

Peer Review Report

Birmingham Heartlands Hospital
West Midlands Regional Adult CF Centre

4 February 2013

Cystic
Fibrosis why
we're here



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I. Executive summary

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

This is a large well-established adult centre, staffed by an enthusiastic and skilled multidisciplinary team (MDT), housed in a dedicated facility and funded by charitable appeal in 2002. The unit is now struggling to accommodate the increasing number of adult patients in its catchment area. Parts of the MDT are quite seriously under resourced and these require urgent attention. There are shared care and outreach facilities and arrangements with surrounding hospitals which could allow the development of an additional adult CF centre for the West Midlands and this should be explored.

I.2 Good practice examples (Maximum 50 words)

1 Excellent MDT approach to CF care

2 Excellent website and patient newsletters enhancing communication

3 Purpose-built unit with dedicated facilities

I.3 Key recommendations (Maximum 200 words)

Urgent review of MDT personnel levels - most areas are under-resourced, in particular psychology, social work, medical staffing and pharmacy.

Review proportion of CF funds top-sliced for local NHS Trust overheads.

Address capacity issues by working with commissioners to provide an additional adult centre to serve the West Midlands: the use of the franchising concept to develop the Wolverhampton shared care service should be explored.

Reconsider the impact of local NHS Trust policies on CF care, including the pooled 7-day physiotherapy service working model and the review of agreed new posts by the EVAS panel.

Carry out a comprehensive *Pseudomonas* genotyping survey to ensure that current cross infection control policies are effective.

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

Increase research output to facilitate intermediate grade medical staff recruitment.

Address patient car parking facilities, a prominent source of complaints.

Address outpatient clinic congestion to reduce the potential for cross infection.

2. Performance against CF Standards of Care

2.1 Models of care

Summary

Number of annual reviews and subsequent discussion with patient falls below required standard - team requires increased resource (medical, physiotherapy, dietetics).

2.2 Multidisciplinary care

Summary

Most aspects carried out well, however service falls down on resource available for outpatient medical/MDT reviews and lack of evidence that other hospitals who process respiratory samples have sufficient expertise to fulfill the CF microbiological guidelines. The service is safe, however not as effective as it could be, due to a lack of resource (medical, physiotherapy, psychology, dietetics, pharmacy, social work).

2.3 Principles of care

Summary

Good overall performance. Infection control measures need to be audited for effectiveness.

2.4 Delivery of care

Summary

Lack of resource hampers fully effective delivery of care.

2.5 Commissioning

Summary

A fundamental principle of care is to minimise contact between patients to prevent cross infection. The unit was purpose built with this in mind. Outpatient capacity is much stretched with high numbers attending. Patients waiting for extended periods in the small waiting area presents a significant risk to health. This is difficult to address within the current accommodation/outpatient schedule. A short term solution must be sought with a view to the longer term to appropriately accommodate increasing numbers.

Regional capacity for care requires consideration due to an increasing number of CF patients. Currently accommodation and workforce is much stretched. The unit, Trust managers and commissioners should work together to develop a regional strategy and plans for addressing capacity need. The development of a second regional centre would be the realistic option. If this were agreed, the panel recommends the 'franchising model' be explored as a mechanism for operationalising this plan. Trust policy impact on CF care also requires consideration. CF care is specialised and requires adequate resource to ensure the MDT can provide an acceptable standard. Some Trust initiatives have an impact on delivery of an acceptable level of care. Of specific note is the impact of the 7 day physiotherapy service leading to reduced quality of care during the weekday period. Patients previously treated by a band 7 CF physiotherapist are seen by a band 5 physiotherapist with limited or no CF experience.

The Trust's vacancy freeze means funding of essential posts (agreed by the Trust) are not allowed to be filled. It is understood most medical services in the Trust are top-sliced by 30% however, CF is top sliced by 39%. Senior management representatives were surprisingly lacking on Peer Review day, therefore we were unable to explore the reasons behind these matters. It was a missed opportunity to explore and understand the CF service in the context of the Trust as a whole. We would recommend Trust managers and commissioners look at the combined impact of Trust policies/initiatives on CF services, with a view to balancing the need for more efficient use of resources with quality of patient care.

3. Registry data

		Male	Female
BMI	Number of patients and % attaining target BMI of 22 for Females and 23 for Males	87 (51%)	63 (57%)
	Number of patients and % with BMI <19 split by sex	21 (12%)	8 (7%)

			Male	Female
FEV₁	Median FEV ₁ % pred at age 16 years split by sex		87.96% (65.02-110.89)	N/A
	Number and median(range) FEV ₁ % pred by age range and sex	16-19 years	79.3% (40.5-120.91)	71.39% (42.5-96.16)
		20-23 years	72.55% (30.22-106.22)	71.23% (32.3-114.03)
		24-27 years	60.01% (31.41-118.92)	67.36% (30.03-105.34)
		28-31 years	51.87% (19.97-96.14)	70.36% (39.84-114.08)
		32-35 years	70.35% (35.24-126.43)	73% (32.33-100.29)
		36-39 years	76.93% (29.11-102.61)	67.5% (28.35-96.46)
		40-44 years	61.17% (52.51-102.03)	51.9% (43.43-96.95)
		45-49 years	46.18% (74.49-87.85%)	46.75% (33.75-108.04)
		50+ years	49.89% (27.07-107.05)	51.45% (36.98-76.64)

