

# Peer Review Report

The James Cook University Hospital  
Middlesbrough

October 2012

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# I. Executive Summary

## I.1 Overview of the service (Maximum 150 words)

The James Cook University Hospital Cystic Fibrosis unit currently provides sole care for around 60 children (aged 0 - 19) over a thirty mile radius.

This unit is not linked to a specialist centre nor does it work with any other network teams. The clinicians and management team at JCUH have an active children's strategy for development and expansion and have the capacity to expand the CF service should this be deemed appropriate.

They have a full multi disciplinary team although they are lacking in resources in some areas.

## I.2 Good Practice Examples (Maximum 50 words)

1 This is a long standing, dedicated, cohesive team providing highly individualised care.

2 The team is supported by AHPs with independent prescriber status.

3 JCUH has excellent inpatient facilities (with en suite facilities), with capacity for expansion, should this be required.

## I.3 Key Recommendations (Maximum 200 words)

Issues relating to the Red and Amber ratings in 2.3 & 2.4 below, should be given careful consideration and addressed as soon as possible.

The MDT is reasonably resourced with regard to its numbers, however clinical psychology is currently at 0.2 WTE. This should be reviewed.

This service is small compared to other specialist centres however it is rather large for a network; there is currently no formal shared care arrangement with any specialist centre. Due to the number and improved clinical status of paediatric patients the unit does not see many of the more complex or unusual complications of CF; these cases should continue to be referred to the specialist CF service at the Newcastle or Leeds.

## I.4 Areas for further consideration (Maximum 200 words)

Treatment should be maximised during IVABs according to the UK CF Standards of Care (2011) i.e. attention to physiotherapy and dietetics.

The Peer Review panel suggests a review of the provision of schooling to inpatients of less than two weeks.

The transition process is very new and will need testing and refining.

The on call process should be fully reviewed with particular focus on an expanding service.

## 2. Performance against CF Standards of Care

### 2.1 Models of Care

**Reported Score:**

**Reviewed Score:**

#### Summary

Although the reviewed score remains satisfactory the panel would recommend that the annual review process be formalised to fully meet the standards of care (2011). Medical and dietetic reports are not always available in a thorough and timely fashion.

There should always be a formal post annual review discussion between the parents and the consultant, to formulate a management plan for the coming year.

### 2.2 Multidisciplinary care

**Reported Score:**

**Reviewed Score:**

#### Summary

Although the Cystic Fibrosis Team at The James Cook University Hospital do not have documented pathways for other specialist referrals, the statement submitted to this peer review panel regarding this could easily be reformatted into a referral pathway

### 2.3 Principles of care

**Reported Score:**

**Reviewed Score:**

#### Summary

A new transition process has recently been introduced; it is hoped that this will eradicate the previously highlighted issues regarding discussion of male infertility prior to transition.

The current UK CF Standards of Care (2011) state that screening for reduced BMD using DXA scans should be initiated from 10 years of age, with serial measurements every 1-3 years. As currently this standard is only achieved in 3% of the James Cook CF patient cohort, this process must be incorporated into the annual review as soon as possible.

## 2.4 Delivery of care

**Reported Score:**

**Reviewed Score:**

### Summary

Although many of the areas of this section do comply with the UK CF Standards of Care (2011), the red rating mainly reflects the way the unusual current model of inpatient care adopted by JCUH for a significant proportion of routine IVABs. Whatever the reason for admission, whether social or clinical, all patients undergoing hospital IV antibiotics should receive a comprehensive care plan as outlined in the the UK CF Standards of Care (2011). This includes review twice weekly by a CF consultant, twice daily physiotherapy and a twice weekly review by a dietitian.

The recent appointment to an administration and clerical post should improve the % of clinic letters sent out within 10 days of consultation (currently only 32%) This should be reviewed.

## 2.5 Commissioning

**Reported Score:**

**Reviewed Score:**

### Summary

The James Cook University Hospital do not formally share care with any other institution, whether specialist centre or network clinic.

Future commissioning arrangements for the CF service at JCUH will be based on a decision made between the specialist commissioners in the North and the JCUH management team.

