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Cystic Fibrosis why we're here

British Thoracic Society

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Peer review report

Leeds and York Adult Service

25 September 2014

Executive summary

Overview of the service

The Leeds Cystic Fibrosis (CF) centre is a well-established service with approximately 400 patients. It provides excellent care from an experienced team with an associated research and clinical trials unit. The inpatient service has transferred to St James's Hospital, but outpatient services currently remain on a separate site at Seacroft Hospital. If the outpatient clinic at Seacroft closes there will be a need to provide a similar appropriate level of service at St James's Hospital. The number of patients is increasing and this places some pressure on providing care, with deficiencies in some staffing levels and some delays in admissions and in starting intravenous antibiotics, but urgent problems are prioritised. There has recently been a temporary shortage of specialist nurses because of illness. The electronic record facilitates continuous review. The York service currently has 24 patients, and the user survey indicates that the service is popular, with an enthusiastic committed team. It evolved before current commissioning specifications were introduced and the York team proposes to develop a combined service with Hull to strengthen that service and to develop towards meeting the patient numbers and criteria for a new combined York/Hull CF centre.

Good practice examples

- The Leeds Electronic Record System is innovative and facilitates continuous review of a patient's progress and needs.
- Both the Leeds and York services have enthusiastic multidisciplinary teams committed to providing excellent care.
- The Leeds Service has an international reputation in clinical care policies, research and clinical trials.

Key recommendations

- The Leeds CF service needs to address staffing levels within the multidisciplinary team as there are deficiencies in the number of nurses, physiotherapists, social workers and psychologists compared to recommended staffing levels in Cystic Fibrosis Trust's 'Standards of Care (2011)'.
- Further planning is needed for outpatient services and day patient facilities at Leeds as it is likely that Seacroft Hospital will soon close. Opportunities to provide a day unit on a single site may be beneficial.
- Based on CF Registry data for patient numbers neither the York nor Hull services currently meet criteria for being CF centres. A proposal has been made to develop a combined York/Hull CF centre, which needs to be developed further to address key issues such as a combined centre director appointment, cross-site working arrangements, combined MDT appointments, financial arrangements between the hospitals and the location of inpatient facilities. The final configuration of services will then need to be decided by commissioners, patients and the hospitals.

Areas for further consideration

- The Electronic Record at Leeds facilitates ongoing review of the patient's needs but the annual review process should be strengthened to give access to social worker, psychology and pharmacy input as appropriate.
- The transfer of prescribing of CF inhaled medications ('repatriation') at both Leeds and York should be prioritised and agreed with commissioners.
- A facility to start intravenous antibiotics in the outpatient clinic at Seacroft in the short term and the development of a day unit at St James's should be considered.
- The home care intravenous antibiotic service delivered through Calea and their delivery arrangements need to be kept under review as some patients and staff have reported problems.
- The staffing levels on the Leeds inpatient unit should be monitored carefully because of the heavy workload in preparing and administering treatments such as intravenous antibiotics.
- The current York service has difficulties in providing an out-of-hours service and is reliant on a small team with limited cover arrangements for any absences, which is not a sustainable model of care for the future such that the options of a combined York/Hull service or other arrangements need to be considered before a service is commissioned.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'

Models of care

Summary

The total number of patients across the Leeds, York and Hull area is rising towards 500 patients. The CF centre at Leeds is a recognised centre of excellence for clinical care and research, but at over 400 patients may experience difficulties in coping with any further rise in patient numbers over the coming years. The current services at York (approximately 24 patients) and Hull (approximately 45 patients) evolved before current commissioning specifications, and based on patient numbers neither service is suitable for recognition as a specialist CF centre. Nationally with the rising number of adult patients it is recognised that there is a need to develop new adult CF centres but this is often difficult to achieve because of a lack of clinical expertise to develop services. The York service has an enthusiastic committed clinical team and a merger with Hull could strengthen a York/Hull combined centre. The precise configuration of services across Leeds, York and Hull has not yet been agreed between the commissioners, hospitals and patients and several potential options could be considered, including:

- Development of a combined York/Hull CF centre.
- Development of a second CF centre based at Hull.
- Expansion of CF centre care at Leeds with outreach services to Hull and York for a total of approximately 500 patients within the next few years.

The preferred model of the York CF team is to develop a combined York/Hull CF centre but further work is needed to develop this proposal by examining patient numbers and patient flows from Paediatrics, and developing agreed plans to appoint a CF centre director, to build a multidisciplinary team across the two sites and to establish joint working arrangements, budgeting and appointments. The Hull adult CF service will be scheduled for peer review in 2015/2016, and this will provide an opportunity to review whether a combined York/Hull model has been established and is sustainable or whether alternative options have to be considered for the provision of services for the future projected patient numbers. Whatever configuration of services is decided upon by commissioners, patients and hospitals, there should be close collaboration between York, Hull and Leeds with some joint educational events, sharing of good practice and support for development of the MDT skills by visits to the established centre at Leeds for training.

Multidisciplinary care

Summary

Both the Leeds and York CF teams demonstrate a high level of enthusiasm and commitment to the care of patients, with many areas of excellent practice. Because of small patient numbers at York and the small team there, the service is highly reliant on individual clinicians with a lack of cross-cover for absences and therefore there are concerns for the future sustainability of the service. At Leeds there are shortfalls in staffing levels, compared to the Cystic Fibrosis Trust's Standards of Care, in some key disciplines such as nurses, physiotherapists, social workers and psychologists.

Principles of care

Summary

Both Leeds and York services follow accepted principles of care. There is a commitment to a multidisciplinary model of care for patients, following current guidelines and practices. There are good practices in relation to infection prevention and control.

Delivery of care

Summary

User feedback surveys and patient interviews confirm a high level of satisfaction with the services at both Leeds and York. The Leeds Electronic Record system is innovative in modernising aspects of care with continuous review of the patient's status and needs. Some adjustment of the annual review process is needed to ensure appropriate patient access to the social worker, psychologist and pharmacist services. The shortage of staff restricts the availability of some disciplines in clinics (eg psychologist, social workers, pharmacist). The York service provides a high level of care for the small number of patients attending, but has insufficient patients for the team to develop knowledge and skills of the full spectrum of complications of CF, and there are difficulties in sustaining a seven day a week service, although there are usually only one to two inpatients at a time.

Commissioning

Summary

The Leeds Adult CF centre is a long-established, major specialist centre, participating fully in delivering care according to guidelines and service specifications within the new commissioning arrangements. The transfer of the prescribing of inhaled CF medications ('repatriation') to the CF centre needs to be priortised and a timetable needs to be agreed with commissioners for completion of this process. The current CF service at York does not have sufficent patients to meet the criteria for being a specialist centre and there is a derogation to the service specification for the Trust to explore developing a joint service with Hull, although the current patient numbers for both York and Hull combined services are still relatively low at about 65 patients, compared to a recommended minimum of 100 patients, and further consideration is needed in deciding on the best configuration of services. A potential commissioning model is for Leeds to act as the centre with outreach services at Hull and York in order to ensure minimum patient numbers are achieved.

UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	409 Leeds 391 York 18

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and % of patients with FEV1 <85% by age range and sex	16–19 years	15; 75.41 (34.78–118.32)	20; 64.77 (20.92–97.6)
		20–23 years	39: 75.78 (18.57–109.69)	27; 67.9 (21.37–127.22)
		24–27 years	32; 51.04 (21.13–109.44)	32; 64.84 (22.64–105.22)
		28–31 years	44; 58.84 (15.53–105.97)	21; 69.53 (26.7–105.47)
		32–35 years	32; 56.65 (18.46–106.26)	26; 61.36 (15.61–98.66)
		36–39 years	20; 71.57 (32.55–113.69)	14; 59.38 (25.12–96.04)
		40–44 years	20; 55.91 (22.75–106.09)	14; 60.25 (22.04–106.95)
		45–49 years	5; 60.61 (21.45–126.79)	7; 47.28 (20.29–94.43)
		50+ years	14; 60.85 (18.73–117.05)	9; 60.25 (20.58–111.77)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=221) 122(55%)	(n= 170) 63(37%)
	Number of patients and % with BMI <19 split by sex	24(11%)	32(19%

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	196 (50%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	107 (55%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	96(49%)
	Number and % of patients on chronic macrolide without chronic PA infection	51 (26%)

Delivery against professional standards/guidelines not already assessed

Consultants

The Leeds Adult Cystic Fibrosis service has three consultant physicians with 1.9 Whole Time Equivalents (WTE) dedicated to cystic fibrosis. There is a very experienced Associate Specialist (1 WTE), and a Research Fellow who rotates every two years. There is additional attendance of a Specialist Registrar, mainly for training purposes, and at least one CF senior house officer who rotates through acute respiratory medicine. The Cystic Fibrosis Trust's 'Standards of Care (2011)' staffing levels would suggest approximately 3.5 consultants for 400 patients, although the balance of the team seems satisfactory for providing care. All members of the team have had specialist training in cystic fibrosis and participate fully in educational events and conferences. Because of the large number of patients there is a significant amount of care needed out-of hours during the evenings and at weekends. The current levels of staffing allow for appropriate seven-day cover, and for consultant ward rounds. The patient feedback survey confirms a very high level of satisfaction with the service.