Data Input	Number of complete annual data sets taken from verified data set (used for production of National Report)	280
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Pseudomonas Chronic PA is 3+ isolates between 2 annual data sets	Number and % of patients with chronic PA infection	197 (70%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	167 (85%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	139 (71%)
	Number and % of patients on chronic macrolide without chronic PA infection	5 (6%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- There are 3 consultants, each of whom has 0.5 WTE directed towards CF (1.5 WTE total). This is well short of that expected for a service caring for 350 patients.
- All consultants have sufficient experience to carry out their CF roles.
- Only 2 of 3 are allowed away at any one time, so there is sufficient holiday cover etc.
- There is a 1:7 respiratory on-call rota involving all chest physicians on the respiratory unit, but the CF consultants perform an unofficial 1:3 on-call rota for advice on a 6 week block. Inpatients are cared for on a 6 week block system.
- There is the facility for all inpatients to be medically reviewed 7 days a week, if necessary.
- CF consultants carry out ward rounds at least twice a week.
- There is one CF Fellow who does the bulk of the inpatient routine work, one deanery trainee respiratory SpR who rotates every 3 months, and a more junior grade doctor who is pulled away to care for other patient groups when there is a staffing crisis. Overall, the junior staff setup is not sufficient for the workload and the CF Fellow has limited career progression opportunity: offering research opportunities would improve recruitment.
- There is a clear Centre Director (Dr Whitehouse).
- Medical clinicians attend both the ECFC and NACFC every year, as well as the BTS and sponsored UK CF meeting.
- There is representation at the yearly CF Trust Centre Directors Meeting.
- The centre has a satellite outpatient service at Coventry for 50 patients, and there are shared care arrangements with Wolverhampton (30 patients) and smaller numbers at Cheltenham and Shrewsbury. There is a suggestion that Wolverhampton will become a CF centre in its own right, since two incumbent clinicians have some CF experience. Any development will require support from Heartlands, and this would be possible by adopting the franchising model.

4.2 Specialist nursing

Excellent team of nurses working within a pleasant specialised unit looking after patients with a complex disease. There is good MDT working and all staff appear friendly, motivated and hard working. The CFNS covers all aspects of care including outpatients, annual reviews, care at home and limited inpatient care, as required.

Recommendations:

- Increase staffing of CFNS – 0.91 shortfall, to allow for more support for inpatients, to attend educational meetings and increase research within the unit
- Reduce the threat to the CFNS's having to cover other specialist nurses and ensure jobs are secure
- Increase support from senior management to allow Specialist Unit status to further develop
- Redevelopment of IV drug room to ensure safe administration of medication to patients
- Increase database hours to allow for improved input of data on Port CF, thereby ensuring correct funding is received
- More pre-mixed drugs for patients to increase quality of life and safety to all patients

4.3 Physiotherapy

Good practice:

- Highly trained and motivated team: all members of the ACPCF, attend conferences and involved in research/audit. Aware of their strengths and weaknesses and appear to work well together to find innovative solutions.
- CF physiotherapy team 7 day working
- Comprehensive treatment options: including sino-nasal treatments, nebuliser trial system, NIV & early implementation of new treatments

Areas for development:

- Access to treatment: 60% of patients see a physiotherapist at clinic visit and 47% had physiotherapy annual review (May 2011 and May 2012). Access to the MDT was mentioned in the patient survey.
- Staffing: Protection of current staffing and further staffing are required in order to maintain/develop the service and to meet recommendations. The shortfall of 2 WTE is a long-term issue (identified in 2007 peer review) which, along with the requirement for specialist CF physiotherapists to cover other areas of respiratory, limits the ability of the team to provide outreach care and ensure equal access to treatment. The panel are in agreement with ways to improve staffing, protect specialist time and maintain/increase quality of the CF service identified by the team:

- 1) Pull out of respiratory on call/weekend service and cover solely the CF service. This would be a forward-thinking move, provided that enhanced staffing levels were implemented to maintain weekly daytime staffing.
- 2) Make increased use of assistant time by moving to a band 3, as well as a band 2 assistant.
- 3) Decrease shortfall of staff by employing a band 6 physiotherapist to provide a good skill mix within current team.

- Future physiotherapy specialist planning: The team is strong and works well with shared leadership. However, there should be regular consideration regarding developing an 8a or consultant post, as identified in the 2007 peer review
- Registry data: 24 patients were registered, therefore physiotherapy-related data is inaccurate. The physiotherapists have a database which demonstrates acceptable inhaled antibiotic and DNase use. The data entry problem is an administrative rather than a physiotherapy issue.

4.4 Dietetics

Staffing: 2.8 WTE led by an experienced knowledgeable, well organised band 7 specialist dietitian of 17 years' experience four days per week. There are good team of 3 band 6 dietitians, 1 full time and 2 part time.

CPD:

Support from the main nutrition and dietetic department. All Attend National Dietetics Interest Group meetings twice year and a member of team attends European CF Conference

Outpatient cover:

4 clinics weekly - dietitian attends each and also the monthly outreach clinic in Coventry

Inpatient cover:

Each patient reviewed minimum twice weekly and more if clinically indicated

Ward rounds /MDT meetings:

Dietitians attend the MDT meeting in which inpatients are discussed, as well as complex outpatients. Ward rounds are not attended

Food Service provision:

2 housekeepers employed to provide 'lite bite' menu in small domestic kitchen. Frozen meals and extra snacks can be provided. There has been very positive feedback from patients on this service – recent audit showed that 35/50 patients rated the food as good, very good or excellent and 13/50 satisfactory. Funding has become available for a further housekeeper to provide the service at weekends

Research/Audit:

Review of standards of care. Audit of vitamin levels, nutritional status – BMI and those feeding regimens

Transition:

Attends monthly MDT transition meetings. Patients reviewed at first clinic appointment. Strong links with paediatric dietitians, to aid transition process.

Heartlands benefits greatly from an experienced team lead and support from the main nutrition and dietetic department.

4.5 Pharmacy

CF has an experienced, knowledgeable friendly and hardworking 0.4WTE pharmacist, therefore there is a 0.6WTE shortfall. Funding is in place to make up some of this shortfall, however pharmacy have yet to appoint. It is recommended this should be undertaken immediately. The pharmacist is a member of UKCFPG and attends national CFPG study day. She has attended European CF conference in past, however not recently. She hasn't attended other National CF study days.

Support provided by a pharmacy technician. Provides dispensing for discharge and self-medication services to the CF patients, when inpatients. Cover is provided when the pharmacist is absent. The pharmacist attends inpatient ward round and MDT. No pharmacist input at annual review due to time constraints. This should be resolved once additional pharmacist time is appointed.

Pharmacy department provides usual support services, but doesn't manufacture desensitisation regimens.

