North Thames
Genomic Medicine Service

Bitesize basics - Consenting for Cystic Fibrosis (CF) carrier testing

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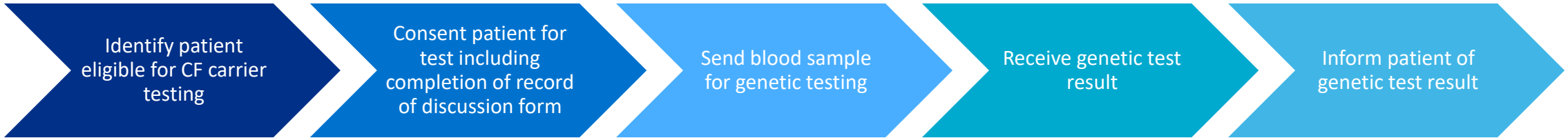
Go to our **WEBSITE** for up-to-date genetic testing information.

This is one segment of an eight-part bitesize basics learning series for Primary Care, focusing on ordering 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: HCP essentials

HCP knowledge checklist to discuss with patients during consenting:

- ❑ Explain what cystic fibrosis 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 testing takes,
- ❑ Discuss with your patient if they would like to have a genetic test, to better understand whether they could be a CF carrier,
- ❑ Discuss with your patient if there is anything about having a CF carrier testing that worries them.

Consenting: Patient questions

Some common questions patients 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 a test decision.

- 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, as we cannot contact family members on their behalf.*

Information correct as of 27 May 2024. The number of common variants tested may change over time.

Consenting: Record of Discussion

After 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.

Tip! Use the RoD form during the consent conversation

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

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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

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Contacts and information

Contact us, email: nt-gmsa@gosh.nhs.uk

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

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

Coming soon! Our *CF Carrier Testing* module video.

Primary author: Ailidh Watson, Genetic Counsellor, GOSH.

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