Specialist nursing

There are currently three Band 6 clinical nurse specialists (CNS), whole time equivalent (WTE) of 2.8. There is a 1 WTE vacancy Band 6 that has been advertised and they hope to recruit soon. There is also a band 2, 0.8 WTE health care assistant. There is a shortfall of 4 WTE CNS.

All CNSs are dedicated and experienced in CF; 0.5 WTE of one post is funded by the bronchiectasis service which is run by the CF consultants. The outpatient facility is not onsite and so patients need to return to St James's to commence home intravenous therapy. They attend local meetings but have been unable to attend national and international conferences due to recent low staffing levels through sickness. Nursing team is highly involved in transition, transplantation and end-of-life care.

Areas of good practice:

- Dedicated, experienced nursing team.
- Established relationship with ward nursing team.
- Nurse prescriber on team.

Areas for improvement:

- Attendance at national and international conferences.
- Time for research, audit and to develop service.

Recommendations:

- Substantial increase in nursing establishment.
- Improve facilities for commencing IV antibiotics either directly in clinic or in a day care area off the ward.
- Increase capacity and speed for home care, and review of Calea service provision.

Physiotherapy

There are 4.46 WTE physiotherapists working with the CF team. This is well below recommendations set out in Cystic Fibrosis Trust's 'Standards of Care (2011)' which is 8 WTE for 400 patients. The physiotherapy team consists of Band 5 to 7 static and rotational physiotherapists, led by a very experienced clinical specialist. The physiotherapy team provide care to both inpatients and outpatients in line with standards of care guidelines. Team members attend MDMs and ward rounds three times a week. Exercise facilities are available for inpatients including a separate gym for cepacia patients on a separate ward. The new appointment of additional staff has enabled a physiotherapy community service which can offer home visits to approximately four to six patients per week. The team is involved in all stages of care from transition to transplant and end-of-life care.

Weekend and on call physiotherapy input is provided as required by the main physiotherapy department. There is currently inadequate staffing to provide a seven-day CF service.

Physiotherapy attendance to European or international CF conferences has been limited due to staffing levels; however physiotherapists do attend regional meetings on a regular basis. Current staffing also limits physiotherapy led research and audit activity.

There are current difficulties in performing annual reviews for all patients due to staffing levels. Continuous electronic assessment is carried out instead, and individuals identified for more formal review. The team are aiming to improve this as well as care pathways for patients requiring continence or musculoskeletal assessment and treatment.

Areas of good practice:

- Experienced lead and dedicated enthusiastic team with additional newly developed community service.
- Inpatient care with access to twice daily airway clearance and exercise. Separate gym facility for cepacia patients.
- Budget available for wide range of airway clearance and nebuliser equipment. Well established NIV service.

Recommendations:

- Increase staffing by 3.54 (WTE) to be in line with the Cystic Fibrosis Trust's Standards of Care to further improve delivery of care. A further uplift would be required to provide a seven-day service.
- Improved access to specialist physiotherapist for continence and musculoskeletal assessment and treatment. Annual reviews should be completed for each patient with appropriate documentation in line with the Cystic Fibrosis Trust's Standards of Care.
- Opportunity should be provided for regular attendance at national and international CF conferences.

Dietetics

The current dietetic service is provided by 2.5 WTE dietitians. This is made up of 1 WTE Band 8b consultant dietitian, 1WTE Band 6 CF dietitian and 1 WTE Band 6 CF/respiratory (0.5 CF/0.5 respiratory). The service benefits greatly by being led by a dietitian with over 20 years of experience of working within cystic fibrosis.

All dietitians are members of the UK Dietitians' CF Interest Group and regularly attend meetings. There is the opportunity to attend national and international conferences.

A dietitian attends all MDT meetings and ward rounds. The CF dietitians cover for each other during periods of leave.

The dietitians actively participate in research and audit.

The dietitians participate in the transition process.

Areas of good practice:

- Proactive dietetic team, who provide good patient care.
- Benefit from being led by a dietitian with national and international recognition.
- Participation in research and audit.
- Good liaison with catering to assure appropriate food provision for patients with cystic fibrosis.

Recommendations:

- The current staffing level is slightly below what is projected for 400 patients from the recommended standards of care and would need to be reviewed with any service improvement initiatives.

Pharmacy

- The clinical pharmacy service consists of a 1 WTE Band 8a pharmacist, which meets the recommendation of 1 WTE for a clinic of 250, although the optimal staffing for larger clinics has not been established.
- In the absence of the dedicated pharmacists, cover is provided by another Band 8a pharmacist with suitable experience. A Band 7 pharmacist training role has recently been established who will be trained in cystic fibrosis.
- Currently the clinical pharmacy service is extended to inpatients only – the pharmacists attend 3 MDT meetings per week. Clinics may move in the future to the same site and the pharmacists see this as an opportunity to review the role of the pharmacist prescriber in clinic.
- There is a self-administration scheme in place: the pharmacists currently check patients own drugs as much as possible; however, this is an area where a medicines management technician (MMT) would improve depth of service and allow the pharmacists to continue to develop more clinical roles.
- There is a home IV provider – although it is acknowledged that this service has recently run into difficulties, there is a plan to re-establish a good service.
- There is a system in place for patients to request certain medicines directly from the pharmacy team which supports adherence and self-management. The service is becoming unmanageable due to increasing patient numbers. At present, repatriation of high cost inhaled drugs has not begun, but the pharmacists have established close links with primary care colleagues.
- The pharmacists are very dedicated, are actively involved in research, and are currently undertaking work on adherence. They are active members of the UK CF pharmacist group of which one is a committee member. Both regularly attend and present at regional, national and international CF meetings.

Areas of good practice:

- Positive clinical relationships with patients in terms of education and support for adherence and self-management of medicines.
- Strong CPD and research focus to ensure highly skilled in the management of patients with complex pharmaceutical needs.

Areas for improvement:

- Not all patients have an annual medication review by a pharmacist.

Recommendations:

- The success of the excellent pharmacy service lies in the commitment of the CF pharmacists; however, there needs to be additional resource and cover/succession planning to ensure the service can continue, with careful thought as to how seven-day working would affect the current level of service.
- Appointment of a 0.5 WTE Band 5 medicines management technician should be considered.
- As the number of patients prescribed high-cost drugs increases, homecare provision needs to be addressed which may require additional resource.

Psychology

Until July 2014, the Leeds Adult Cystic Fibrosis service had had minimal clinical psychology input (0.1WTE of a Band 8c, consultant clinical psychologist) for the previous 18 months. A full-time Band 7 specialist clinical psychologist has recently been appointed and so there is now 1.1 WTE; the recommended staffing for this service according to the Cystic Fibrosis Trust's 'Standards of Care (2011)' would be 3.2 WTE.

Both psychologists are registered with the Health & Care Professions Council and are members of the UK Psychosocial Professions in Cystic Fibrosis (UKPPCF) group. The consultant psychologist attends the European CF Society conference each year and the specialist clinical psychologist has attended the annual UKPPCF study days. Although new in post, the specialist psychologist has worked in a large CF centre before and has been involved in research; she receives clinical supervision from the consultant psychologist who has extensive clinical and research experience in cystic fibrosis.

The specialist clinical psychologist attends the weekly multidisciplinary team (MDT) meetings and one out of the two MDT ward rounds.

If both psychologists are absent, cover is provided by liaison psychiatry or by the on-call psychologist from the clinical psychology department as appropriate.

Areas of good practice:

- There are good links with the psychologist in the paediatric CF service and, with the imminent appointment of a youth worker, there are plans to develop the transition process.
- Both psychologists are very active in research into the psychosocial aspects of cystic fibrosis.
- The psychologists have job plans, and that of the specialist psychologist has allocated time for work with inpatients.

Areas for improvement:

- Patients at the Leeds adult CF service do not have formal annual reviews and there is, therefore, no formal method for reviewing patients' psychological status on a yearly basis.
- Owing to the limited psychology time, there is no routine availability of clinical psychology at outpatient clinics. In addition, because of the gap in provision before the recent appointment, there is a large backlog of referrals and there is currently a waiting list of up to three months for outpatients.

Recommendations:

- Annual screening/assessment by a clinical psychologist is specified in the Cystic Fibrosis Trust's Standards of Care.
- With the current level of provision, the psychologist will find it difficult to be involved in providing psychological input at key stages such as diagnosis, planning a family/fertility issues, end-of-life or transplantation unless a patient is specifically referred to them.
- The recommended clinical psychology staffing in the Cystic Fibrosis Trust's Standards of Care for this patient population is 3.2 WTE, so the 1.1 WTE provision in this service represents a shortfall of 2.1 WTE.

Social work

Provision: There is one part time social worker (SW) working with the Leeds CF team for their 400 and growing number of patients; she is qualified, experienced and managed through the CF team and local authority social work team. The permanent post holder is on maternity leave and the post is being covered by another SW with similar qualifications. There is a suggestion that both post holders will be retained when the maternity cover ends but this needs urgent clarification. The SW covering was on her last day of service on the day before the peer review visit and had her contract extended for just three months a few hours before the visit. It is essential that this issue is addressed and the provision of at least 1 FTE equivalent worker is secured long term as soon as possible. There should actually be at least three full time workers for an effective social work service, so the service has been grossly understaffed for some years. Due to staffing constraints, SWs struggle to get to CF training events and can only provide a crisis service to a small number of patients. They cannot possibly meet the requirements of the Standards of Care guidelines.