Good practice:

Good involvement in production of patient information leaflets. This covers a wide range of subjects.

Produces financial reports and works with the team in analysis of information.

Currently performing audit of FPI0 prescriptions and using this to aid adherence.

Pharmacist involved with the introduction of new medicines into the Trust.

Recommendations

1. Appointment is made to cover 0.6WTE shortfall.
2. Pharmacist attends annual reviews.
3. Pharmacist continues to attend UK CF pharmacists group meetings.
4. Pharmacist has opportunity to attend national study days and European CF conference.
5. The provision of Homecare is considered as an option for all patients.

4.6 Psychology

Good Practice:

- Advanced communication training for Staff,
- reduction in waiting list time to three months, meets target to see in-patient referrals,
- committed psychologist with good relationships with team members,

Points for development:

- The psychologist offers as good a service as is possible within the limited WTE of the service. Would benefit from a Lead psychologist and skill mix to fulfil the requirements of the CF Standards of Care.
- Referral –based rather than routine involvement at key life stages including, annual review, transition, end of life care, transplantation, planning families. – limited time for psychological care to be integrated in all care pathways (e.g. transplant, end of life, transition, pregnancy)
- Increased staffing would enable psychologist to attend out-patient MDT,

1. UKPPCF Meetings attended: annually. UKPPCF List serve used? Yes
2. The psychologist attends 100% of CF MDT meetings for discussion of inpatients, but does not attend outpatient clinics.
3. There is no cover for the psychologist when absent.
4. The psychologist attends conferences and UKPPCF Study Days.
5. The psychology service is audited annually.
6. The psychologist's ad hoc involvement, if part of general referral, is not routine.
7. Advanced communication training for Staff, MI training for staff, reduction in waiting list time to three months, meets target to see inpatient referrals, good relationships with team members
8. Opportunity to attend outpatient MDT, service development so that psychological care is integrated in all care pathways (e.g. transplant, end of life, transition, pregnancy)
9. The psychologist offers as good a service as is possible within the limited WTE of the service.

Recommendation:

Would benefit from a Lead psychologist and skill mix to fulfil the requirements of the CF Standards of Clinical Care.

4.7 Social work

Good practice:

- Excellent website contributions - helpful and informative way to disseminate information to patients.
- Wealth of knowledge and experience in CF.
- Good relationships with team members.

Points for development:

- Access to SW now much reduced which limits opportunities to cover clinics routinely e.g. to meet new patients, review or monitor progress of others - only there on request, to see specific patients. Unable to attend post-clinic meetings to provide background on social issues or do home visits.
- Patients would benefit from opportunity to discuss the impact of the government's welfare reforms – constant "fire-fighting" for those hit by the changes but limited to those who actively make contact, often after a crisis has occurred, when it's harder to resolve. The least articulate patients, least likely to seek help, are faring worst & local advice services are being cut - no time to routinely seek them out, in advance, nor to advocate for them.
- Employment: patients would benefit from routine advice to young people seeking their first job; older adults, experiencing difficulties at work, now only seen on request – but early input important in helping to reinforce positive attitudes to employment with CF & in troubleshooting difficulties to help people remain in work for longer.

The Social Worker (SW) is an experienced, knowledgeable, long term member of staff. Cover is no longer provided for annual leave. Access to the SW is much reduced, limiting patient opportunities to explore sources of support which might benefit them – people tend not to ask for help if they are unaware help exists. The SW is not able to keep up to date with social situations or update the MDT re: relevant issues.

- Outpatients: previously covered clinics routinely. Now only on request. Doesn't attend post-clinic meetings. No cover for Cepacia clinics.
- Inpatients: Aimed to see inpatients once during an admission, for a psychosocial update, now on request only.
- Annual Reviews: Never covered - on request only, however tries to contact specific people (e.g. to meet newcomers or if aware of potential social issues).
- Home visits: almost never unless exceptional circumstances e.g. severe social pressures/ cross infection concerns.
- Transition: used to aim to meet all new patients and families in clinic, now on request only.
- Late diagnosis: originally seen for routine assessment, now only on request only.
- Other transfers: used to see almost all newcomers, to introduce and explain role, now only on request only.

Areas of work with limited input:

- Transplantation: used to provide input with patients known to the social worker, discussing pre and post-transplant concerns . Now only involved, where requested re: help available for expenses incurred.
- End-of-life issues: input almost non-existent, limited to practical advice. Used to have regular pre-bereavement contact with families and provided follow-up support. Used to run bereavement meetings with the CF nurses.
- Education: no longer routinely sees or advises all potential students about specialist resources. Uptake seems more haphazard now, as some patients don't access available help
- Employment: no longer offers routine advice to young people seeking their first job; older adults experiencing difficulties at work are now only seen on request. However, early input is important in helping to reinforce positive attitudes to employment with CF and in troubleshooting difficulties, to help people remain in work for longer.
- Benefits: huge issue, with the relentless impact of the government's welfare reforms – constant "fire-fighting" for those hit by the changes. Limited to those who actively make contact, often after crisis has occurred, when it is harder to resolve. The least articulate patients, least likely to seek help, are faring worst and local advice services are being cut - The SW has no time to routinely seek them out in advance, nor to advocate for them.
- Housing: no time for liaison regarding rehousing/repairs (support letters or phone calls; advice re practical help given on request), so random, not necessarily targeted at those who might benefit most.