## 3. Registry data

<b>BMI</b>	Adult sites only	Number of patients and % attaining target BMI of 22 for Females and 23 for Males		
		Number of patients and % with BMI <19 split by sex		
	Paediatric Sites Only	Median BMI percentiles in age categories	0-3 years	no data
			4-7 years	76.4
			8-11 years	40
			12-15 years	no data
16-19 years	no data			
<b>FEV1</b>	Paediatric Sites Only	Number of patients and % with FEV1 >85% by age group and sex	0-3 years	0
			4-7 years	0
			8-11 years	0 females, 5 male
			12-15 years	1 female, 3 males
	Adult Sites Only	Median FEV1% pred at age 16 years split by sex		
			Number and Median(range) FEV1 % pred by age range and sex	
<b>Data Input</b>	Number of complete annual data sets taken from verified data set expressed as a % of actual patient numbers		96%	
	Number of newborn screened patients since last data set (further verification is needed regarding recent diagnosis, not from newborn screening, where information will not be included on the registry. This query has been referred to the Registry Steering committee)		unknown	
<b>Pseudomonas</b> Chronic PA is 3+ isolates between 2 annual data sets	Adult sites only	Number and % of patients with Chronic PA infection		
		Number and % of patients with Chronic PA infection on inhaled antibiotics		
	Paediatric Sites Only	Number and % of patients with Chronic PA infection on inhaled antibiotics by age group	0-3 years	0/0
			4-7 years	0/0
			8-11 years	0/0
			12-15 years	1 (100%)
16-19 years	2 (100%)			
<b>Macrolides</b>	Number and % of patients on chronic macrolide with chronic PA infection		1 (3%)	
	Number and % of patients on chronic macrolide without chronic PA infection		2(4%)	

# 4. Delivery against professional standards/guidelines not already assessed

## 4.1 Consultants

1. Job plan. There are 2 consultants with 0.6 WTE for 61 patients. This is in line with CF Trust Standards of Care 2011 recommendations (0.8/75).
2. Training/experience. The lead consultant is experienced. The recently appointed second consultant has experience but was not a grid trainee.  
  
Clinical experience in the unit will inevitably be limited by the relatively small size of the clinic, meaning that uncommon complications will not be encountered. They now have 2 patients with CFRD, one with NTM and have had patients with ABPA in the past. Nevertheless this means that continued liaison with a CF Specialist centre is important.
3. Cover for annual leave. The 2 consultants cover for each other, which would be problematic if leave dates clashed.
4. On call cover. On call cover is provided by the 2 consultants and 2 CF nurses, for the families and ward teams. The 2 consultants only cover ward duties 20 weeks per year so 32 weeks of the year are covered by the general paediatricians. The nurses 'know which of the consultants are around' although there is no formal rota. This cover is for telephone advice only (unless one of the consultants is actually on call that evening).
5. Inpatients – seen by a doctor 7d/week. They are seen by a trainee but these are general paediatric trainees so their CF experience is likely to be limited. 3 monthly IVAB patients are not necessarily seen by a doctor. There are no respiratory grid trainees but the trainees often have an 'interest' in resp paed. Longlines are done by a nurse, consultants or an SpR. In a unit where the trainees are not respiratory trainees, it would be sensible for nurse specialists to be more active on the ward rounds.
6. Consultant WR 2/week. Not necessarily seen by a consultant 2/week, especially those having 3 monthly IV antibiotics. Patients are prioritised to be at school during the day. Those having regular IVABs are usually the sicker patients, or those not receiving much treatment at home, so are often the ones needing the closest supervision.
7. Intermediate grade cover. See 5.
8. Team leader/director. This is Dr Hampton.
9. Learning/networking. 80% MDT have attended a CF educational meeting. Consultant attendance at NACFC or ECFS alternate years. Attendance at CF Trust Centre director's meeting the last 2 years.
10. Miscellaneous.
  - Bronchoscopies rarely done and only by the second consultant.
  - No local guideline, they use the Leeds management book and have some newly written SOPs.
  - Clinic letters sent within 10d – only 32%.

