



UK CF Registry

Demographics

Encounters are locked annually by the Registry team as part of the reporting cycle. If you require a record to be edited please contact registry@cysticfibrosis.org.uk

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Site: Aberdeen Royal Infirmary. Case ID: 220402

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1. Patient information	2. Genotyping	3. Diagnosis
CONSENT		
1.1. Has a valid UK CF Registry consent form been signed and dated for this patient?	<input checked="" type="radio"/> Yes <input type="radio"/> Consent withdrawn <input type="radio"/> Not known	?
1.2. Upload a scanned copy of the consent form (optional)	<input type="button" value="Choose File"/> No file chosen <input type="button" value="Upload"/> <input type="checkbox"/> Not available	?
PATIENT INFORMATION		
Basic information		
1.3. Surname of patient	<input type="text"/>	?
a. Surname of patient at birth (if different)	<input type="text"/>	
1.4. Forename of patient	<input type="text"/>	?
1.5. Middle name of patient	<input type="text"/> <input type="checkbox"/> Not known	?
1.6. Gender of patient	<input type="radio"/> Male <input type="radio"/> Female	?
Age		
1.7. Enter DOB	<input type="text" value="DD/MM/YYYY"/>	?
1.8. Ethnicity of patient	<input type="radio"/> White (British) <input type="radio"/> Asian (Other) <input type="radio"/> White (Irish) <input type="radio"/> Mixed (White and Black Caribbean) <input type="radio"/> White (Other) <input type="radio"/> Mixed (White and Black African) <input type="radio"/> Black (Caribbean) <input type="radio"/> Mixed (White and Asian) <input type="radio"/> Black (African) <input type="radio"/> Mixed (Other) <input type="radio"/> Black (Other) <input type="radio"/> Other (Chinese) <input type="radio"/> Asian (Indian) <input type="radio"/> Other (Any other ethnic group)	?

Asian (Pakistani) Prefer not to say

Asian (Bangladeshi) Not known

i. If ethnicity is 'Other', please specify

ID Numbers

1.9. NHS number of patient Not known or not applicable

1.10. CHI number Not known or not applicable

Registry Team alerted to duplicate NHS/CHI number? Email sent Email not sent

Address Details

1.11. Postcode of patient

1.12. Was the patient born in the UK Yes No

a. County of birth

Select...

i. Other details, please specify

b. Birth country

Select...

i. Other details, please specify

GP Information

1.13. GP postcode Not known

GENOTYPING

2. Has the patient been genotyped? Yes No

2.1. Date genotyping sample taken Not known

2.2. How many mutations have been identified?

2.3. Genetic mutation 1 (Legacy/Protein/cDNA)

a. Genetic mutation 1 specify

Mutation 1 Poly-T tract

5T

7T

9T

Not known/Not applicable

2.4. Genetic mutation 2 (Legacy/Protein/cDNA)

a. Genetic mutation 2 specify

Mutation 2 Poly-T tract

5T

7T

9T

Not known/Not applicable

2.5. Genetic mutation 3 (Legacy/Protein/cDNA)

a. Genetic mutation 3 specify

Mutation 3 Poly-T tract

5T

7T

9T

Not known/Not applicable

Exit

BIRTHWEIGHT

3.0. Birthweight

(kg) Not known

?

DIAGNOSIS

3.1. Date of Diagnosis

?

a. Date diagnosis of CF was confirmed with the patient or parent

b. Indicate if diagnosis date is accurate or estimated

Estimated Exact

3.2. How did the patient present with CF?
Check all applicable

?

- Family history
- Newborn screening
- Not known
- Genotype
- Prenatal / antenatal
- Other

a. Other CF associated complications / signs
Check all applicable

?

- Persistent or acute respiratory infection
- Oedema
- Electrolyte imbalance
- Failure to thrive/malnutrition
- Bronchiectasis
- Pancreatitis
- Fertility investigations
- Liver disease
- Meconium Ileus
- Surgically
- Medically
- Not known
- Nasal polyps
- Rectal prolapse
- Steatorrhea/abnormal stools/malabsorbtion

How was Meconium Ileus complication managed?

If 'Other', please specify

Diagnostic chloride sweat test

3.3. How many diagnostic chloride sweat tests have been done?

Select... ▼

?

	Date		Value
Test 1	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 2	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 3	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 4	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known

Test 5 Not known

(mmol/litre)
 Not known

New born screening

3.4. NBS undertaken?

Yes No

a. If no, why not?

- Born before NBS started
- Born outside UK
- NBS declined
- Appropriate sample not obtained before 8 weeks
- Not known

a. NBS Result

- Carrier
- Equivocal
- Suspected
- Not suspected
- Not known

i. Suspected - IRT?

Select...

ii. Carrier - IRT?

Select...

iii. Equivocal - IRT?

Select...

iv. Not Suspected - IRT?

Select...

b. NBS IRT results

i. Date 1st IRT sample taken

Not known

a. IRT result

(ng/ml or µg/l - mean value)

ii. Date 2nd IRT sample taken

Not known Not taken

a. IRT result

(ng/ml or µg/l - mean value)

c. Laboratory Details

i. Which laboratory was the sample sent to?

Select...
 Not known

a. if other,

ii. Date sample sent to Lab

Not known

3.5. Referral Details

a. Date patient referred to regional CF team

Not known

b. Date patient seen by regional CF centre

Not known

c. Date patient seen by local CF centre

Not known
 N/A (not shared care)

Faecal elastase

3.6. Was a diagnostic faecal elastase sample taken?

Yes No

a. Date of sample

Not known

b. Result

(mcg/ml) Not known

OUTCOME

Death

3.7. Has the patient died?

Yes No



a. Date of death

DD/MM/YYYY

i. Is date of death an estimate?

Yes No

b. Cause of Death

Select...

If 'Cancer', please specify

- Bowel
- Breast
- Brain
- Cervical
- Liver
- Lung
- Lymphoma
- Oesophageal
- Ovarian
- Pancreatic
- Skin
- Testicular
- Other

Other

c. ONS Date of Death

01/01/0001 00:00:00

d. ONS Primary cause of death

Diagnosis reversal

3.8. Diagnosis reversed?

Yes No



a. Diagnosis reversal date

DD/MM/YYYY

b. Reason for reversal of diagnosis?

Select...

i. If 'Other', please specify

Not known