5. User feedback

		Completed surveys (by age range)						
		16-18	19-20	21-30	31-40	41-50	51-60	61+
Male		3	5	13	9	9	1	1
Female		3	2	22	13	5	2	1

		Overall care			
		Excellent	Good	Fair	Poor
From your CF team		60	28	2	0
From the ward staff		37	30	9	0
From the hospital		29	45	14	2

Areas of excellence

- 1 Steady, consistent nurses
- 2 CF newsletter – good communication with patients
- 3 Surveys done to continually get patient input

Areas for improvement

- 1 Waiting times for routine IP access and emergency admissions
- 2 Food – still needs improving despite having highlighted it on hospital surveys
- 3 Cleanliness of hospital and IPs – still needs improving

6. Appendices

Appendix I

Performance against standards of care

Reported and Actual compliance below follows a Red Amber Green rating defined as the following

Green = Meeting all Standards of care (2011)

Amber = Failing to meet all Standards of care (2011) with improvements required

Red = Failing to meet Standards of care (2011) with urgent action required

I Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
I.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review.	90%	Amber	Amber	accepted from team data
I.2 Specialist centre care	% of patients with completed data on the registry.	90%	Green	Green	combined registry data
I.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review.	90%	Red	Red	accepted from team data

2 Multi-disciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include AR).	95%	Green	Green	adult unit with few shared care patients
	Do staffing levels allow for safe and effective delivery of service?	Y/N	No	No	service is safe but lack of resource prevents full effectiveness
	% of MDT who receive an annual appraisal.	100%	Green	Green	interview
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	interview
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	interview
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	interview
	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	provided
	Respiratory samples analysed by a microbiology laboratory fulfilling the CF Trust standards.	100%	Green	Green	shared care samples not evidenced
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	unclear	Amber	insufficient resource
	% patients with CFRD reviewed at a joint CF / Diabetes clinic.	100%	Red	Green	inhouse specialist diabetes service

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission.	100%	Green	Green	visit
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Green	Green	do not cohort for Pseudomonas transmissibility
3.2 Monitoring of disease	% attempted eradication of 1st isolates Pseudomonas Aeruginosa in the previous 12 months.	100%	Green	Green	visit
	% patients admitted within 7 days of the decision to admit and treat.	100%	Green	Green	accepted from team
3.3 Complications	% aminoglycoside levels available within 24 hours.	60%	Green	Green	accepted from team
3.4 CFRD	% patients > 12 years of age screened annually for CFRD.	100%	Green	Green	accepted from team
3.5 Liver disease	% patients > 5 years of age with a recorded abdominal ultrasound in the last 3 years.	100%	N/A	N/A	adult centre
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	N/A	N/A	adult centre
3.7 Reduced BMD	% patients >10years of age with a recorded DEXA scan in the last 3 years.	100%	Database		

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% patients seen by a CF consultant a minimum of twice a week whilst inpatient.	100%	Green	Green	interview
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP / shared care consultant / patient or carer, within 10 days of consultation.	100%	Green	Green	interview
	% dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	Trust data

	% patients reviewed by a CF CNS at each clinic visit.	100%	Red	Red	resource issue
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Red	Green	interview - CF nurse always available
	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Amber	Amber	accepted from team
	% patients reviewed by a physiotherapist twice daily, including weekends.	100%	Red	Green	weekend physio always available
	% availability of a CF specialist dietitian at clinic.	100%	Green	Green	interview
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	60%	Green	Green	interview
	% availability of clinical psychology for inpatients and at clinic.	100%	variable	Red	resource issue
	% availability of social worker for inpatients and at clinic.	100%	variable	Red	resource issue
	% availability of pharmacist for inpatients and at clinic.	100%	Green	Green	interview
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	interview
4.4 End of life care	% patients receiving advice from the palliative care team at end of life.	75%	Green	Green	interview

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months.	<1%	2 (<1%)	<1%	interview
5.2	Number of clinical incidents reported within the past 12 months.	<1%	5 (1.4%)	1.4%	interview
5.3	User survey undertaken a minimum of every 3 years.	100%	Green	Green	interview

Appendix 2

Staffing levels

	75 Patients	150 Patients	250 Patients	Birmingham Heartlands
Consultant 1			2.5	0.5
Consultant 2				0.5
Consultant 3				0.5
Staff grade / Fellow			1	1.0 (but on-call, effective 0.5)
Specialist registrar			1	1
Specialist nurse			5	5.11 (includes 1.0 diabetes nurse)
Physiotherapist			6	5.79
Physiotherapy assistant				
Dietitian			2	2.91
Clinical psychologist			2	0.5
Social worker			2	0.5
Pharmacist			1	0.4
Clinicians assistant				
Secretary			2	3
Admin assistant				
Database coordinator			1	1
CF unit manager				1

Appendix 3

Registry data

CF Registry data Birmingham Heartlands	
Demographics of centre	
Number of active patients (active being patients with data within the last 2 years) registered	318
Number of complete annual data sets taken from verified data set (used for production of National Report)	280
Median age in years of active patients	27
Number of deaths in reporting year	1
Median age at death in reporting year	26

Age distribution (Ref: 1.6 National Report)		
Number in age categories	16-19 years	32
	20-23 years	61
	24-27 years	52
	28-31 years	52
	32-35 years	21
	36-39 years	20
	40-44 years	21
	45-49 years	15
	50+ years	13

Genetics	
Number of patients and % of unknown genetics	12(6%) no genetics 36(13%) unidentified gene on 1 allele

BMI (Ref: 1.13 National Report)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	87 (51%)	63 (57%)
Number of patients and % with BMI <19 split by sex	21 (12%)	8 (7%)

FEV₁ (Ref: Figure 1.14 National Report)		
	Male	Female
Median FEV ₁ % pred at age 16 years split by sex	87.96% (65.02-110.89)	N/A
Number and median (range) FEV ₁ % pred by age range and sex		
16-19 years	79.3% (40.5-120.91)	71.39% (42.5-96.16)
20-23 years	72.55% (30.22-106.22)	71.23% (32.3-114.03)
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32-35 years	70.35% (35.24-126.43)	73% (32.33-100.29)
36-39 years	76.93% (29.11-102.61)	67.5% (28.35-96.46)
40-44 years	61.17% (52.51-102.03)	51.9% (43.43-96.95)
45-49 years	46.18% (74.49-87.85)	46.75% (33.75-108.04)
50+ years	49.89% (27.07-107.05)	51.45% (36.98-76.64)