## 4.2 Specialist Nursing

1. Both of the CF Nurses are members of the UK CFNA and attend meetings annually. One is a Committee member of this group as well as chair of Northern CF Nurses Group.
2. There is always at least one CFNS present at MDT meetings where patients are discussed comprehensively - both in patients and out patients.
3. Both CFNS are a Band 7. They have designated clinics based on geographical area but cross cover for each other for annual leave. There is always a CFNS in clinic. Children and families know both nurses.
4. Bi-annual attendance at European CF conference. Regularly attend Northern CF meetings.
5. Involved in Torpedo trial and have recently completed Tides study. Transition is a major service improvement in the last 5 years and a comprehensive transition document has been written. Transition clinics are due to start next year. Both are in the second year of their MSc and will be looking at aspects of service evaluation as part of this.
6. Both CFNS are heavily involved in newborn screening, diagnosis and transition. For family planning and genetic advice they provide basic information and refer onwards as appropriate. Although small numbers they have had experience of transplantation and often will initiate initial discussion during a home visit. Experience of end of life care but this has declined over recent years.

### Good practice

The nurses have been actively involved and worked hard to develop transition. This is a work in progress and a transition clinic is due to start next year. However not all patients are fully transitioning at the age of 18.

There are comprehensive home IV guidelines in place.

Both nurses are committed to the service and improving the patient experience. Both nurses are non medical prescribers.

### Areas for improvement

Continue to develop transition,

Actively contribute to the annual assessment process.

Due to a lack of admin support a large proportion of the nurses' time has been spent on admin activities. With more admin support for the team more ward time should be considered.

## 4.3 Physiotherapy

Two physiotherapists, equivalent of IWTE Band 7, provide cover for the CF unit, cross covering each other during periods of absence. They undertake all outpatient work, provide an outreach service, attend MDT meetings, take responsibility for nebuliser equipment / medication and undertake most of the spirometry within the unit. In addition one physiotherapist has a Supplementary prescribing role and takes responsibility for prescription of nebulised medications and reversibility testing. Day to day treatment for in patients is however undertaken by respiratory physiotherapists from acute services. There is no regular attendance at ward round (very few patients in at any one time) but all patients are discussed at the weekly MDT. Exercise facilities are available during admission. Both physiotherapists are clearly key members of the MDT and are integrally involved in patient care throughout all the key life stages

Both are ACPCF members and although have not been able to attend recent ACPCF meeting do regularly attend other regional or national study days. Both have attended one European CF conference in the past 5 years.

Areas of good practice:

- Supplementary prescribing role
- Provide a very accessible service with evening clinics for teenagers/young adults
- Know the patients very well and offer an individualised service

Areas for consideration:

Inpatient arrangements are unusual as in most centres the specialist CF physiotherapist would have a greater involvement on a day to day basis. IVs are often undertaken in hospital rather than home for social reasons -these children may not get twice daily treatment if "well." Children requiring three monthly IVs inevitably tend to be those with potentially more severe disease, therefore during admissions, whatever the reason, it may be opportunistic to intensify/maximise treatment.

The transition process is relatively new and may need refining when established

As the physiotherapist are largely responsible for the Spirometry, regular update training should be considered

## 4.4 Dietetics

Dietetic service split between 3 individuals and 3 sites, Middlesborough, Stockton and Northallerton. Reports good ability to cover the service but raises questions about fragmenting and dilution of CF knowledge.

Dietitians attend CF MDTs and carry out annual reviews on the majority of CF children.

Not attending national CF dietitians meetings. One of three is a member of the UK dietitians CF interest group. The other 2 have applications in process

Evidence provided for attendance at European CF Conference and northern region CF meetings.

Evidence of active participation in audit and service improvement for CF patients eg. Vitamin D audit.

The Teeside CF service as a whole has only recently implemented a transition process and therefore does not currently have a transition clinic in place.

Good practices noted

Dietitian present at all clinics and able to see all patients owing to small patient numbers (6-8 per clinic)

Evening clinics reduce interruption to schooling and improve accessibility for adolescents.

Vitamin D audit

Areas for improvement

Attend national CF dietitians meetings

Catering for the increased nutritional needs of children with CF as inpatients - increase range of menu options, savoury snack foods and food availability in the evenings.

0.2 dedicated dietetic time from previous peer review, remaining 0.3 is 'historical'. In the current economic climate this time needs protection and plans made to expand for increased patient numbers.

Reporting of annual review needs to be formalised.

Provision of specialist services eg infants with meconium ileus currently have to go to Newcastle for neonatal surgery. (Gastrostomy insertion can be done on site)



## 4.5 Pharmacy

The CF Pharmacist (JP) is allocated 0.2wte currently, with a business case in progress to increase this to 0.3wte. The pharmacist is a member of the CF Pharmacists Group and attends educational meetings such as ECFS (Prague) and CFPG Study Days.

