North Thames
Genomic Medicine Service

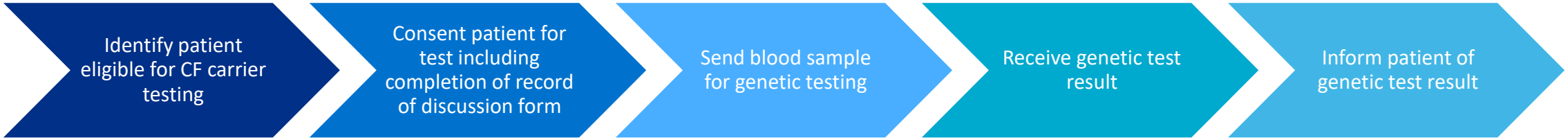
# Bitesize basics - Consenting for Cystic Fibrosis carrier testing

Published 05 September 2024. Content is current at time of publication.
Go to our **WEBSITE** for up-to-date genetic testing information.

# This is one segment of an eight-part bitesize basics learning series for Primary Care, focusing on ordering Cystic fibrosis (CF) carrier testing:

1. How genetic testing is changing in Primary Care
2. What is CF carrier testing?
3. Should I order a CF carrier test?
4. Is ethnicity important in CF carrier testing?
5. Consenting for CF carrier testing
6. How to order a CF carrier test?
7. What do I do with a CF carrier test result?
8. Genetics quiz – CF carrier testing

# CF carrier testing pathway




Consenting a patient for CF carrier testing is an important step in the testing pathway.

It is essential that this discussion takes place prior to ordering this test.

# Consenting essentials

You can use this checklist to discuss with patients whilst consenting:

- ❑ Explain what CF is and how CF is inherited through families
- ❑ Explain why your patient is eligible for genetic testing
- ❑ Explain what the genetic test looks for
- ❑ Explain how long the test takes
- ❑ Check if there is anything about having a CF carrier test that worries them

# Consenting: Patient questions

Some common questions patients may ask during a genetic testing consent conversation:

- Why am I being offered this test?

*A: Which test directory criteria does your patient meet? What does this mean for them?*

- Do I have to have the test?

*A: Genetic testing should always be a patient's choice. They have the option to take time to think about whether or not they would like a test.*

➢ What does the test look for?

A: *The 50 most common variants in the CFTR gene that cause cystic fibrosis in the Northern European population.*

➢ What will my results mean?

A: *Your patient will either receive a result that confirms their carrier status or reduces the chance that they are a carrier.* (This is covered in more detail in the "What do I do with a CF carrier test result?" resource in this series.)

➢ Is it my responsibility to tell my relatives about my result?

A: *Yes, it is important that a patient is prepared to share their result with family members, so that their relatives have an opportunity to have CF carrier testing.*

Information correct at time of publishing. The number of common variants tested may change over time.

# Consenting: Record of Discussion

During your discussion with the patient, you should also complete a “record of discussion” (RoD) form.

A complete RoD form should be saved as part of the patient’s clinic notes for their appointment.

# Where can I find the RoD form?

An electronic copy of the current "non-WGS record of discussion" form can be found here:

https://norththamesgenomics.nhs.uk/genetic-test-ordering/sending-a-sample/

This form is designed to support and document the consent conversation. You can use this form during your discussion with the patient.

# The record of discussion form

| | |
|---|---|
| Patient Name | |
| Date of Birth: | |
| Medical record Number: | |
| NHS Number: | |

NHS
North Thames
Genomic Laboratory Hub

## Record of discussions form to summarise clinical consent

This form relates to the person being tested.
All of the statements below remain relevant even if the test relates to someone other than yourself, for example your child or dependent.

I have discussed genetic testing with my health professional and understand that:

***Family implications***
1.The results of my test may have implications for me and members of my family. I understand that my results may also be used to help the healthcare of members of my family.

***Uncertainty***
2. The results of my test may have findings that are uncertain and not yet fully understood. To decide whether findings are significant for myself or others, my data may be compared anonymously with other patients' results across the country and internationally. I understand that this could change what my results mean for me and my treatment over time.

***Unexpected information***
3. The results of my test may also reveal unexpected results that are not related to why I am having this test. These may be found by chance and I may need further tests or investigations to understand their significance.

***DNA storage***
4. Normal NHS laboratory practice is to store the DNA extracted from my sample even after my current testing is complete. My DNA might be used for future analysis and/or to ensure that other testing (for example that of family members) is of high quality.

***Data storage***
5. The data from my test will be securely stored so that it can be looked at again in the future if necessary.

***Health records***
6. Results from my genomic test will be part of my patient record, a copy of which is held in a national system only available to healthcare professionals.

I agree to genetic/genomic investigations*:

**insert details here, e.g. to investigate the cause of my child's developmental delay / family history of cancer /heart disease etc*

**Patient/parent signature:**

Patient/parent name:

Date:

**Discussion undertaken by:**

Clinician Signature:

Clinician Name:

Consultant's name (if different from the above):

Date:

**Genetics Reference Number:**

☐ Recorded remotely by clinician, no patient signature

1 copy for notes, 1 copy for patient to retain

V4.03

NHS
North Thames
Genomic Medicine Service

# Contacts and information

To contact the North Thames Genomic Medicine Service, email: nt-gmsa@gosh.nhs.uk

To contact the North Thames Genomic Medicine laboratory hub, email: gos-tr.norththamesgenomics@nhs.net

Visit our website: https://norththamesgenomics.nhs.uk

For a more comprehensive understanding of the information provided in this bitesize resource, please download our *CF Carrier Testing Toolkit:*

https://norththamesgenomics.nhs.uk/wp-content/uploads/2024/05/20240905-NTGMS-Toolkit-Cystic-Fibrosis-CF-Carrier-Testing-in-Primary-Care.ppt

Primary author: Ailidh Watson, Genetic Counsellor, GOSH.

NHS
North Thames
Genomic Medicine Service