Lung infections (Ref: 1.15 National Report)		
Chronic Pseudomonas Aeruginosa (PA)		
Number of patients in each age band	16-19 years	32
	20-23 years	61
	24-27 years	52
	28-31 years	52
	32-35 years	21
	36-39 years	20
	40-44 years	21
	45-49 years	15
	50+ years	13
Number of patients with chronic PA by age band	16-19 years	23
	20-23 years	42
	24-27 years	34
	28-31 years	32
	32-35 years	16
	36-39 years	16
	40-44 years	14
	45-49 years	13
	50+ years	7
Burkholderia Cepacia (BC)		
Number and % of total cohort with chronic infection with BC complex	10 (4%)	
Number and % of cenocepacia	0	
MRSA		
Number and % of total cohort with chronic infection with MRSA	14 (5%)	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	7 (3%)	

Complications (Ref: 1.16 National Report)	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	34 (12%)
CFRD	
Number and % of total cohort requiring chronic insulin therapy	129 (46%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	23 (8%)
CF Liver Disease	
Number and % of total cohort identified with Cirrhosis with Portal Hypertension (PH) and Cirrhosis with no Portal Hypertension	4 (1%) with PH; 4 (1%) no PH

Transplantation (Ref: 1.18 National Report)	
Number of patients referred for transplant assessment in reporting year	8
Number of patients referred for transplant assessment in previous 3 years	2010 = 8, 2009 = 10, 2008 = 7
Number of patients receiving lung, liver, kidney transplants in last 3 years	2011 = 1, 2010 = 1, 2009 = 2, 2008 = 4

IV therapy (Ref: 1.21 National Report)		
Number of days of hospital IV therapy in reporting year split by age groups	16-19 years	507
	20-23 years	1175
	24-27 years	723
	28-31 years	629
	32-35 years	95
	36-39 years	285
	40-44 years	245
	45-49 years	249
	50+ years	181
Number of days of home IV therapy in reporting year split by age groups	16-19 years	326
	20-23 years	924
	24-27 years	840
	28-31 years	1321
	32-35 years	356
	36-39 years	400
	40-44 years	302
	45-49 years	239
	50+ years	239
Total number of IV days split by age groups	16-19 years	833
	20-23 years	2099
	24-27 years	1563
	28-31 years	1950
	32-35 years	451
	36-39 years	685
	40-44 years	547
	45-49 years	488
	50+ years	420

Chronic DNase therapy (Ref: 1.22 National Report)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV ₁ % pred <85% (ie: below normal) on DNase	79% (167) (n=212 with FEV ₁ <85%)
If not on DNase % on hypertonic saline	6(4%)

Chronic antibiotic therapy (Ref: 1.22 National Report)	
Number and % of patients with chronic PA infection	(n=197) 70% with chronic PA
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	167(85%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	139(71%) with chronic PA; 5(6%) without chronic PA

CF Registry data Wolverhampton

Demographics of centre	
Number of active patients (active being patients with data within the last 2 years) registered	24
Number of complete annual data sets taken from verified data set (used for production of National Report)	24
Median age in years of active patients	20.5
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (Ref: 1.6 National Report)

Number in age categories	16-19 years	9
	20-23 years	7
	24-27 years	1
	28-31 years	4
	32-35 years	0
	36-39 years	2
	40-44 years	0
	45-49 years	1
	50+ years	0

Genetics

Number of patients and % of unknown genetics	3(12%) patients with unidentified genetics on 1 allele
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BMI (Ref: 1.13 National Report)

	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	6(55%)	7(54%)
Number of patients and % with BMI <19 split by sex	1(9%)	1(8%)

FEV₁ (Ref: Figure 1.14 National Report)

	Male	Female
Median FEV ₁ % pred at age 16 years split by sex	N/A	N/A
Number and median (range) FEV ₁ % pred by age range and sex		
16-19 years	77.36% (52.78-79.1)	65.98% (34.42-114.96)
20-23 years	89.53% (82.14-101.03)	45.84% (43.66-58.88)
24-27 years	N/A	53.22% (53.22)
28-31 years	62.95% (40.7-85.21)	58.55% (35.58-81.52)
32-35 years	N/A	N/A

36-39 years	25.63% (25.63)	89.29% (89.29)
40-44 years	N/A	N/A
45-49 years	47.36% (47.36)	N/A
50+ years	N/A	N/A

Lung infections (Ref: 1.15 National Report)

Chronic Pseudomonas Aeruginosa (PA)

Number of patients in each age band	16-19 years	9
	20-23 years	7
	24-27 years	1
	28-31 years	4
	32-35 years	0
	36-39 years	2
	40-44 years	0
	45-49 years	1
	50+ years	0

Number of patients with chronic PA by age band	16-19 years	5
	20-23 years	4
	24-27 years	0
	28-31 years	4
	32-35 years	0
	36-39 years	1
	40-44 years	0
	45-49 years	1
	50+ years	0

Burkholderia Cepacia (BC)

Number and % of total cohort with chronic infection with BC complex	2(8%)
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Number and % of cenocepacia	0
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MRSA

Number and % of total cohort with chronic infection with MRSA	0
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Non-Tuberculosis Mycobacterium (NTM)

Number and % of total cohort with chronic infection with NTM	2(8%)
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Complications (Ref:1.16 National Report)

ABPA

Number and % of total cohort identified in reporting year with ABPA	4(17%)
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CFRD

Number and % of total cohort requiring chronic insulin therapy	8(33%)
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Osteoporosis

Number and % of total cohort identified with osteoporosis	3(12%)
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CF Liver Disease

Number and % of total cohort identified with Cirrhosis with Portal Hypertension (PH) and Cirrhosis with no Portal Hypertension	1(4%) with PH, 1(4%) with no PH
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Transplantation (Ref: 1.18 National Report)	
Number of patients referred for transplant assessment in reporting year	1
Number of patients referred for transplant assessment in previous 3 years	2010=3, 2009=3, 2008=1
Number of patients receiving lung, liver, kidney transplants in last 3 years	0