The pharmacist introduces themselves to all newly diagnosed patients as part of the MDT.

The pharmacist attends clinic at the CF teams request and is available to see patients as needed.

The pharmacist attends MDT meetings following clinics at James Cook (but not the other 2 hospitals) and the three monthly team meetings.

The pharmacist sees all admitted patients and performs a level 2 medicines reconciliation with them. If the patient is due an annual review during the admission the pharmacist will perform a full medicines use review, however, this does not happen for patients not admitted to the unit.

The pharmacist is a non-medical prescriber and organises the homecare service for patients being discharged on intravenous antibiotics.

The service currently prescribes all high cost nebs for their patients and have a budget allocated for CF medicines. The pharmacist analyses the spend against the budget.

The pharmacist does not currently write the medicines related patient information leaflets but proofreads any as requested.

The pharmacist is the named pharmacist for the TORPEDO study and was involved in an adherence study which was presented as a poster at ECFS (Prague).

## 4.6 Psychology

1 Recently joined the UKPP-CF, although have attended events in the past.

2. All CF team meetings attended, MDTs where possible and meet on regular (monthly) planned basis with specialist nurses for consultation and case discussion. No attendance at ward rounds routinely.

3. No cover is currently available for absence.

4. Copenhagen, Prague and Hamburg conferences attended. Other UK study days in past. Adherence day in Birmingham in October 2012 - attending with team member.

5. Several small projects and larger piece of work on adherence. A DVD was made with teenage patients and an experiential adherence study undertaken with team which the psychologist planned and coordinated. Paper presented at Prague conference. This led, as part of the team development process, to patient centred improvements in clinic appointments and service quality.

6. Due to limited psychology time available, involvement in key life stages is determined by need. Team refer patients having difficulty with diagnosis. In the past the psychologist worked actively with transplant patients but not recently as there is now a local adult CF service. Often involved in transition issues both in consultation sessions and direct work, as well as thinking about service delivery for the transition stage of care.

Good practice: Psychology is well established in the team and work undertaken is done flexibly to help address patient difficulties in the way most appropriate to patient context. Regularly do joint appointments with CF nurses and patients/families. 'Psychological' approaches and thinking are embedded in team processes.

Areas for Improvement: More resource would facilitate involvement at diagnosis and annual screening.

## 4.7 Social Work

There is currently no Social Work service in place. The CF nurses have tended to offer support with issues such as claiming benefits, completing benefit forms and writing supporting letters for families. However, according to the Staffing Action Plan, and discussion with one of the CF Nurses, 4 sessions from Barnado's Social Work team have been negotiated, and are due to be implemented soon. These social workers have experience of CF from their work with the Newcastle CF service, and it is anticipated that their input will increase the team's understanding of the role of social workers in CF and what they can offer.

## 5. User feedback

	Completed surveys (by age range)			
	0-5	6-10	11-15	15+
Male	4	3	3	
Female	3	3		

	Overall Care			
	Excellent	Good	Fair	Poor
From your CF team	15	3		
From the ward staff	10	5	2	
From the hospital	9	5	2	

### Areas of excellence

- 1 CF Team – dedicated, approachable, knowledgeable.
- 2 Out of hours service – able to contact own CF Team member rather than ward staff.
- 3 Ward facilities

### Areas for improvement

- 1 Home IV antibiotics – pre-filled syringes not always available to all patients.
- 2 IP care - not seeing all team members due to going off to own school. If ill enough for IVs then input from all MDT is felt necessary.
- 3 Ward staff knowledge - to understand CF patient needs.

# 6. Appendices

## Appendix I

### Performance against standards of care

#### I Models of care

Standard	Audit Question	Expected Compliance	Reported Compliance	Actual Compliance	Panel Comments
<b>I.1 Models of care</b>	% patients seen at least once a year by the specialist centre for an annual review.	90%	Green	Green	
<b>I.2 Specialist Centre Care</b>	% of patients with completed data on the registry.	90%	Green	Green	
<b>I.3 Network Clinics</b>	% of patients who have had a discussion with the consultant and an action plan following annual review.	90%	Green	Amber	There should always be a formal post annual review discussion between the parents and the consultant, to formulate a management plan for the coming year.