Annual reviews: The SW does not have the time to carry out any annual reviews for patients, though would be very keen to carry out this part of the role. See above – there is little likelihood that the social worker(s) would be able to carry out anything other than firefighting with the number of hours and number of patients involved.

Outpatients: The SW sees patients by arrangement at outpatient's clinics as her time allows. As a single worker this means she cannot attend most clinics or keep up with or screen most outpatients for social and emotional issues.

Inpatients: The social worker is often based on the ward and sees patients who need contact with her relatively easily, but only as time allows.

Areas of good practice:

- A qualified experienced worker in post for several years in an established post. Cover provided by a similar worker who would be willing to stay on if further hours were agreed permanently.
- The SWs have a CF specialism and are seen as part of the team. She is involved in all meetings etc. SW has backing from the team for trying to obtain increased resources though in practice this has not led to a long term improvement as yet.
- A good service is provided for inpatients when time allows and there are good relationships with ward-based staff.

Areas for improvement:

- The role is greatly under resourced and thus the SWs are unable to do more than crisis management work. The position has deteriorated over recent years, as when the current post holder first worked in the role some years ago there were more social work hours than at present and somewhat fewer patients.
- In addition, the SW is expected to provide one day per month cover on duty for the local authority (LA) to cover the costs of being managed by them. The SW has to use LA recording systems which are time consuming and unrelated to the CF post. The post does not fit easily within the LA structure. There are political difficulties due to the post being located within the local authority and costs are higher than if the post was taken inhouse.
- The SWs are willing to be employed by the NHS and that might be a way forward to enable there to be proper staffing for the role.

Commissioner report

Leeds underwent a peer review four years ago and progress has been made in meeting the recommendations from that report. One such recommendation was for Leeds to establish a satellite unit in York which was to be run as a franchise. York is not a satellite of Leeds and the units are not currently linked. Whilst additional staffing has been secured recently, there continues to be a shortfall in the number of staff required to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)'. The repatriation of drugs needs to be prioritised within the hospital Trust and timetable agreed with commissioners for completion of this. During the review it was noted that there are plans to share access to medical notes and test results with patients and innovative ways of doing this were being explored.

York cystic fibrosis service is very small, currently with only 18 patients. There is an outstanding derogation to the service specification for the Trust to explore developing a joint service with Hull, in order to meet the requirements of the specification. Hull itself only has 40 patients; therefore the minimum number of 100 adult patients would not be reached by joining the two services. During the review the staffing numbers were reported to be over what is required, but the ongoing development and maintenance of the skills of the team was raised as a result of the small number of patients. The sustainability of the team is a further concern as there are single members of the MDT.

The view of local commissioners is that the overarching principle is the need to ensure that standards are achieved and that the best outcomes for patients are also achieved consistently. In terms of a commissioning model, in order to facilitate compliance with the service specification, to ensure sufficient patient numbers, to provide a local service with consistent outcomes, the option of Leeds being a centre and having outreach services at York and Hull will need to be explored.

User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	4	26	25	8	6	2
Female	6	4	16	22	8	2	2

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	103	24	3	0
From the ward staff	77	26	7	0
From the hospital	66	46	15	0

Areas of excellence:

1 Accessibility
2 Cleanliness
3 Cross-infection

Areas for improvement:

1 Food – poor quality.
2 Home IV service – delivers wrong goods/wrong times.
3 Car parking

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'

Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

Green = Meeting all the Cystic Fibrosis Trust's Standards of Care

Amber = Failing to meet all the Cystic Fibrosis Trust's Standards of Care with improvements required

Red = Failing to meet the Cystic Fibrosis Trust's Standards of Care with urgent action required

Hospital name

St James Hospital, Leeds

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	The Electronic Record is used for continuous review of the patient's status and needs. There are some deficiencies in access to some of the MDT for annual review.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	Complete dataset for 409 patients (391 for Leeds and 18 for York).
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	N/A	N/A	No network clinics.

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Red	Red	All patients see doctors, nurses, dietitian and physiotherapist but access to social work, psychology and pharmacist is not routine.
	Do staffing levels allow for safe and effective delivery of service?	Y	Green	Green	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Red	Red	Because of staffing shortfalls some of MDT have had difficulty attending educational events.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	

2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	High level of direct care by consultants and associate specialist.
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Amber	Amber	68% but 95% offered appointments.

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	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	Separate ward for Burkholderia. Standard precautions.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Amber	86% admitted within 7 days. Urgent problems prioritised with access to side rooms on ward 10 if needed.

3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Amber	Amber	63% had OGTT and most others assessed by glucose monitoring as appropriate.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Amber	Amber	79% for 2-year data.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Amber	Amber	74%: some patients failed to attend DEXA appointments.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	Electronic Record facilitates production of letters.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	Shortfall of physiotherapists precludes full weekend service.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Amber	Green	95% reviewed by dietitian as appropriate.
	% availability of a clinical psychologist at clinic	100%	Red	Red	Psychology service is accessed by referral.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist for inpatients	100%	Red If urgent ref to Psychology dept	Red	Problems with Psychology staffing levels recently.
	% availability of a social worker at clinic	100%	Red	Red	Social Work service is by referral.
	% availability of a social worker for inpatients	100%	Red	Red	
	% availability of pharmacist at clinic	100%	Red	Red	Pharmacist available if needed.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	7	<1%	
5.3	User survey undertaken a minimum of every three years	100%	Red	Amber	Satisfactory. User survey as part of peer review.
5.4	Service level agreements in place for all	100%	N/A	N/A	

Staffing levels (paediatric)

Whole time equivalent (WTE) or programmed activity (PA)

	75 patients	150 patients	250 patients	St James Hospital, Leeds 404 patients
Consultant 1	0.5	1	1	0.7 WTE
Consultant 2	0.3	0.5	1	0.7 WTE
Consultant 3			0.5	0.5 WTE
Staff grade/fellow	0.5	1	1	1 WTE
Specialist registrar	0.4	0.8	1	0.3 WTE
Research fellow				1 WTE
Specialist nurse	2	3	5	3.8 WTE
Physiotherapist	2	4	6	4.46 WTE
Dietitian	0.5	1	2	2.5 WTE
Clinical psychologist	0.5	1	2	1 WTE
Social worker	0.5	1	2	1.1 WTE
Pharmacist	0.5	1	1	1 WTE
Secretary	0.5	1	2	1.7 WTE
Database coordinator	0.4	0.8	1	0.4 WTE

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2013	
Demographics of centre – St James Hospital, Leeds	
Number of active patients registered (active being patients within the last two years)	416 (total network)
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	409; Leeds 391, York 18
Median age in years of active patients	29
Number of deaths in reporting year	10
Median age at death in reporting year	31

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	35 (9%)
	20–23 years	66 (17%)
	24–27 years	64 (16%)
	28–31 years	65 (16%)
	32–35 years	58 (15%)
	36–39 years	34 (9%)
	40–44 years	34 (9%)
	45–49 years	12 (3%)
	50+ years	23 (6%)

Genetics	
Number of patients and % of unknown genetics	17 (4%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=221) 122(55%)	(n= 170) 63(37)%
Number of patients and % with BMI <19 split by sex	24(11%)	32(19%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	23(96%)	28(89)%

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Medium FEV1% predicted at age 16 year split by sex		0	0
Number and medium (range) FEV1 %n predicted by age range and sex	16–19 years	15; 75.41 (34.78–118.32)	20; 64.77 (20.92–97.6)
	20–23 years	39: 75.78 (18.57–109.69)	27; 67.9 (21.37–127.22)
	24–27 years	32; 51.04 (21.13–109.44)	32; 64.84 (22.64–105.22)
	28–31 years	44; 58.84 (15.53–105.97)	21; 69.53 (26.7–105.47)
	32–35 years	32; 56.65 (18.46–106.26)	26; 61.36 (15.61–98.66)
	36–39 years	20; 71.57 (32.55–113.69)	14; 59.38 (25.12–96.04)
	40–44 years	20; 55.91 (22.75–106.09)	14; 60.25 (22.04–106.95)
	45–49 years	5; 60.61 (21.45–126.79)	7; 47.28 (20.29–94.43)
	50+ years	14; 60.85 (18.73–117.05)	9; 60.25 (20.58–111.77)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	35
	20–23 years	66
	24–27 years	64
	28–31 years	65
	32–35 years	58
	36–39 years	34
	40–44 years	34
	45–49 years	12
	50+ years	23
Number of patients with chronic PA by age group	16–19 years	15
	20–23 years	23
	24–27 years	35
	28–31 years	40
	32–35 years	32
	36–39 years	20
	40–44 years	20
	45–49 years	5
	50+ years	6

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	27 (7%)
Number and % of *cenocepacia*	6 (0.3%)
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	15 (4%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	26 (7%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	38 (10%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	124 (32%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	25 (6%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	22(6%) with PH; 10(3%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	20
Number of patients referred for transplantion assessment in previous three years	49
Number of patients receiving lung, liver, kidney transplants in previous three years	16