IV therapy (Ref: 1.21 National Report)		
Number of days of hospital IV therapy in reporting year split by age groups	16-19 years	31
	20-23 years	26
	24-27 years	0
	28-31 years	18
	32-35 years	0
	36-39 years	7
	40-44 years	0
	45-49 years	0
	50+ years	0
Number of days of home IV therapy in reporting year split by age groups	16-19 years	137
	20-23 years	206
	24-27 years	42
	28-31 years	139
	32-35 years	0
	36-39 years	57
	40-44 years	0
	45-49 years	66
	50+ years	0
Total number of IV days split by age groups	16-19 years	188
	20-23 years	232
	24-27 years	42
	28-31 years	157
	32-35 years	0
	36-39 years	64
	40-44 years	0
	45-49 years	66
	50+ years	0

Chronic DNase therapy (Ref: 1.22 National Report)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV ₁ % pred <85% (ie: below normal) on DNase	84% (16) (n=19 with FEV <85%)
If not on DNase % on hypertonic saline	1(5%)

Chronic antibiotic therapy (Ref: 1.22 National Report)	
Number and % of patients with chronic PA infection	15(58%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	14(93%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	8(50%) with chronic PA; 4(50%)

Appendix 4 – User survey results

Other hospitals attended

	Completed surveys (by age range)						
	16-18	19-20	21-30	31-40	41-50	51-60	61+
Male	3	5	13	9	9	1	1
Female	3	2	22	13	5	2	1

How would you rate your CF team

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	47	35	7	0	0
Communication (verbal/written)	47	34	8	1	0
Out of hours access (via phone or ward)	16	24	24	7	17
Home care/community support (appointments/advice)	24	21	14	2	29

How would you rate your outpatient experience

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	40	45	4	1	0
Waiting times	17	39	19	14	0
Cross infection/segregation	36	39	10	2	1
Cleanliness (room)	33	42	11	1	1
Annual review process	27	40	16	3	2
Transition (paediatric to adult)	19	24	4	1	41

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	15	24	18	10	22
Cleanliness (cubicle/bathroom)	20	29	15	5	20
Cross infection segregation	33	29	6	1	20
Food (quality/quantity)	9	26	26	9	20
Exercise (gym equipment/facilities)	24	24	10	2	28

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	30	22	7	2	29
Availability of equipment (physiotherapy aids/nebuliser parts)	41	29	7	2	10
Car parking (availability/ease of reach)	3	23	29	32	2

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	60	28	2	0	0
Of the ward staff	37	30	9	0	13
Of the hospital	29	45	14	2	0

Comments about CF team/hospital

The staff themselves are excellent, the only problems that arise are usually a result of low staff levels or funding. Waiting times 15mins.

Found change from child to adult care hard, not see same doctor at each time in clinic. Also feel adult care not got quite the same aim of keeping me as well as I am at the moment which is very good, all okay with them as long as not drop too much.

Always take a personal interest into your health.

Gym equipment availability not enough when an inpatient.

I do not go into hospital much any more but when I did I was impressed with food much better. But rooms could do with painting and curtains getting a bit untidy looking.

I have not been an inpatient recently but I feel that there has been a marked change in outpatients recently (last year). There service is 'leaner and meaner' no doubt due to budgetary constraints. You now see same team members (physio, dietician, diabetes) on a 'need to' basis rather than routinely (or by request). This may be unavoidable and may not affect the actual medical care but it does reduce patient satisfaction at outpatient visits.

The CF team is very good - just issues with access to them e.g. waiting times. It is obvious there are not enough staff employed for numbers of patients. There are also issue with funding of new treatments if you are not in specific areas which is frustrating. Car park often does not have spaces left.

Parking very bad and over priced when you can park. Even side streets full over 1 hour to get parking space. As for staff some very miserable and look down their noses at you. Need more disabled bays.

CF team are excellent. Ward staff are usually very good. A few need to understand hand washing better. The rooms are filthy though!!

This year have had to wait quite a while to be admitted to start IVs the CF ward is getting busier and busier. Also care on ward has slipped due to staff being too busy and under staffed. I don't blame them for this because if they had more staff the care would improve. I have been in hospital x4 times this year and seem to be getting worse.

There aren't enough disabled spaces in the car park. Car parking for blue badge holders should be free as it is in other hospitals.

Appointments - excellent. Advice - fair. AR thorough but often too repetitive. A high level of support is given. It is reassuring to feel you are seeing specialists who have current knowledge and seem to be often looking at new treatments. Sometimes patient care needs to be more individual rather than seeing your condition in comparison to others. Better support could be given for e.g. individual feelings about illness were recognized. The hospital could save money if they adopted an email system for some communication perhaps if patients opt in.

A lovely supportive team.

The medical care I receive is excellent. The main problem is the extortionate car parking fees, when I make frequent visits to the hospital the total amount I have to pay for parking is quite substantial. The situation is ridiculous and needs addressing.

Long times to wait for admissions especially if unwell.

I have found Heartlands brilliant for home IVs or inpatient IVs only problem with Heartlands is expensive car park and Cafe but that is nothing to do with the CF unit

I feel very well supported by the team at BHH. I have not been an inpatient for some years so feel unable to comment on those aspects.

The cleanliness of the rooms needs greatly improving I have been in a number of times and there has been quite a lot of dust in the inpatients rooms. The portion sizes and quality of food is very poor!!!

I only use Heartlands as an outpatients.

Appointments by email would be excellent.

Car parking I think you should have card so you don't have to pay.

Always willing to support Home/work visit make treatment more manageable. Know patients well. Core team are superb! Would like to see same consultant more often. Cross infection - occasionally have to wait in main are but not often.

I was very disappointed when a few months ago I was not informed regarding my recent diagnosis of pseudomonas weeks before.

I have only just moved to Heartlands from the children's in Birmingham. Cross infection seems to be a nightmare, having to wait 30 mins in a waiting room with 5 other CF patients, some who look and sounded ill, is not good, we had all been told I am and there was no individual rooms available to use this was not a once off but the norm. Not good enough.

Overall they are always pleasant to deal with and I feel I can trust them to do the best for me with respect to my care.

Team work really hard to help as best they can. Have MRSA so don't use equipment in gym.