## 2 Multi-disciplinary care

Standard	Audit Question	Expected Compliance	Reported Compliance	Actual Compliance	Panel Comments
<b>2.1 Multi-disciplinary care</b>	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include AR). Do staffing levels allow for safe and effective delivery of service?	95%	Green	Green	
	% of MDT who receive an annual appraisal.	100%	Green	Green	
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Red	Although the Cystic Fibrosis Team at The James Cook University Hospital do not have documented pathways for other specialist referrals, the statement submitted to this peer review panel regarding this could easily be reformatted into a referral pathway.
	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the CF Trust standards.	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Green	
	% patients with CFRD reviewed at a joint CF / Diabetes clinic.	100%	Green	Green	

### 3 Principles of Care

Standard	Audit Question	Expected Compliance	Reported Compliance	Actual Compliance	Panel Comments
<b>3.1 infection control</b>	% of patients cared for in single en-suite rooms during hospital admission.	100%	Green	Green	
	% of patients cohorted to out-patient clinics according to microbiological status.	100%	Green	Green	
<b>3.2 Monitoring of disease</b>	% successful eradication of 1st isolates Pseudomonas Aeruginosa in the previous 12 months.	100%	Amber	Amber	
	% patients admitted within 7 days following assessment.	100%	Green	Green	
<b>3.3 Complications</b>	% aminoglycoside levels available within 24 hours.	60%	Green	Green	
<b>3.4 CFRD</b>	% patients > 12 years of age screened annually for CFRD.	100%	Green	Green	
<b>3.5 Liver disease (paediatrics)</b>	% patients > 5 years of age with a recorded abdominal ultrasound in the last 3 years.	100%	Green	Green	
<b>3.6 Male infertility</b>	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Red	Red	A new transition process has recently been introduced.
<b>3.7 Reduced BMD</b>	% patients >10years of age with a recorded DxA scan in the last 3 years.	100%	Red	Red	The current UK CF Standards of Care (2011) state that screening for reduced BMD using DXA scans should be initiated from 10 years of age, with serial measurements every 1-3 years

### 4 Delivery of Care

Standard	Audit Question	Expected Compliance	Reported Compliance	Actual Compliance	Panel Comments
<b>4.1 Consultations</b>	% patients seen by a CF consultant a minimum of twice a week whilst in-patient.	100%	Amber	Amber	all patients undergoing IV antibiotics should receive a comprehensive care plan as outlined in the the UK CF Standards of Care (2011)
<b>4.2 In-patients / out-patients</b>	% clinic letters completed and sent to GP / shared care consultant /patient or carer, within 10 days of consultation.	100%	Red	Red	

	% dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	
	% patients reviewed by a CF CNS at each clinic visit.	100%	Green	Green	
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Red	Green	This has been amended to align with the UK CF Standards of Care. Patients have access to CF CNS daily.
	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Green	Green	
	% patients reviewed by a physiotherapist twice daily, including weekends.	100%	Red	Red	all patients undergoing IV antibiotics should receive a comprehensive care plan as outlined in the the UK CF Standards of Care (2011
	% availability of a CF specialist dietician at clinic.	100%	Green	Green	
	% patients reviewed by a CF specialist dietician a minimum of twice per-week during an in-patient stay?	60%	Red	Red	all patients undergoing IV antibiotics should receive a comprehensive care plan as outlined in the the UK CF Standards of Care (2011
	% availability of clinical psychology for in-patients and at clinic.	100%	Green	Green	
	% availability of social worker for in-patients and at clinic.	100%	Red	Red	The issue of availability of a social worker has been addressed
	% availability of pharmacist for in-patients and at clinic.	100%	Green	Green	
<b>4.3 Homecare</b>	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	
<b>4.4 End of life care</b>	% patients referred to palliative care team at end of life.	75%	Green	Green	

## 5 Commissioning

Standard	Audit Question	Expected Compliance	Reported Compliance	Actual Compliance	Panel Comments
<b>5.1</b>	Number of formal written complaints received in the past 12 months.	<1%	Green	Green	
<b>5.2</b>	Number of clinical incidents reported within the past 12 months.	<1%	Green	Green	
<b>5.3</b>	User survey undertaken a minimum of every 3 years.	100%	Green	Green	

