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British Thoracic Society

BIPRS

Peer review report

University Hospital Lewisham
Adult Cystic Fibrosis Centre

23 January 2014

1. Executive summary

1.1 Overview of the service

The adult cystic fibrosis service at Lewisham Hospital currently provides full care to 52 adults with cystic fibrosis. The multidisciplinary team (MDT) is extremely dedicated and provides an individualised service that is valued by its patients. The outpatient and inpatient facilities are excellent and provide sufficient capacity for current patient numbers. There is an active home intravenous antibiotic programme. Review of the Lewisham registry data did not identify any specific concerns regarding patient outcomes, with the caveat that the number of patients is small (n=45). The longer–term viability of the service will be dependent on either identifying a referral base to support growth and hence funding for the additional key MDT members required to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)' or through integration with a neighbouring CF centre.

1.2 Good practice examples

1. An extremely dedicated MDT that provides an individualised service that is valued by patients.
2. Excellent outpatient and inpatient facilities that provide sufficient capacity for current patient numbers.
3. Comprehensive patient management protocols.

1.3 Key recommendations

1. In order to meet the Cystic Fibrosis Trust's Standards of Care, the following additional multidisciplinary team members are required: 0.4 WTE specialist nurse; 1.0 WTE physiotherapist; 0.3 WTE psychologist; 0.3 WTE social worker; 0.3 WTE pharmacist; 0.3 WTE database coordinator.
2. To remain viable in the longer term, the service will need to identify a referral base to support growth in patient numbers and hence funding for the full MDT or integrate with a neighbouring CF centre.

1.4 Areas for further consideration

1. Provide support for MDT attendance at national and international CF educational meetings (it would also be particularly helpful to allow rollover of CPD budgets year to year to facilitate attendance at an international CF meeting alternate years).
2. Blood samples for tobramycin levels are currently sent to Bristol which leads to a delay in reporting and prevents the safe prescription of this essential antibiotic at weekends. A local service for Tobramycin assays should be identified.
3. Develop service line-reporting to allow a better understanding of income, service expenditure and Trust overheads.
4. Improve inpatient food provision and car parking (see patient feedback).

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

2.1 Models of care

Summary

The Lewisham adult CF centre currently cares for 52 patients, which is below the recommended number for specialist CF centre status in the Cystic Fibrosis Trust's Standards of Care.

In order to meet the Cystic Fibrosis Trust's Standards of Care, the following additional multidisciplinary team members are required: 0.4 WTE specialist nurse; 1.0 WTE physiotherapist; 0.3 WTE psychologist; 0.3 WTE social worker; 0.3 WTE pharmacist; 0.3 WTE database coordinator.

To remain viable in the longer term, the service will need to identify a referral base to support growth in patient numbers and hence funding for the full MDT or integrate with a neighbouring CF centre.

89% of patients attended for an annual review.

45/52 (87%) patients have had data entered in to the Cystic Fibrosis Trust Registry for 2012.

2.2 Multidisciplinary care

Summary

The Lewisham multidisciplinary CF team is extremely dedicated and provides an individualised service that is valued greatly by its patients.

88% of patients are seen at least twice a year by the full specialist centre MDT.

In order to meet the Cystic Fibrosis Trust's Standards of Care, the following additional multidisciplinary team members are required: 0.4 WTE specialist nurse; 1.0 WTE physiotherapist; 0.3 WTE psychologist; 0.3 WTE social worker; 0.3 WTE pharmacist; 0.3 WTE database coordinator.

2.3 Principles of care

Summary

100% of patients are cared for in single en suite rooms during hospital admissions.

Although there is only one CF outpatient clinic per week, segregation is maintained through use of the whole outpatient suite and staggered appointment times. However, this system would not work if patient numbers increase.

Pseudomonas eradication protocols are adhered to.

66% of aminoglycoside levels are available within 24 hours (although prescription is limited to days when results can be received promptly).

There is satisfactory screening for CFRD, CFLD and CF related low BMD.

2.4 Delivery of care

Summary

75% of patients see a CF consultant a minimum of twice a week whilst an inpatient.

66% of patients are reviewed by a CF specialist physio at each clinic visit, 71% of inpatients are reviewed by a physio twice a day, there is no availability to see a clinical psychologist in outpatients or as inpatients, and there is no availability to see a social worker in outpatients.

The delivery of care would be enhanced by the appointment of key MDT members including: 0.4 WTE specialist nurse; 1.0 WTE physiotherapist; 0.3 WTE psychologist; 0.3 WTE social worker; 0.3 WTE pharmacist; 0.3 WTE database coordinator.

2.5 Commissioning

Summary

In order to meet the Cystic Fibrosis Trust's Standards of Care, the following additional multidisciplinary team members are required: 0.4 WTE specialist nurse; 1.0 WTE physiotherapist; 0.3 WTE psychologist; 0.3 WTE social worker; 0.3 WTE pharmacist; 0.3 WTE database coordinator.