A really key person in my care team is the Coventry community nurse. This service is not provided by Heartlands and I feel in time I may lose her. She provides a consistency, an understanding and an advocacy aspect to my care that is invaluable to me and I feel should be incorporated into everybody's CF team.

Annual review dates can be sporadic between getting firstly appointments then relevant tests to receiving patient report ward based care staff nurse accountability when things go wrong, generally pleased otherwise. Credit to nutrition input. Drs to communicate changes much earlier avoid unnecessary surprises i.e. tests lengths of stay.

Good.

Comments about CF team/hospital (continued)

It is overall the best CF centre I have been a patient of. The availability of dietitians, physios etc is particularly excellent. Continued improvements of quality and variety to the inpatient food served is something I would definitely want to see.

Waiting times can be up to an hour bit long. More often than not doctors (some do some don't) use the hand sanitizers to help stop cross infection. The patients do and the CF nurses at outpatient clinics and on ward rounds as an inpatient doctors don't often wash hands/use gel between patients. Gluten free choice of meals as an inpatient is poor - get same main meal every day (meat & veg) for 2 weeks!!! Annual review - seems to take a long time to do all lung function tests and see all physio, would prefer it all to be done on one day no matter how it takes rather than spread over 2-3 visits.

Some of the nurses on the ward need to learn more about people with CF as some are clueless. The cleaners need to do better as some just don't make much effort at all!

The car park is too expensive. Out of all the hospitals I go to this is the only one that I have to pay even with a Blue Badge.

Annual Review often annual tests are booked on several different days. Would be nice if they could all be included/booked on the annual review day otherwise really good.

The community support is a bit too far away from my house I feel a more local option would be a good idea, this is not the CF centers responsibility so the home care they can provide is good. I found the transition difficult at the time as I went from paediatric to adults as I went from no say on my care to complete responsibility, with the opposite happening to my parents. The car park is very busy not big enough.

Heartlands CF centre has always been 1st class. With exceptional patient facilities i.e. laptops, extra meals TVs.

The dedication and expertise of the CF consultants and physios (whom I rely on most of all) is second to none. They make decisions with me rather than just for me and explanations/rationale provided is always clear. It's a clean modern hospital and CF ward and clinic which is reassuring too. Ward staff retention/continuity is good so you feel confident and reassured of good inpatient care.

They are always willing to try. Excellent care/professionalism. Appointments hard to get, almost always now.

Overall CF team are fantastic however weekend admissions over weekends are terrible, staff have no idea what they are doing as many cover from other wards.

Some consultants are OK some not. Money needs to be raised for an entire refit some bathrooms are perfect breeding ground for bacteria. Also not happy that its not exclusive to CF patients. Most bacteria is airborne and people leaving doors open that are not CF people. IVs given late!

Waiting times can be long. Car parking is extortionate which is increased by waiting times and is very busy. Ward staff can be lovely, few are not can be insensitive and rude.

I do believe the service given in Ward 26 is excellent. the only issue I have is paying for parking at my frequent visits (every 8wks).

My CF team are approachable and helpful and know me as an individual. I have been with the Heartlands Hospital team over 20yrs and they feel part of my extended family. A big thank you goes to them all.

It would be good if I could see the same consultant at each visit so they could get to know me and I could get to trust them. I find it annoying when I attend clinic and see someone different at each visit.

Waiting for prescriptions afterwards can take a long time up to 1.30hrs difficult after finishing appointments and just want to go.

CF nurses attention to hygiene/hand washing etc is excellent but some junior doctors need reminding to wash hands after examining patients and should NOT shake hands with CF patients.

Difficulties in being referred for specialist treatment. I regularly only see junior doctors who I have to persuade to refer me. I recently waited in severe pain for 23 weeks for test on esophagus. Twice this year I have needed to be admitted but told no beds, and when I have been admitted told I need to be admitted 3 or 4 days waiting on a bed. Several times during the year I have observed non CF patients on the ward when CF patients are on the board waiting to come in.

Not having follow up letters for annual reviews 2 years running.

When an inpatient it's really hard to rest with so many people coming in and out of the room. I don't like to be woken at 6am to have blood sugars done when they are fine in the morning, its the evening meals I have trouble. It's really hard to sleep.

The only problem with the CF unit is it is too successful and is very busy due to too many patients. It is not local to us the CF unit is use to this but the rest of the hospital services are not.

Waiting times are awful now. I used to be in clinic for approx 1-2hrs now it seems I am there for at least 2-3hrs, add on pharmacy waiting time and it seems to take an entire afternoon and is leading to more and more money being spent on parking charges. More doctors/doctors beginning clinic earlier would help particularly as many patients have long journeys home in rush hour after clinic and some have children to collect.

The hospital is always clean, the staff always wash their hands before dealing with new patients. Help is always there when it is needed and everything is clearly explained and any questions are answered quickly and clearly.

Really helpful at all times, friendly and easy to approach. Personally I think the food is horrible and I always order take out when on ward.

Car parking is terrible - difficult to get a space. Home IV deliver service excellent. CF nurses not always willing to do home visits. Continuity of care poor - always new doctors.

Appendix 5

Patient/parent interviews

Patient 1

Spoke about cross infection and outpatients patient happy that she was put straight into a room and was in a clinic specific to her Pseudomonas. Pulmonary function is done in the room.

In patient facilities a good with en-suite rooms provided, with fridge TV/Laptop free Wifi. And additional things to keep patients occupied like the card making lady and trolley with crosswords and books. Food has the lite bite menu and snacks provided.

Patient 2

Patient was frustrated by the out of hours waiting have to go to A&E waited to see on call doctor from ward 26 (CF ward) and took 8 hours to be seen. Even when you need a bed via outpatient/routinely you have to wait over a week.

Annual Review (AR), only get told things if something is wrong. Ppatient has to ask if they want to know anything no formal letter ever given.

Nurses on ward are excellent. Gym provided, swap a physio session for gym. Physio provided x 2 while IP

When needing IVs PIC line is booked in theatre.

Patient 3

Different clinic for different bugs.

Don't see the same Dr always see registrar.

Steady consistent nurses that know you.