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	463
	20–23 years	826
	24–27 years	1095
	28–31 years	1083
	32–35 years	821
	36–39 years	323
	40–44 years	212
	45–49 years	117
	50+ years	49
Number of days of home IV therapy in reporting year split by age group	16–19 years	571
	20–23 years	409
	24–27 years	1435
	28–31 years	1351
	32–35 years	1665
	36–39 years	602
	40–44 years	742
	45–49 years	131
	50+ years	242
Total number of IV days split by age group	16–19 years	1034
	20–23 years	1235
	24–27 years	2530
	28–31 years	2434
	32–35 years	2486
	36–39 years	925
	40–44 years	954
	45–49 years	248
	50+ years	291

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV1, % predicted <85% (ie below normal) on DNase	n = 290 on DNase 230(79%)
If not on DNase, % on hypertonic saline	4(1%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	196 (50%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	107 (55%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	96 (49%) with chronic PA; 51 (26%) without

Patient survey

St James's Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	2	4	26	25	8	6	2
Female	6	4	16	22	8	2	2

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	83	38	9	1
Communication	82	42	6	3
Out-of-hours access	62	39	15	1
Homecare/community support	73	29	3	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	76	48	9	1
Waiting times	56	49	13	5
Cross-infection/segregation	88	39	4	0
Cleanliness	94	36	2	1
Annual review process	71	44	8	2
Transition	44	28	4	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	40	34	14	6
Cleanliness	73	18	3	0
Cross-infection/segregation	65	24	2	0
Food	15	26	30	20
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	52	27	4	2
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	35	32	14	4

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	69	21	4	0
Availability of equipment	70	35	3	0
Car parking	20	36	35	31

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	103	24	3	0
Of the ward staff	77	26	7	0
Of the hospital	66	46	15	0

Comments about CF team/hospital

"The home IV team needs replenishing with good staff. Nurses have left/moved/gone off sick – this has impacted. I have always done home IVs for many years. The waiting time to start has gone from within the week to up to a fortnight on one occasion. I am seeing staff struggle to keep up with ward outpatient visits. I usually put three hours' parking on the metre due to waiting times on the ward. I am worried that staff seem in such a rush that critical attention to detail is missed."

"I haven't been an inpatient for a number of years but did spend a number of months there prior to transplant and my memories are always pretty positive."

"I spoke to someone off the CF ward and asked to get some Tacrolimus as I had run out over the weekend and I did not get any joy from the staff I spoke to."

"St James's has an outstanding CF unit. The staff are fantastic and always go above and beyond for their patients. However, due to being beholden to hospital rules the food is terrible and of poor quality and the staff are under considerable pressure due to understaffing which can affect service from time to time. CF parking also needs addressing."

"Smoking outside the hospital – should be banned as I have to walk through it to get on the ward. Plus smoke can be smelt on the ward."

"I have attended Seacroft and St James's for over 20 years. The staff at every level are excellent. Their attitude professionalism and knowledge is excellent. They changed my life and continue to do so."

"I think communication has become very poor on the ward. I feel hospital is the wrong environment for someone with CF/diabetes and more money needs to be put into community care. People do not thrive in a hospital environment. It needs addressing. Not enough parking; area always full."

"I have felt for a while there have been a few issues with staffing on the home side of the team. ie home visits for flushing."

"Overall satisfactory service, however there can be room for improvement in terms of quicker service, good communications amongst team members and hospital food is rubbish!"

"As an older CF patient (late diagnosis) sometimes feel my worries and fears for the future are not always understood fully! And when I become unwell prefer to be in hospital than at home."

"My team is great. The support I have received all my life has been first class. Someone is always there when needed and all problems are quickly solved and when I needed help with housing issues they provided excellent support."

"The staff on the unit are excellent but they seem very stretched. The hospital is fair but again seems under staffed."

"Overall as a family we always see dedicated doctor, physio, dietitian, no complaints at all. But social worker help and advice needs looking at."

"I do not live in the Leeds area. The team always fit me in wherever they can and help with any needs or queries I have. The only improvement would be out-of-hours doctors and see regular doctors and not the new, less trained in cystic fibrosis."

"Not enough staff so means longer wait when needing treatment. Too long waiting times. When ill need treating immediately otherwise things get worse. Would be nice to not sometimes just feel like a number to the ward and feel more welcomed sometimes."

"Dedicated CF ward/inpatient parking too limited. Can be taken up with long-term ward patients; that's if available at all as often used for taxis and non CF parking."

"Haven't been in hospital for two years which is excellent for me and this is down to how great the CF team have been. LGI bone scan department made a mistake recently when measuring and weighing me which gave an invalid result of the scan. There was a recent mistake when doing Voriconazole levels and back at the lab the wrong drug was tested for in my blood and so the level of Voriconazole was never detected."

"I am extremely happy with my care. Particularly the holistic approach which all staff adopt. They never just address my medical needs but also support my role as a wife and mum with cystic fibrosis. I also feel very privileged to be under the care of a forward thinking, committed team."

"I have attended the adult CF unit for almost 20 years. I cannot fault the staff at all. Over the last couple of years waiting times for ward admission and home IV has increased. I assume this is due to volume of patients now attending the unit. The hospital should allow for this increase and provide the ward with more rooms/staff (in an ideal world)!"

"Advice given by telephone excellent, but sometimes have to wait two to three days for someone to phone me back in response to queries. More support from doctors when first diagnosed with diabetes would aid management and acceptance."

"I see a physiotherapist, dietitian, doctors and nurse every eight weeks and they are fantastic!"

"It is very obvious that the CF ward I attend is very low on staff at the moment resulting in longer waiting times for treatment."

"Parking costs very expensive."

"Great care and an extremely caring group of staff. Much appreciated."

"They are wonderful. Dedicated and caring."

"I find the staff easy to talk to and helpful with my needs in treating my condition."

"Excellent team, no complaints at all. Very happy."

"Very helpful, friendly, always there to offer advice. Not afraid to ask the staff anything and know you will always get the best answers. Very caring!"

"Cannot fault them – service they provide under a very strained NHS system is extraordinary."

"Since transplant haven't needed much care but still feel 'loved and wanted'!"

"The staff on ward 6 at St James are wonderful!"

"The carer should have access to patient results."

"Always very professional, but very friendly and approachable."

"I've never had any problems and the whole team are always so supportive of everything I need and do."

"Excellent service, always someone to talk to. No problems at all. Very happy with every aspect of my care."

"Very good service. Never stayed on ward."

"No late openings or flexibility for those who work."

"They are fantastic, always there, patient and understanding."

"Sometimes at outpatients I have to go into rooms that have just been vacated by another patient; this makes me feel uncomfortable."

"Really friendly staff. Good facility. Poor position of the smoking shelter at St James makes the rooms smell of smoke."

"Excellent team, service 100%, only drawback is lack of parking but that's a hospital issue not CF unit."

"Love my doctor and I am very well looked after, wouldn't go anywhere else."

"Have never used inpatient facility, probably because outpatient care is so good."

"A truly excellent team."

"The Leeds unit is fantastic. All staff are very professional and expert, but also very kind. I am always treated as an individual – the level of medical and pastoral care is second to none."

"Generally very helpful, jovial, thorough and accommodating."

"Transplant patient so not needing unit for IV treatment. Cannot fault unit with various other CF related issues; always contactable."

"Never enough beds and understaffed, leading to feeling guilty when phoning for emergency treatment when unwell."

"The CF team are excellent. There is a great consistency of care and advice across the whole team and it's very easy to get in contact with any of them outside of clinics. The overall feeling is that of a positive partnership between myself and the team. Car parking always an issue, but this is out of the control of the CF team."

"Excellent service - no problems with standard of care."

"They're all great to me!"

"I've been under the care of the CF team for 22 years. I have only good things to say about the team for all the help and things they have got me through!"

"The team's excellent, however they are clearly short-staffed. Whilst this isn't noticeably affecting patient care It's very annoying seeing good staff run ragged trying to keep things going. Dr E and the liaison team are particularly good."

"I would rate my care at Leeds very highly. From housekeepers to clinical staff they all do excellent work and appear to care greatly about what they do. My quality of life is in no small part down to all their care and commitment. I love them all!"

"More car parking spaces and CF patients should have permanent parking permits for clinic visits given to them while they are a patient at the clinic."

"Very helpful CF team, always looking out for my needs."

"The team are really friendly, caring."

"I have an amazing team who work together and are very patient focused. I also attend my transplant clinic at another hospital and it is much better at my CF clinic."

"Good home care - during IVs. Poor care during hospital admission as I am one of the patients who are segregated and admitted to ward 9 – normally full of elderly patients – I have had bad experiences – 1) I have been given the incorrect drugs, 2) drugs have been given incorrectly"

"Think the staff at my CF unit at St James are fantastic! Wouldn't be here today if not for their top level approach to care."

"I wouldn't be here without them that's for sure."

"The only real problem as an inpatient is the quality of the food. I was amazed to learn it starts 'life' in South Wales, then transported to Leeds, re-heated etc. As for my care from the team/hospital it's second to none and for this I am truly grateful."

"The care that I receive is consistent, reliable, comprehensive and efficient. Many thanks to the team!"