## Appendix 2

### Staffing Levels

	75 Patients	150 Patients	250 Patients	The James Cook University Hospital Middlesbrough
Consultant 1	0.5			0.4
Consultant 2	0.3			0.2
Consultant 3				
Staff Grade / Fellow	0.5			
SpR				
Specialist Nurse	2			1.5
Physiotherapist	2			1.0
Physiotherapy assistant				
Dietitian	0.5			0.5
Clinical psychologist	0.5			0.2
Social Worker	0.5			0.4 (underway)
Pharmacist	0.5			0.2
Clinitians assistant				
Secretary	0.5			0.5 (underway)
Admin assistant				
Database coordinator	0.4			
CF Unit manager				

## Appendix 3

### Registry Data

CF Registry Data	
<b>Demographics of Centre</b>	
Number of active patients (active being patients with data within the last 2 years) registered	49 (61 patients in 2012)
Number of complete annual data sets taken from verified data set (used for production of National Report)	47
Median age in years of active patients	10
Number of deaths in reporting year	1
Median age at death in reporting year	10 years 7 months

<b>Age Distribution</b> (Ref: 1.6 National Report)		
Number Adult Sites Only		
Number and % in age categories Paediatric Sites Only	0-3 years	7 (15%)
	4-7 years	10 (21%)
	8-11 years	13 (28%)
	12-15 years	11 (23%)
	16-19 years	6 (13%)



<b>Genetics</b>	
Number of patients and % of Unknown genetics	3 (6%)

<b>BMI (Ref: 1.13 National Report)</b>			
Adult Sites Only	Number of patients and % attaining target BMI of 22 for Females and 23 for Males		
	Number of patients and % with BMI <19 split by sex		
Paediatric Sites Only	Median BMI percentiles in age categories	0-3 years	no data
		4-7 years	76.4
		8-11 years	40
		12-15 years	no data
		16-19 years	n/a

<b>FEV<sub>1</sub> (Ref: Figure 1.14 National Report)</b>			
Paediatric Sites Only	Number of patients and % with FEV1 >85% by age group and sex	0-3 years	0
		4-7 years	0
		8-11 years	0 female, 5 males
		12-15 years	1 female, 3 males
		16-19 years	1 female, 1 male
Adult Sites Only	Median FEV1% pred at age 16 years split by sex		
	Number and Median(range) FEV1 % pred by age range and sex		

<b>Lung Infections (Ref: 1.15 National Report)</b>			
<b>Chronic Pseudomonas aeruginosa (PA)</b>			
Paediatric Sites Only	Number of patients in each age band	0-3 years	7 (15%)
		4-7 years	10 (21%)
		8-11 years	13 (28%)
		12-15 years	11 (23%)
		16-19 years	6 (13%)
	Number of patients with chronic PA by age band	0-3 years	0
		4-7 years	0
		8-11 years	0
		12-15 years	1
		16-19 years	2
Adult Sites Only	Number of patients in each age band		
	Number of patients with Chronic PA by age band		

<b>Burkholderia cepacia(BC)</b>	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of cenocepacia	0
<b>MRSA</b>	
Number and % of total cohort with chronic infection with MRSA	0
<b>Non-Tuberculosis Mycobacterium (NTM)</b>	
Number and % of total cohort with chronic infection with NTM	0

<b>Complications (Ref:1.16 National Report)</b>	
<b>ABPA</b>	
Number and % of total cohort identified in reporting year with ABPA	0
<b>CFRD</b>	
Number and % of total cohort requiring chronic insulin therapy	0
<b>Osteoporosis</b>	
Number and % of total cohort identified with osteoporosis	0
<b>CF Liver Disease</b>	
Number and % of total cohort identified with Cirrhosis with portal hypertension & Cirrhosis with no Portal Hypertension	0
<b>Transplantation (Ref:1.18 national Report)</b>	
Number of patients referred for transplant assessment in reporting year	0
Number of patients referred for transplant assessment in previous 3 years	0
Number of patients receiving Lung, Liver, Kidney transplants in last 3 years	0

<b>IV Therapy (Ref:1.21 National Report)</b>		
Number of days of hospital IV therapy in reporting year split by age groups	0-3 years	14
	4-7 years	2
	8-11 years	12
	12-15 years	0
	16-19 years	0
Number of days of home IV therapy in reporting year split by age groups	0-3 years	
	4-7 years	12
	8-11 years	2
	12-15 years	14
	16-19 years	
Total number of IV days (%)split by age groups	0-3 years	
	4-7 years	14
	8-11 years	14
	12-15 years	14
	16-19 years	14