AR – tests scattered hit and miss. Next clinic went through everything, but nothing the previous 5 years.

Only get to see CFNS if requested.

On the same ward as Pseudomonas patients, but warning sign up. Home IVs box delivered make up drugs yourself.

Cleanliness of ward has improved since TV programme, but still can be worked on. Food still needs improvement.

Physio x 2 while IP. Get replacement physio equipment when needed.

Accessibility for IP bed is bad when needing IVs and not well still waiting for bed.

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>)	No	MDT aware that large clinic patient numbers mean patients may have to wait for a room as not sufficient space
Do patients spend any time in waiting room?	Yes	They plan to increase number of clinics to decrease number of patients per clinic, decrease waiting time and ensure optimal infection control. This has implications as staff already overstretched
Is there easy access to toilets?	Yes	Clean and adequate
Where does height and weight measurements take place? Is this appropriate?		In individual clinic rooms
Where are lung function tests done for each visit?		In individual clinic rooms
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Wifi available, able to use mobile phones
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?	N/A	
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	New one in preparation at present

Additional comments

Clean and spacious outpatient clinic. However, too many patients per clinic pose a cross infection risk at present. This should be addressed as soon as possible

Environmental walkthrough – ward

Ward name Ward 26

Microbiology status All microbiology

		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	Dedicated CF ward
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	Well equipped, fridge, TV's and en suite
Number of side rooms?		20	16 beds on main ward and 4 negative pressure rooms in annex adjacent to ward
Do the en-suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Showers. Concerns were raised during visit by a patient on infection control, regarding shower drainage. One large bathroom with bath appears underutilised
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	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents / carers / partners to stay overnight?		Yes	2-bedded, well-equipped relatives room on ward requires a hot drinks facility. Carers may also stay overnight in rooms on put up bed or in chairs
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Visiting ends at 10pm however, exceptions are made for those who are very unwell
Is there access to fridge/microwave either in the side rooms or in a patient kitchen?		Yes	
What facilities are provided for teenagers?			Wifi, laptops
Is there access to a gym or exercise equipment in the rooms?		Yes	well equipped single-patient use gym and equipment available. One patient commented there was not enough equipment for everyone whilst an inpatient.

What facilities are there to help with school and further studies?		Desk in room, Wifi and laptops available
Is there a relative's room?	Yes	Good-sized, two single-bedded with en suite shower, TV and fridge - however, requires hot drinks facility
What internet access is there?		Wifi
What facilities are there to enable students to continue work and study?		Desk in room, Wifi and laptops available
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in bedroom and bathroom for washing. However, no sterilising facility
What facilities are provided for those with MRSA?		Same facilities as all other patients. However, barrier nursed, therefore must exercise in own room
What facilities are provided for those with B.Cepacia?		Same facilities as all other patients. However, barrier nursed in negative pressure rooms in annex to ward, therefore must exercise in own room
What facilities are provided for those with other complex microbiology?		Same facilities as all other patients. However, barrier nursed, therefore must exercise in own room
Are patient information leaflets readily available on ward?	Yes	
Transition patients - can they get tour of ward facilities?	Yes	

Additional comments

The room where ward nurses prepare IVs is inadequate for use. It is poorly ventilated, too hot and not a safe environment for staff, as they are exposed for long hours to potentially toxic drugs. This must be addressed on a health and safety basis immediately. Plans to extend and better ventilate the room are underway. Trustees of CF Centre are prepared to part fund. However, hospital management have not as yet agreed to finance the change. This must be addressed immediately.

Environmental walkthrough – other

	Yes/no/ number/ n/a	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free for inpatients and annual review. Normal charges for outpatient visits
Other hospital areas		
Clear signage to CF unit and/or ward.	No	From main hospital entrance not clear for new attendees. No signs to CF Centre, only to ward 26. Once inside hospital signs clear to ward 26. New signage inside ward very clear to in/outpatients
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 scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	Yes	However, not much waiting time at Boots and it is a large open space. Most patients have home delivery of IVs or collect drugs from ward
Patient information		
Is PALS well advertised – leaflets, posters?	Yes	In clinic and on ward good. However, may be useful in every patient bedroom to have the correct procedure for suggestions and complaints displayed.
Are there patient commentv / feedback boxes?	Yes	patient satisfaction survey undertaken regularly

Additional comments

<p>Ward signage with own logo very clear. However, signage from main hospital entrance requires improvement for new attendees.</p>
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Appendix 7

Panel members

Dr Martin Walshaw*	Consultant and Clinical Lead for Birmingham Heartlands Peer Review
Sarah Halstead*	Commissioner
Tim Gleeson	Pharmacist
Dr Sam Phillips*	CF Specialist Psychologist
Judith Duguid*	CF Clinical Nurse Specialist
Ingrid Small	CF Specialist Dietitian
Sophie Lewis	Clinical Care Patient Adviser
Tracey Daniels	CF Specialist Physiotherapist

Lynne O'Grady* Peer Review Project Lead for CF Trust

* Peer Review Core Panel members attended Birmingham Heartlands Hospital on Peer Review day

Appendix 8

Other information

The ward nurses were represented by one staff nurse and the ward manager on peer review day and could not attend the afternoon feedback session due to staffing levels.

Further information was obtained from a pro-forma sent separately to staff.

There is a joint nursing establishment between ward 26 (the CF unit) and ward 24, a respiratory ward which houses the acute NIV unit.

Staffing levels on ward 26 are currently 3 qualified nurses 24 hours a day, 2 HCAs in the daytime and 1 overnight. Nurses on ward 26 feel under pressure when there are dependant patients, and this is exacerbated when nurses need to be moved to ward 24 during the winter months when the acute NIV unit is full.

Funding for ward 26 is shared between the CF and general medical budgets: beds on ward 26 are often used for non-CF patients, but CF admissions take priority.

Some CF patients are unaware of the joint funding arrangements and this causes ill-feeling towards general medical admissions: this needs to be addressed.

Currently ward 26 is without a Lead Nurse: this has appeared on the Directorate's risk register for the last few months.