"They are exceptional."

"The waiting time in between seeing a doctor and other professionals is poor."

Patient/parent interviews

Patient A

Good practice/positive comments:

Patient A referred to an absolutely brilliant CF team considering the number of patients they're treating. He explained that there's a philosophy of 'shared responsibility' (CF team and patient) and that they go above and beyond for him. He sees them at weekends, on the ward early mornings and until 7pm. He felt that he wouldn't be here now without them and that they've given him a lot of help/advice when applying for university.

He felt that there are very good segregation measures in place and that hand hygiene and infection control measures are adhered to by staff.

He believed that annual review is well arranged – the team do his annual review assessments whilst he's on the ward.

Outpatient clinic: he is directed straight to a side room and so safely isolated. Service is very accommodating with appointments, but Friday clinics (chronic PA) are busy.

Inpatient care: he reported good care on the ward, but that staff are overworked.

Areas for improvement/less positive comments:

Patient A felt that food on the ward is pretty bad; though an NHS problem. They bring in pre-cooked meals. He explained that patients have made sarcastic comments on Hospital Trust's catering feedback forms, to which there's been no response. He can't fault house-keepers as the food is hot and on time. He has full English breakfast which he considers fine; toastie and salad or similar for lunch and there's a good range of trolley snacks. Due to the hospital menu, he said he knew that some CF patients spend £100–£200 on food whilst in on the ward.

He felt staff on the ward are overworked. He added that there's a noticeable strain on ward staff – drugs are late at times, but that he understands why. He added that the Hospital Trust takes staff off the CF ward to work on other wards which he saw as a problem.

He complained of smoking outside the building below the ward which he felt is still a problem. He added that a smoker's shelter was built for them, but not used. Instead they smoke below the CF ward which is five floors above. A 'Smoking Marshall' was employed but he's not sure what's happened to him/her. "The smoking's still going on...always the same", he added.

Homecare: He explained he'd been having problems with Calea homecare service recently. Last admission was two months ago to start IVs then finish them at home. His IVs are in eclipses, pre-mixed.

Patient B

Good practice/positive comments:

Patient B felt that the CF Centre is an outstanding unit. CF team is excellent and the patients are classed as individuals, ”It’s like a family’, she added.

She said that outpatient clinic is exceptionally good, attending every four weeks. Hand hygiene amongst staff is excellent. Cross-infection measures are good and she added that patients are segregated, given set appointment times, and that she sees the whole team.

Inpatient ward: Patient B believed that catering is generally good, has improved, with plenty of choice and piping hot food. She added that physiotherapy and exercise provision is very good – ward gym access once or twice daily, Wii provided too.

Areas for improvement/less positive comments:

Patient B called annual review a long appointment.

She explained that she was late diagnosis and felt that the CF team didn’t understand her shock and the support she needed at first; she felt on her own. She’s now able to express herself and the CF team now understand the support she needed and still needs.

She’s had home IVs twice. She said she felt pressurised to do home IVs which she’s not comfortable with – ie to get treatment sooner rather than waiting for a bed on the ward. She has fear/worry about self-administering IVs at home alone. She felt the team don’t understand the home pressures.

Smoking outside our ward – outside at ground level – is still a problem, according to Patient B. There are four CF inpatient side rooms at the front of the building. She added, “with the windows open it smells of smoke and my friends/visitors remark that my room smells smoky.”

Patient C

Good practice/positive comments:

Patient C described segregation as good in outpatient clinics, where patients are seen quickly and the team are friendly. He added that the CF team gives good explanations of treatments and always asks him if he’s happy with a particular treatment. He went on to say that the team always clean hands and uses aprons.

He felt it’s easy to be able to contact his MDT and easy to contact someone out of hours, by phoning the ward.

Areas for improvement/less positive comments:

Patient C felt that Calea homecare service used to be good with IV deliveries, but has been quite poor recently – ie feed delivered to neighbour, no prior notification by email/text of delivery being made, delivery driver rude.

General comments: He explained that his annual review is conducted as one appointment at the same hospital. DEXA scan and liver scan take place at the same site, but not at the same time.

Patient is relatively well and so does not have experience of the ward/inpatient care.

Patient D

Good practice/positive comments:

Patient D explained that her outpatient clinics are at Seacroft, which is easier to get to for her and that there is free parking for those on DLA.

She mentioned that segregation and cross-infection measures are strict. Eg physio brings the lung function machine to her clinic room rather than patients going into the same room after one another; patients with *Burkholderia cepacia* are asked to use a different lift.

Patient D felt she can usually get to see her CF team the next day at clinic or as a ward-based assessment – eg as a day case to start IVs.

She felt that the CF service is patient-led rather than the team dictating, which she's happy about, and that they recognise that she's sensible.

Her home IVs are ready made up, heparin also pre-drawn.

Areas for improvement/less positive comments:

Patient D felt that food on the ward is not great, vegetarian options are limited and that portion sizes are small (however, "fried breakfast is good").

Calea homecare company: She's had problems with the delivery company – recently delivered at the wrong time and missed some parts of the order.

Admission times: Can have to wait for a week, or sometimes up to two weeks for a bed on the ward, although the team will offer to find her a bed on a non-CF ward. She reported sometimes having to wait to start home IVs.

She referred to a shortage of liaison nurses recently, but she knows they're trying to sort it.

Smoking: Patient D complained that people are "always smoking outside the hospital, below the CF ward."

Patient E

Good practice/positive comments:

Patient E referred to the CF centre as "a brilliant centre with a good, helpful CF team who get me in as quickly as possible."

He described the liaison nurses as especially good.

Explained segregation, Patient E said that he's directed straight into a side room at clinic where he stays and that segregation and hand hygiene are both very good and that staff wear aprons; ward is kept spotless.

He felt it is a lot better for patients since moving things to St James's Hospital, though Seacroft he felt was better for outpatients as it's quieter – lung function, bloods and x-ray are just around the corner.

Home IV service (Calea) he referred to as "a great service".

Areas for improvement/less positive comments:

He has encountered problems getting DEXA scan appointments.

Parking at St James's Hospital is a problem, according to Patient E: three bays across the road for CF patients, so they have to cross the road, go up to the ward to get a permit then return to the car with a permit. He suggested that a permit be provided at reception for those who are too unwell to walk far.

He recommended a better explanation of how Calea home service works for first time users of IV homecare – ie a leaflet to explain. First time he received delivery; he just received a fridge and all the medications/ancillaries, but didn't know what to do next.

Other general info: His annual review MOT takes place at one of the outpatient clinic appointments. He attends clinic every other month. "My DEXA scan is every three years at Leeds General Infirmary."

Patient F

Good practice/positive comments:

Patient F described physiotherapists as great for coming out to see her at home, to check her oxygen sats, discuss her physio and exercise. She felt dietetic support is excellent and meals on the ward are good, portion size is good, but the menu needs variation.

Patient F described segregation and hand hygiene as good, and added that rooms are deep-cleaned on the ward. She described ward cleanliness as impeccable.

Patient F is happy with advice and support from the CF team and she's pleased to have been offered new drugs – eg Cayston.

Her home IV service is fine; sometimes the drugs come pre-mixed, depending on which antibiotic she's taking. Meropenem isn't pre-mixed.

Areas for improvement/less positive comments:

Patient F made the following comments:

Psychologist post is in transition, with a new psychologist in post.

Bedside buzzer not answered when she's got low oxygen sats and feels faint.

She feels rushed to leave on the day of discharge.

On the ward she is in isolation and so feels a burden. She added that if she doesn't call for support, the long line stops working. She feels a burden for asking for it to be flushed off.

She suggested Room 8 (previously a bathroom) on the ward needs to be reconsidered; no ventilation in room. Needs a window that can be opened.

Bank agency staff should note down data in her notes

She was dissatisfied that she'd been promised referral to another specialist (non-CF) team, but it has not been followed up.

She felt that DVDs and TV are not enough for those isolated by bugs. She added that there needs to be some variation in entertainment for inpatients. There's no ward Wi-Fi, nor laptops provided.

She felt that it needs explaining that you can order food from the ward children's menu or order double portions. She believed that some patients don't eat well on the ward.

Other general info: Patient F's annual review MOT takes place when at clinic or on the ward.

Peer review day interviews

Patient One

Female patient, 49 years of age. Lives with her husband and two grown up children in their twenties. She was diagnosed when she was 42 years old after a lifetime of being treated for asthma and later in her thirties was treated for Bronchiectasis. She has one brother who has tested negative for cystic fibrosis and her children are carriers.

The patient lives about 20 minutes by car from the hospital. Either her family bring her in or there is a bus available. The hospital will also provide a taxi facility if required.

The patient has not been admitted since March, she is on day two of her stay.

Areas of excellence:

She is treated well as a person by the team members and is on first name terms, she thinks very highly of them.

The hospital rooms are spotlessly clean, and she does not venture out of her room during her stay.

She can be given a time slot to use the gym; however she prefers to use the weights brought to her room.

She loves the food, it is excellent.

Areas for improvement:

At diagnosis, she would have benefitted from being given more information. She felt she had to do a lot of research into the condition as there was little information offered at that time. It may be better now though for late diagnoses?