<b>Chronic DNase Therapy (Ref: 1.22 National Report)</b>		
<b>Dnase (Pulmozyme)</b>		
Paediatric Sites Only	% of patients aged 5 -15 years on Dnase	83%
	If not on Dnase % on hypertonic saline	0
Adult Sites Only	% of patients aged >16 years with FEV1 % pred <85% (ie: below normal) on Dnase	
	If not on Dnase % on hypertonic saline	

<b>Chronic Antibiotic Therapy (Ref: 1.22 National report)</b>	
Number and % of patients with Chronic PA infection	3 (6%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	3 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	With 1 (3%) Without 2 (4%)

# Appendix 4 – User survey results

## Other hospitals attended

	Completed paediatric surveys (by age range)			
	0-5	6-10	11-15	15+
Male	4	3	3	
Female	3	3		

	Completed adult surveys (by age range)			
	16-20	21-25	26-30	31-35
Male				
Female				

## How would you rate your CF Team

	Excellent	Good	Fair	Poor	N/A
Accessibility (appts/advice)	14	3			
Communication (verbal/written)	13	5			
Out of hours access (via phone or ward)	10	7			
Homecare/community support (appts/advice)	9	8			

## How would you rate your Outpatient experience

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	11	5	1		
Waiting times	8	8	1		
Cross infection/segregation	8	8	1		
Cleanliness (room)	10	7	1		
Annual Review process	8	8	1		
Transition (paediatric to adult)		2			5

## How would you rate your in-patient care (Ward)

	Excellent	Good	Fair	Poor	N/A
<b>Admission waiting times</b>	4	4	1	1	1
<b>Cleanliness</b> (cubicle/bathroom)	5	5	5		1
<b>Cross infection segregation</b>	6	5	3		1
<b>Food</b> (quality/quantity)	2	8	3	2	1
<b>Exercise</b> (gym equipment/facilities)	3	5	1	2	5
School/Play group	3	1			8

## How would you rate:

	Excellent	Good	Fair	Poor	N/A
<b>Home Intravenous Antibiotic (IVs) service</b>	7	5		1	2
<b>Availability of equipment</b> (physio aids/nebuliser parts)	6	8	1		
<b>Car parking</b> (availability/ease of reach)	3	4	5	3	1

## How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
<b>Of your CF team</b>	15	3			
<b>Of the Ward staff</b>	10	5	2		
<b>Of the hospital</b>	9	5	2		

The hospital is 45 mins drive away as we cannot use the Friarage Hospital, this makes it harder. The ward staff are not always on the ball and some rooms are ill equipped and depressing. It was difficult to get more syringes and needles when IVs due to distance from the hospital.

We feel as a family very supported and happy with our daughters care and really hope this continues in the future. Hospital entrance still is a concern with people smoking.

I can only praise the CF Team. They are there and available when I need them for my son. I think CF Team are a fantastic team they are always on the end of the phone when needed for medical reasons or support

CF Team excellent and the care and dedication to detail are wonderful. They are simply the best.

The CF Team are excellent. They have become more like friends and family to us. I cannot fault them in any way at all.

Helpful approachable caring and knowledgeable just a few comments to describe the CF Team keep up excellent work.

Also accessible empathetic to our needs

Sometimes do not have phone calls returned. Sometimes when arriving for appointments other CF patients coming in at the same time so it can make me feel on edge about cross infection

# Appendix 5

## Patient/Parent Interviews

### Telephone Interviews

#### Parent 1

General chat about service, spoke highly of the CF team. Several parts of the service his child had not used yet but everything else was commended. Asked to name one area of excellence and he said team spirit and one area of improvement was the building and the smokers outside.

#### Parent 2

Spoke about the weekend out of hours service and that it was voluntary consisting of the Dr/Nurses/Physio taking it in turns. Works well and they have always been able to get hold of someone and satisfied with the service. IP child was always given a room with facilities, extra food given and a fridge so able to put in own child's foods. OP asked about the way it works and cross infection (comment made on survey) parent said that the cross over of patients coming in and going out is minimal but usually know the faces of other CF patients and so can avoid them. Parent not concerned by this though.

