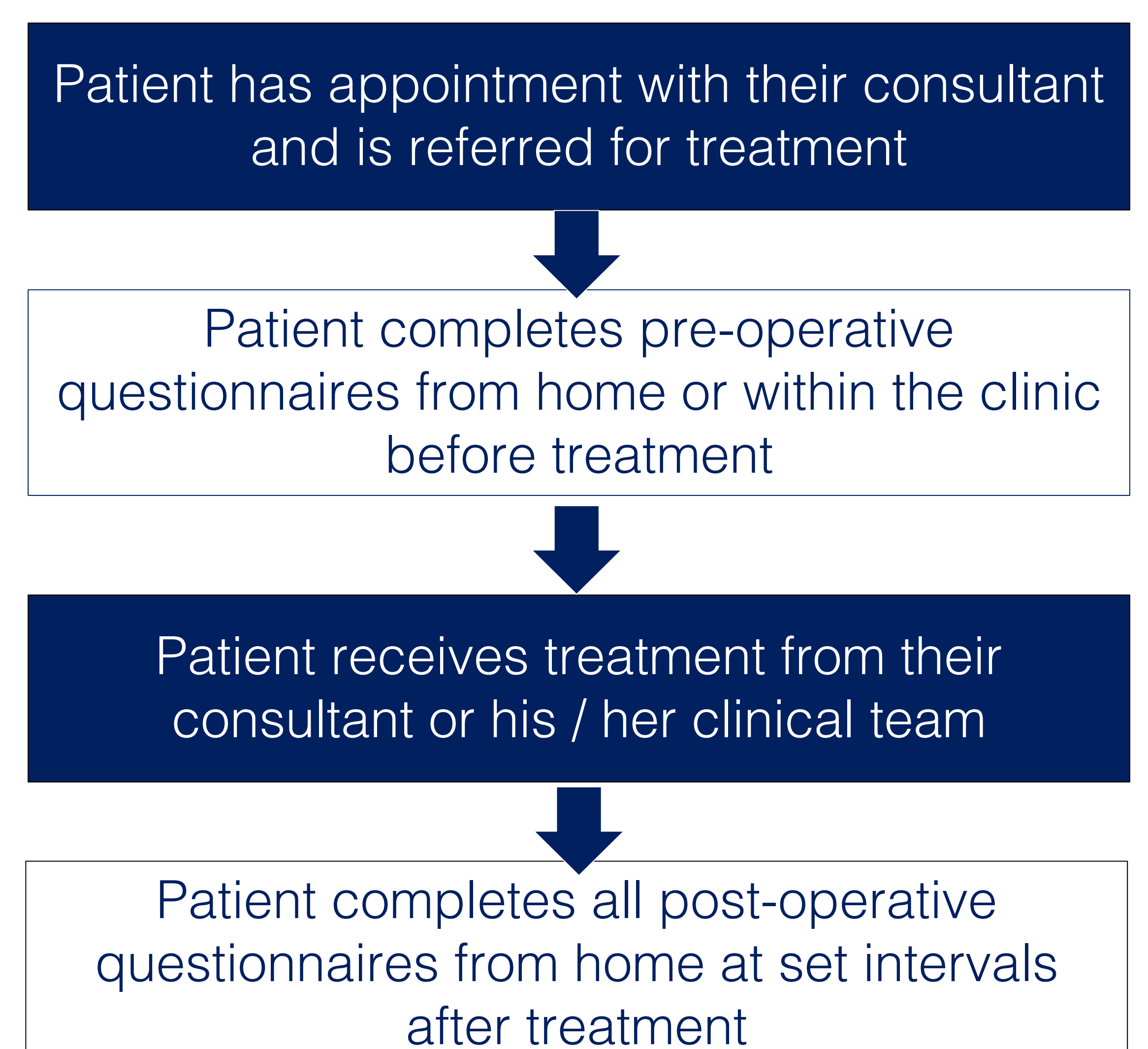
Using simple computer software, we can track your recovery far into the future, giving you peace of mind and allowing us to ensure you are receiving quality care.

How it works

The flow chart to the right gives you an idea of how the process works. At every clinical interaction/treatment we will refer to the registry and decide together how to input the various bits of information (variables).

Giving your consent is voluntary and you should be asked by your hospital if you would like to give you agree.

Declining to take part will not affect the care you receive and you can withdraw your consent to have your personal details held on the database at any time by contacting Amplitude below.



Who to contact for further information

For Patients:

Nicole Taub from the ACPGBI

e. NTaub@acpgbi.org.uk

For Clinicians:

Amplitude Customer Support team

e. customer.support@amplitude-clinical.com

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Frequently asked questions

Why have I been approached?

As you are considering having an operation. This doesn't necessarily mean you will have/opt for surgery just that you are be considered for it.

What will happen to me if I take part? What do I have to do?

Your consultant will discuss this with you and provide you with this leaflet. It is essentially a series of short questionnaire but if you decide that you are happy to take part, you will be guided through the process.

What are the possible disadvantages and risks of taking part?

None. Replying to an email intermittently which will take a few moments.

What are the possible benefits of taking part?

Your team will receive automatic feedback and our hope is that it will facilitate communication between the doctor and the patient.

Who is organising and funding this database?

We are very grateful to the Ileostomy and Internal Pouch Association (IA) charity and the Association of Coloproctology of Great Britain and Ireland for their kind sponsorship.

What if something goes wrong and I wish to complain about the database?

Should you have any complains please bring them to the attention your surgeon or the ACPGBI via the contact emails below.

What are the considerations for data protection?

All healthcare processes abide by GDPR and your Consultant is registered with the ICO (Information Commissioners Office) as a data controller. Your data is completely secure and will not be shared identifiably.

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