Patient two

Female. Diagnosed as a child. Rarely admitted. Has attended several major CF centres in England and Netherlands over time due to moving with work.

Areas of excellence:

Clean, homely environment, recently painted

Treated well by nurses and all team members. Care is very good.

Areas for improvement:

No complaints except that the fridges are noisy at night, so she has to switch off.

Deliveries at night via lorries outside her room disrupt her sleep. Therefore, even in hot weather she needs to keep the window shut.

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

Microbiology status: All except *B. Cepacia* patients on J12

	Hospital Name	St James's Hospital, Leeds
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	8 large well ventilated rooms.
Do patients spend any time in waiting room?	No	Patients taken directly to room and staff visit them in room.
Is there easy access to toilets?	Yes	Five unisex toilets.
Where do height and weight measurements take place? Is this appropriate?		In individual clinic room.
Where are the lung function tests done for each visit?		In individual clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	No	Annual review day as all parts of annual review performed over a 12 month period.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Once-monthly clinic run efficiently by dietitian and diabetologist.
Transition patients – can they get tour of outpatients' facilities?	Yes	Video tour, checklist, meet with paediatric and adult nurse, consultant and MDT at clinic.
Transition/new patients – do they get information pack?	Yes	

Additional comments:

- If future investment were to be made in Seacroft, ethernet would be very useful.

		Hospital name	St James's Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		14	12 side rooms on JO6, 2 on J12 for patients with *B. Cepacia* and 2 on J10 for acute admissions which would then be transferred to JO6.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Showers
Do CF patients have to share any bathroom facilities?		No	All rooms are en suite but if a patient wants a bath there is only one bathroom.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Locker with key.
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	Carers room with kitchen and table, 2 bed settees and hot drinks facility and microwave.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Within reason.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	All rooms have a fridge. Also, patients' kitchen – cross-infection prevention is considered. Access to washing machine, dryer and iron.
What facilities are provided for teenagers?			DVDs, IT, TV, X boxes, dongles.

Environmental walkthrough: ward

Ward name: J06 adult CF unit

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	One patient at a time in gym, always supervised. Good equipment for rooms.
What facilities are there to help with school and further studies?		IT, Flexible practice allowing patients to attend college and exams. Letters of support provided as required.
Is there a relatives' room?		Yes, carers' room.
What internet access is there?		Ethernet, dongles ordered. Good hospital Wi-Fi however, not available for patients at present.
What facilities are there to enable students to continue to work and study?		IT, computers in every room.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Encourage patients to use cooled, boiled water in plastic container/bowl to clean equipment with filtered water.
What facilities are provided for those with MRSA?		Side room, full isolation, special sticker on door.
What facilities are provided for those with *B. cepacia*?		J12. Side room, isolation if more than one patient however, this is unusual.
What facilities are provided for those with other complex microbiology?		JO6, side room, full isolation, special sticker on door. Hydrogen Peroxide Vaporisation between patients.
Are patient information leaflets readily available on ward?		TV screens with information on ward, website available and information provided also as required.
Transition patients – can they get a tour of ward facilities?	Yes	Visit by liaison nurse, receive video tour with information pack, transfer includes adolescent clinic and can visit ward.

Additional comments

- Ward very clean and tidy; recently repainted. Staffed by enthusiastic and caring staff.
- Negative pressure rooms would be beneficial in future.
- The additional five rooms with clinical space on the ward are well equipped clean and suitable for day care. They do, however, require access to a toilet.
- In future a specialised dedicated day case/outpatient unit requires further consideration in case of closure of the Seacroft outpatient unit.

	Hospital name	St James's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	4 spaces free parking at Leeds. Also, permits can be given for free parking. Patients have to pay for parking at Seacroft outpatients. If outpatients moved to Leeds then free and adequate parking will need to be considered.
Other hospital areas		
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, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	Flow is controlled to areas such as X ray where there could possibly be a risk. Different lifts are used by those with different microbiology however.
Do patients have to wait at pharmacy for prescriptions?	No	Patients are given FP 10 prescriptions to take to their community pharmacy
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Feedback via 'Friends and Family' programme and results displayed on the ward.

Additional comments

- Smoking shelter located directly outside main entrance and below CF unit located on sixth floor. Would strongly recommend this is moved immediately from near the main entrance. Main entrance and some rooms on ward smell very smoky. This is unacceptable and presents a health risk as smoke comes directly into the ward, patient rooms and staff areas. On hot days patients and staff have the choice of being too hot or the smell of smoke. This could be easily rectified by moving the smoking shelter away from the hospital building and operating a strict no smoking policy in the hospital and grounds.

Consultant

The York cystic fibrosis service is led by a single consultant who has an interest in cystic fibrosis, has had training in CF, and attends educational events and CF conferences. The service is therefore very reliant on one doctor and it is difficult to provide cover for leave and for out-of-hours care. Informal arrangements exist for contacting this consultant out-of-hours, and with the current small patient numbers there are usually only one to two inpatients at any point in time. The patient feedback survey and interviews confirm a high level of satisfaction with the service provided. The difficulties in providing full care in this setting are recognized, and the favoured option of the York team is to develop services in conjunction with Hull.

Specialist nursing

There is currently 1 Band 7, 0.6 whole time equivalent (WTE) clinical nurse specialist (CNS). This meets the cystic fibrosis standards of care as there are 23 patients. He also works in bronchiectasis for 0.4 (WTE). The cystic fibrosis service is covered five days per week.

The service benefits from a dedicated and enthusiastic CNS. He attends local network meetings and is encouraged to attend national and international conferences which he will do. He will shortly be a nurse prescriber.

As he meets the standards for nursing time unfortunately there is no provision for cover in his absence. Currently plans are in process to train a Band 5 nurse from the ward (who will be back filled) to become a link nurse to cover for sickness and annual leave.

Areas of good practice:

- Clinically skilled in inserting midlines and accessing ports.
- Home care service available if required.
- Personal service for patients from dedicated CNS.

Areas for improvement:

- Cover for sickness and annual leave.
- Difficulty in maintaining education of ward staff due to low patient numbers.

Recommendations:

- Establish a link nurse who can cover for sickness and annual leave.
- Social worker time required as CNS has to carry out this role which impacts on nursing time.

Physiotherapy

Physiotherapy care provided by one specialist physiotherapist (0.8 WTE). In the absence of the specialist CF physiotherapist, cover is provided by a Band 6 with experience in cystic fibrosis.

Recent restructure of therapy services has resulted in physiotherapy cover being extended across both paediatric and adult CF care with no additional staffing. A business case is currently under review for an additional Band 6 physiotherapist (0.8 WTE).

Inpatients are offered twice daily airway clearance and exercise during the week. Treatment is available as appropriate at the weekends. Members of the physiotherapy department that cover weekends and on call have opportunity for supervision and training in CF care. Exercise equipment is available to use in patient rooms and there is limited availability to a well-equipped physiotherapy gym.

Home visits are offered as appropriate.

Areas of good practice:

- Specialist physiotherapy input by experienced, motivated physiotherapist who has strong links with the ACPCF and regular attendance at conferences. The physiotherapist has prescriber rights which have been found to be beneficial. Works as integrated member of the CF team.
- Inpatient and outpatient care in line with the Cystic Fibrosis Trust's 'Standards of Care (2011)' including annual reviews with detailed documentation. Additional continence/musculoskeletal clinics offered as part of annual review where patients are assessed by specialist physiotherapists and offered treatment as appropriate.
- Wide variety of airway clearance techniques available. Ring fenced budget for equipment. Good working relationship with nurses to provide NIV service.

Recommendations:

- Small number of patients may not offer adequate opportunity to maintain clinical skills/ development. Exposure to more complex patients at larger centres on a regular basis would be beneficial.
- Improved access to exercise facilities would enable patients to perform a wider range of exercise as inpatients.
- For the current number of adult patients the 0.8 WTE staffing is slightly above the recommendations in the standards of care (0.7 WTE). However, further physiotherapy staffing would be required if input is continued to paediatric CF patients.

Dietetics

The current dietetic service is provided by 0.2WTE Band 6 dietitian.

The dietitian is a member of the UK Dietitians' CF Interest Group and regularly attends meetings. The dietitian has had the opportunity to attend CF conferences but due to limited study leave allowance and covering more than one speciality these opportunities have not been taken.

The dietitian will attend ward rounds when they occur but there is not a formal structure to when they occur due to low patient numbers.

Cover is provided for inpatients but not outpatients during periods of leave.

The dietitian has participated in audits.

There is no formal transition clinic, due to low patient numbers, transition is dealt with on a case by case basis. Links are set up with the paediatric dietitians to ensure a clear handover of patient care.

Areas of good practice:

- A keen and enthusiastic dietitian who works hard within the current service to provide patient care.
- Participation in audit.
- Good liaison with catering to assure appropriate food provision for patients with cystic fibrosis.

Recommendations:

- The current staffing level of 0.2 WTE is generously within current recommendations of 1.0 WTE dietitian for 150 patients. The dietitian's job is flexible and she fits her CF work around her other clinical specialities. If patient numbers are to increase she may need to ensure protected time for CF care.
- With exposure to a low critical mass of patients it would be beneficial for the dietitian to set up more formal clinical supervisory support from an experienced dietitian working in a larger CF centre.