# Appendix 6

## Environmental walkthrough – Outpatients department

### Outpatients/CF clinic

	Yes/No/ Number/ N/A	Notes/Comments
Is there sufficient space in the clinic area to ensure optimal cross infection control? ( <i>reception, waiting room etc</i> )	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where does height and weight measurements take place? Is this appropriate?	Yes	In central area, segregation guidelines adhered to.
Where are lung function tests done for each visit?		In room
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Annual review appointments are split across a number of visits
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?	N/A	Patients are seen in clinic
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Tes	New pack has been created

### Additional Comments

All CF patients are known to staff therefore segregation is strictly adhered to. Patients are escorted to one of four rooms and the teams visit the patients.



# Environmental walkthrough – Ward

Ward Name \_\_\_\_\_

Microbiology status \_\_\_\_\_

		Yes/No/ Number/ N/A	Notes/Comments
Is ward a dedicated CF Ward or ward suitable for CF Care? ( <u>underline which one</u> )		Yes	On general children's ward
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		7	Not all ensuite therefore used for day patients to have IVs
Do the en-suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Keys are not available at present but the process is in hand
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Until 9pm
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents / carers / partners to stay overnight?		Yes	
Visiting hours – Are there allowances for CF patients/families out of normal hours?		Yes	
Is there access to fridge/microwave either in the side rooms or in a patient kitchen?		Yes	Fridge in all rooms with microwave in parent kitchen
Are there appropriate play facilities available?		Yes	
What facilities are provided for teenagers?			Adolescent unit available with special areas for teenagers. This is still segregated for CF patients.

Is there access to a gym or exercise equipment in the rooms?	Yes	
What facilities are there to help with school and further studies?	Poor	Schooling only kicks in after two weeks as an inpatients but then facilities are good.
Is there a relative's room?	Yes	
What internet access is there?		Dongle provided if necessary
What facilities are there to enable students to continue work and study?	Most patients are offered home IVs or opportunity to attend their own school	
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Milton tanks are available if required
What facilities are provided for those with MRSA?		Strict isolation policy, no MRSA at present
What facilities are provided for those with B.Cepacia?		Strict isolation policy, no B Cepacia at present
What facilities are provided for those with other complex microbiology?		Full policy with necessary facilities available
Are patient information leaflets readily available on ward?	Yes	
Transition patients - can they get tour of ward facilities?	Yes	

### Additional Comments

Entonox is provided for patients having long lines inserted or if patients are needle phobic.

3D Distraction TV is also used to good effect for many patients

## Environmental walkthrough – Other

	Yes/No/ Number/ N/A	Notes/Comments
<b>Car Parking</b>		
Any concessions for patients and families?	Yes	All free for those on benefits, or for long term inpatients
<b>Other Hospital areas</b>		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross infection control e.g. Radiology, pharmacy, Dexa?	Yes	
Do patients have to wait at pharmacy for prescriptions?	No	Medications are brought to the ward
<b>Patient Information</b>		
Is PALS well advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

### Additional Comments

# Appendix 7

## Panel Members\*

Cystic Fibrosis Trust Project Lead: Nikki Samsa

Cystic Fibrosis Trust CCPA: Sophie Lewis

Patient Representative: Penny Higgins

Panel Lead & Physio: Ammani Prasad

Consultant: Dr Ian Balfour Lynn

Psychologist: Claire Dixon

Nurse: Sandra Hall

Dietitian: Robyn Huggins

Pharmacist: Amanda Bevan

\*Core panel members

# Appendix 8

## Other information

Comments made regarding suggested review of inpatient care are due to the panel consensus that those patients having routine 3 monthly IVABs due to social circumstance tend to be those who are not receiving good home treatment or those who have more severe disease, so are less likely to be suitable for home IVABs.

Children do not receive any schooling input unless they are inpatients for a period of longer than two weeks. For children with chronic diseases such as CF this may result in a considerable loss of education time.

Although accessibility to the service is excellent, this places a burden to the members of the MDT on call. This will only increase should the unit expand and careful consideration needs to be given as to how the service modifies its practices, e.g. routing all out of hours calls through the ward, therefore managing the expectations of patients and their families, yet still providing an excellent service.

The psychologist should be involved in newborn screening and the annual review process.