Pharmacy

The clinical pharmacy service is provided by a 0.8 WTE Band 8a directorate pharmacist for gastroenterology/respiratory medicine, whose time is split 50:50 for core pharmacy services and ward/directorate work. There is no recommendation from the Cystic Fibrosis Trust's 'Standards of Care (2011)' for a clinic of this size.

- The pharmacist is interested in increasing the pharmacy support to the CF team as the service grows. They are not a member of the CF pharmacist group, but recently attended the Cystic Fibrosis Trust's medical conference. They have not been involved in any CF research/audits due to limited time.
- The pharmacist does not attend MDTs, but works closely with the physiotherapist and consultant and is available for advice. Clinics and annual reviews are not currently supported.
- On the one day per week when the senior pharmacist does not work, cover for the ward is provided by a Band 6 pharmacist who has limited time and minimal training in CF, although there are senior pharmacists for advice if necessary. The senior pharmacist delivers an annual CPD session on cystic fibrosis.
- Patients benefit from a home IV service. There is a self-administration scheme in place with assessments undertaken by the pharmacist or by a physiotherapist. There is a pharmacist on call out of hours, medicines information and aseptic services which can provide CIVAS. A homecare service is available for the provision of high-cost drugs, although there is a plan to bring the dispensing of these back into the Trust. Home IV assessments are undertaken by the CF nurse specialist.

Areas of Good Practice:

- Provision of home IV service.
- Patients can self-administer medicines during in-patient stays to support adherence.

Areas for improvement:

- One day per week when the senior pharmacist is not available, there is only a 'pick-up' pharmacy service to the ward which is less flexible than the other days.

Recommendations:

- The pharmacist should join the UK CF Pharmacist group.
- As the service grows, consideration should be given to the appropriate time to appoint a 0.5 WTE Band 8a pharmacist (required for 75 patients) to develop clinical pharmacy services to CF patients, including inpatient and outpatient review.

Psychology

York adult cystic fibrosis service has a Band 8b Highly Specialist Clinical Psychologist (0.2wte). She is registered with the Health & Care Professions Council (HCPC) and is a member of the UK Psychosocial Professions in CF (UKPPCF) group. She attends the UKPPCF study days and attended the European CF conference in 2014.

The psychologist attends all the fortnightly CF multidisciplinary team meetings where both inpatients and outpatients are discussed. She is unable to attend the team business meetings as these are held on a day on which she doesn't work; she does, however, receive the meeting minutes.

The psychologist invites all patients for an annual psychological review and those who do not attend are sent screening questionnaires to complete. This has resulted in roughly two-thirds of patients being seen by the psychologist for an annual review.

The psychologist responds to outpatient referrals within two weeks. She endeavours to see inpatients within one week of referral and is planning to introduce ring-fenced time on the ward to facilitate this.

There is no psychology cover for annual leave or sick leave, but the team are aware of the hospital's emergency psychiatric service.

Areas of good practice:

- Clinical psychology involvement for newly diagnosed patients and for those being considered for transplant.
- The psychologist works closely with other team members, especially the dietitian.
- The psychologist endeavours to meet all new patients transitioning from child services and is carrying out a research project into the transition process.

Areas for improvement:

- The psychologist does not have a base at the CF unit and there is no clinical space there in which she can see patients. This means that patients have to be seen in the general psychology outpatients department, which is not always appropriate. In addition, the lack of a 'base' has inevitably led to the psychologist feeling less 'embedded' in the team.
- The psychologist works in the hospital for two days per week and has two sessions allocated for CF work; while she does try to be as flexible with her time as possible, this does mean that it is extremely difficult to attend some clinics/meetings routinely and many patients may not be able to access psychological input.

Recommendations:

- Optimisation of the limited psychology resource would be facilitated by the psychologist being based in the CF unit and her being able to see outpatients there.

The recommended clinical psychology staffing in the Cystic Fibrosis Trust's 'Standards of Care (2011)' for this patient population is between 0.1 and 0.2 WTE. While the provision at the York centre does not, therefore, represent a shortfall in absolute terms, it does not allow the psychologist to attend all meetings and severely restricts the availability of psychology input at all the points in the patient journey as recommended in the Cystic Fibrosis Trust's Standards of Care.

Social Work

There is no SW working with the York adult CF team for their 20 patients. This would be problematic to organise as only one day of SW provision would be required for the number of patients.

Annual Reviews:. N/A

Outpatients: N/A

Inpatients: N/A

Strengths: The team would like to have social work input, and is psychosocially minded. It has a very holistic approach to its patients' wellbeing – evidenced by provision of food vouchers, free parking, newsletters and seeking patient opinion.

Difficulties: The team has a very small service which has raised a number of peer review issues. The plan is to look at working with another service, possibly Hull. This may result in possibly working on shared social work input as Hull do not have a SW either but a shared service may be able to recruit to a post. (The UKPPCF would be able to advise on recruitment if this looks helpful.)

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

Green = Meeting all the Cystic Fibrosis Trust's Standards of Care

Amber = Failing to meet all the Cystic Fibrosis Trust's Standards of Care with improvements required

Red = Failing to meet the Cystic Fibrosis Trust's Standards of Care with urgent action required

Hospital name

York Teaching Hospital

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	York is not currently recognized as a full specialist centre.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	N/A	N/A	No network

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Red	All patients seen by doctor, physiotherapist, dietitian, but no routine social worker, pharmacist or psychology review.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis 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	Green	

2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red: patient numbers are too small for specific clinic.	Amber	Very few patients with diabetes.

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	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	

3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Red 42% had 32% diagnosed 21% declined 5% unclear	Amber	Some patients did not attend for diabetes screening.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Amber	81% had DEXA.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Red Additional 0.2 admin support recently.	Amber	Some delays in summaries. Additional administrative support now in place
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Amber	80% receive.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	
	% availability of a clinical psychologist at clinic	100%	Red Sees patients outside of clinic.	Red	Psychologist access available by referral.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist for inpatients	100%	Red Works 2 days a week.	Amber	Psychology time being increased.
	% availability of a social worker at clinic	100%	Red In business case	Red	No social worker appointed.
	% availability of a social worker at for inpatients	100%	Red In business case	Red	
	% availability of pharmacist at clinic	100%	Red Phone advice only.	Red	Pharmacist available if needed.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A no end-of-life issues in last year.	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	6	6	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	N/A	N/A	

Staffing levels (paediatric)

Whole time equivalent (WTE) or programmed activity (PA)

	75 patients	150 patients	250 patients	York Teaching Hospital 20 patients
Consultant 1	0.5	1	1	9 PAs for CF and respiratory.
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.4	0.8	1	2 WTE available for CF and respiratory.
Specialist nurse	2	3	5	0.6
Physiotherapist	2	4	6	0.8
Dietitian	0.5	1	2	0.2
Clinical psychologist	0.5	1	2	0.2
Social worker	0.5	1	2	0 funding with business case.
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	0.2 database time included in time.
Database coordinator	0.4	0.8	1	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2013	
Demographics of centre – York Teaching Hospital	
Number of active patients registered (active being patients within the last two years)	N/A
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	18
Median age in years of active patients	26.5
Number of deaths in reporting year	0
Median age at death in reporting year	N/A

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	3 (17%)
	20–23 years	3 (17%)
	24–27 years	4 (21.5%)
	28–31 years	3 (17%)
	32–35 years	1 (5.5%)
	36–39 years	1 (5.5%)
	40–44 years	1 (5.5%)
	45–49 years	1 (5.5%)
	50+ years	1 (5.5%)

Genetics	
Number of patients and % of unknown genetics	1 (5.5%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	n=10, 4: 40%	n=8, 3: 37.5%
Number of patients and % with BMI <19 split by sex	1,10%	1, 12.5%
Number of patients and % with BMI <19 split by sex on supplementary feeding	1(100%)	1(100%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Medium FEV1% predicted at age 16 year split by sex		0	0
Number and medium (range) FEV1 %n predicted by age range and sex	16–19 years	0	3; 69.98 (57.58–69.68)
	20–23 years	2; 50.02 (27.06–72.98)	1;54.95
	24–27 years	2; 73.3 (67.03–79.56)	2; 50.97 (24.67–77.26)
	28–31 years	2; 67.73 (52.21–83.25)	1; 67.63
	32–35 years	1; 108.33	0
	36–39 years	1; 95.56	0
	40–44 years	1; 27.46	0
	45–49 years	0	1; 52.28
	50+ years	1; 51.61	0

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	3
	20–23 years	3
	24–27 years	4
	28–31 years	3
	32–35 years	1
	36–39 years	1
	40–44 years	1
	45–49 years	1
	50+ years	1
Number of patients with chronic PA by age group	16–19 years	1
	20–23 years	1
	24–27 years	2
	28–31 years	2
	32–35 years	1
	36–39 years	0
	40–44 years	1
	45–49 years	1
	50+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	2 (11%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (5.5%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	2 (11%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	2 (11%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	5 (28%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	1
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	0
	20–23 years	63
	24–27 years	0
	28–31 years	6
	32–35 years	0
	36–39 years	0
	40–44 years	11
	45–49 years	0
	50+ years	14
Number of days of home IV therapy in reporting year split by age group	16–19 years	10
	20–23 years	26
	24–27 years	4
	28–31 years	4
	32–35 years	0
	36–39 years	0
	40–44 years	17
	45–49 years	0
	50+ years	0
Total number of IV days split by age group	16–19 years	10
	20–23 years	89
	24–27 years	4
	28–31 years	10
	32–35 years	0
	36–39 years	0
	40–44 years	28
	45–49 years	0
	50+ years	14

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV1, % predicted <85% (ie below normal) on DNase	n=16; 13 ;(81%)
If not on DNase, % on hypertonic saline	1 (6%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	9 (50%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	9 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	6(60%) with chronic PA; 5(56%) without chronic PA.

Patient survey

York adults CF unit

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	0	0	2	2	1	0	0
Female	1	2	3	1	0	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	10	3	0	0
Communication	9	4	0	0
Out-of-hours access	5	4	2	0
Homecare/community support	5	3	2	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	7	6	0	0
Waiting times	4	4	3	0
Cross-infection/segregation	9	2	2	0
Cleanliness	9	2	2	0
Annual review process	7	4	1	0
Transition	6	2	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	6	2	3	0
Cleanliness	9	1	1	0
Cross-infection/segregation	7	2	1	0
Food	3	4	3	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	7	3	1	0
Physiotherapy availability to assist/assess airway clearance and exercise during weekends	4	4	1	0

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	6	3	2	0
Availability of equipment	8	5	0	0
Car parking	7	5	1	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	9	4	0	0
Of the ward staff	5	6	1	0
Of the hospital	5	5	3	0

Comments about CF team/hospital

"They're lovely, happy and friendly people. "

"I have absolutely no complaints."

"Really good overall."

"My CF team are there when I need them which is a great comfort to me."

"CF team help a lot and make you feel comfortable."

"Mostly excellent, although bed availably has become more of an issue in recent times."

"My CF team is honestly one of the best I've had. They're all very helpful and try to come up with a care plan specific to your needs."

"Fantastic team at York, always a phone call away and can't do enough for me."

"My CF York team are my family, they do their utmost best. I would not be here without them. The hospital have brilliant, caring staff who always make time for you even if it is only five minutes. Down side is the parking, but that is being dealt with which is good. Food is awesome; very happy."

Patient interviews

Patient One

Good practice/positive comments

Patient One felt that the CF team is always there when needed; this made her feel secure.

She receives good advice from the CF team and she felt that they keep an eye on her FEV1 and weight. She has access to the whole CF team at outpatient clinic, including psychosocial support.

Patient One felt that the consultant involves her in any decision making about her treatments, taking into account this patient's asthma too. If she's panicking, the CF team will see this patient quickly she felt.

This patient reported good segregation measures at York CF unit, separate rooms for outpatient clinics and good use of hand gel/hand hygiene by staff and patients.

When she first attended York (as late diagnosis) she weighed two stones less than she does now – good diet and good appetite she felt. She's happy with the dietetic advice, but is incidentally pancreatic sufficient. She doesn't have IV antibiotics; only nebulised.

She's offered annual review appointment each year – X-ray, DEXA scan, CT scan and "'loads of blood tests." Patient 1 explained that annual review outcome is reported back to her by letter; a very detailed letter, with all results and typed word for word. Her annual review tests all take place at York Hospital, the DEXA scan at the Nuffield behind York hospital.

Patient One described good facilities for disabled parking, right outside front door of hospital and she explained patients are given permits if staying at the hospital.

Patient One had no suggestions for improvement to the York CF service. She said she felt secure knowing the CF team is there. She did not require home visits.

Outpatients/CF clinic

	Hospital Name	York Teaching Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Spacious waiting area.
Do patients spend any time in waiting room?	No	Patients register at desk and go direct to one of three clinic rooms.
Is there easy access to toilets?	Yes	Male/female and disabled.
Where do height and weight measurements take place? Is this appropriate?	Yes	In clinic room.
Where are the lung function tests done for each visit?		Clinic room – hand held spirometer using separate flow heads.
Are clinic rooms appropriately sized?	Yes	Well equipped, bright and clean.
For annual review patients, are any distractions provided?	N/A	Would bring own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Close relationship with DSN and can call for advice during regular clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	CNS and physiotherapist known from paeds dept. Patients meet for informal chat, tour and introduced to team.
Transition/new patients – do they get information pack?	Yes	Very informative detailed pack supplied.

Additional comments:

- Dedicated cleaner on hand if required to clean rooms in between patients.
- *Burkholderia cepacia* patients would be seen at the end of clinic; a separate room booked.
- Patients can see team out of clinic hours.
- They can be seen in a well-equipped treatment room on the ward when required. IVs can be started here.
- Mallard restaurant – newly refurbished and functioning. Seating area in the process of being completed. Impressive, large and bright, self-service, with a large variety of food cooked inhouse; drinks and snacks available. Two to three items available to order from menu. Vouchers for free food funded by Trust issued to inpatients and those at annual review appointment.

		Hospital name	York Teaching Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Suitable	Would not generally admit more than one patient at any 1 time.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		2	The rooms went through a total refurbishment 2 and a half years ago for CF patient admittance.
Do the en suites have:	**Toilets?**	Yes	1 room has an en suite toilet and basin, the other has wet room shower.
	Wash basins?	Yes	
	Bath or shower?		
Do CF patients have to share any bathroom facilities?		No	All rooms are en suite but if a patient wants a bath there is only one bathroom.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Lockable drugs locker and also side cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Rooms have wall-mounted flat screen TVs.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Z bed can be put in room. Could also stay in relative's room.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Open	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Each room has a fridge.
What facilities are provided for teenagers?			Wi-Fi, TV, DVD player – patients tend to bring own laptops, IPads etc.

Environmental walkthrough: ward – 21 patients (rising to 24 patients by year end)

Ward name: 34 – 33rd Floor (lift access)

Microbiology status: General respiratory – suitable for 30 patients

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Gym session can be booked. Patients tend not to use gym for cross infection reasons and prefer weights, pedals or bike brought to their room.
What facilities are there to help with school and further studies?		Wi-Fi
Is there a relatives' room?	Yes	Room can be booked, it contains a bed for overnight stay.
What internet access is there?		Wi-Fi
What facilities are there to enable students to continue to work and study?		Patients bring own IT in.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in room. Advise patients to take parts home and boil. There is access to clinical cleaning services during I/P stay.
What facilities are provided for those with MRSA?		Own room – follow guidelines.
What facilities are provided for those with *B. cepacia*?		Own room – follow guidelines.
What facilities are provided for those with other complex microbiology?		Own room – follow guidelines.
Are patient information leaflets readily available on ward?	Yes	Printed as required or directed to website. Information also in transition pack.
Transition patients – can they get a tour of ward facilities?	Yes	Supported by an informative transition pack.

Additional comments

- Transition – CNS and physiotherapist are familiar faces from the paediatric service, patient is taken for an informal meeting, then taken for a tour of facilities.
- CNS and physiotherapist are both prescribers. Ward pharmacist delivers prescriptions to inpatients.
- Team mobile phone – one team member will have the phone for patient access.
- Art Therapy team – set up and ready for use. Artwork around hospital created by patients.
- Dedicated ward cleaner available.
- The ward has just had a deep clean, all patients were evacuated to another ward for four days during the deep clean completion, this is planned to take place annually.

- Rooms have been completely refurbished for CF patient admission, windows have been replaced. Rooms are a good size, look bright, freshly painted and very high standard of cleanliness. Contain fridge, sink, magnetic board for personal pictures, privacy curtain, and bedside cabinet with hanging space.
- Kitchen – distribution point for staff to prepare drinks, sandwiches and snacks.
- Gym – Large large busy gym room containing various equipment: three bikes, exercise balls and trampettes, steps, two cross trainers, three treadmills, weight machine and free weights, three therapy couches.
- Patients can also get membership, funded by the Trust, for local gyms.

Environmental walkthrough: Other

	Hospital name	York Teaching Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free, patients have ticket validated for free parking during out/in patient stay. Two storey car park and ample disabled parking bays in car park at main entrance.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Clear large board. Colour coded junction direction.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		X ray – seating for 20+. By appointment only. DEXA – carried out at Nuffield Hospital. Under 20's go to Hull, by appointment. Pharmacy – patients sent to by 'Healthcare at Home'
Do patients have to wait at pharmacy for prescriptions?		Rarely
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Large notice board detailing contact information.
Are there patient comment/ feedback boxes?	Yes	

Additional comments

- The physiotherapist drove the project forward for free parking for CF in/outpatients. This has received good feedback from patients.

Panel members

Stephen Bourke	Consultant	Newcastle adult CF centre
Sarah Collins	Dietitian	Royal Brompton Hospital
Kate Chapman	Psychologist	Churchill Hospital, Oxford
Anne Dealtry	Social worker	Nottingham University Hospital
Keith Thompson	Pharmacist	Royal Brompton Hospital
Victoria Carrolan	Physiotherapist	Birmingham Heartlands Hospital
Nicky Gilday	Nurse	Birmingham Heartlands Hospital
Nesta Hawker	Commissioner	Regional Programme of Care Manager Internal Medicine
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust

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