To remain viable in the longer term, the service will need to identify a referral base to support growth in patient numbers and hence funding for the full MDT or integrate with a neighbouring CF centre.

3. UK CF Registry data

		Male	Female
Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	19 (53%)	26 (35%)
	Number of patients and % with BMI <19 split by sex	3 (16%)	8 (31%)

University Hospital, Lewisham			**Male**	**Female**
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and median (range) FEV_1 % pred by age range and sex	16–19 years	3, 104.2% (66.9-113.7)	2, 70.1% (62.02-73.11)
		20–23 years	6, 78.9% (48.5-95.5)	8, 56.6% (25.6-87.5)
		24–27 years	4, 64.3% (19.1-104.2)	8, 67.8% (45.5-90.9)
		28–31 years	1, 41.2%	4, 58.1% (41.2-65.8)
		32–35 years	1, 35.6%	1, 54.1%
		36–39 years	0	1, 45%
		40–44 years	0	1, 28.9%
		45–49 years	2, 52.9 % (22.8-83)	1, 37.1%
		50+ years	2, 52.4% (28.9-76)	0

Data input	Number of complete annual data sets taken from verified data set	45

***Pseudomonas aeruginosa* (PA) Chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	24 (53%)
	Number and % of patients with chronic PA infection on Coliston	21 (88%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	16 (67%)
	Number and % of patients on chronic macrolide without chronic PA infection	8 (38%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- Consultant care is provided by two experienced respiratory physicians who each provide 0.3 WTE sessions to the CF service, which is in line with the staffing recommendation in the service specification. The CF consultants cross-cover their cystic fibrosis commitments when one of them is away.
- The consultants are very enthusiastic about their work and have a good working relationship with the MDT.
- Patient feedback of the CF service is extremely complimentary.
- The consultants run one CF clinic per week, but patients can be seen on an ad hoc basis if unwell. Segregation is maintained through use of the whole outpatient suite and staggered appointment times.
- There are two consultant ward rounds per week and one MDT (attended by both consultants) in which both inpatients and outpatients are discussed. Inpatients are seen by a CF consultant within 24 hours of admission.
- There is no specific CF consultant on call rota, but in practice out–of–hours emergency admissions are rare and the CF consultants are happy to be called to provide advice when not on call themselves.
- The CF consultants attend ~one international CF meeting alternate years and a specific CF educational event annually, in addition to the winter British Thoracic Society (BTS) meeting.

4.2 Specialist nursing

Currently 1.0 WTE (Band 7) CNS for 52 patients, which falls short of the staffing level recommended by the Cystic Fibrosis Trust's Standards of Care.

The Clinical Nurse Specialist (CNS) is extremely dedicated, hard working and passionate about his role and provides a high level of service. He is a member of the Cystic Fibrosis Nurses Association (CFNA) and attends local, national and international meetings and conferences.

When the CNS is on leave the service is managed predominantly by the paediatric respiratory CNS in conjunction with the ward manager.

Areas of good practice:

- Independent nurse prescriber. Practices within the outpatient and ward setting.
- Homecare service for patients receiving home IVs.
- Personal service due to small patient numbers.
- Utilises other agencies to support current level of service.

Areas for improvement:

- Undertake and develop nursing research.
- Continue to educate new ward staff.

Recommendations:

- Employ 0.4 WTE CNS to support and provide cross cover – consider a developmental role with dual ward/CNS responsibility.
- Increase physiotherapy and psychosocial support to free time for CNS to undertake own nursing research, audit and develop role.
- Secretarial support.

4.3 Physiotherapy

- Outpatient (OP) care provided by 0.3 WTE Band 7 specialist CF physiotherapist (team lead).
- No dedicated funding for inpatient (IP) care, so majority provided by a Group 3, Band 6 general medical rotational physiotherapist, under team lead supervision.
- Team lead leave covered by Group 2, 8a physiotherapist.
- Overall current physiotherapy input provided by 0.5 WTE. Recommended staffing for 52 patients is 1.5 WTE, so under-resourced by 1.0 WTE.

Areas of good practice:

- Experienced and committed team lead and 8a physiotherapist are members of the Association of Chartered Physiotherapists in CF (ACPCF). Team lead able to attend national study days and with 8a physiotherapist, attends regional/local meetings. Team lead: attends weekly multidisciplinary team (MDT) meetings; integral component of MDT; involved in patient care at all key life stages and audit locally.
- 100% of outpatients including transition and annual review clinics are seen by the CF physiotherapist lead. Recent improvements in physiotherapy provision in all outpatient clinics, all CF patients now reviewed by physiotherapy in all outpatient clinics.
- Very good adherence to Physiotherapy National Standards of Care (ACPCF 2009), despite staffing shortfall.

Areas for improvement:

- Good level of input for daily inpatient airway clearance, seven days a week. Considered good quality (particularly weekdays), but would be further improved if consistently provided by physiotherapists with more CF experience.
- As no dedicated funding for inpatient care exists (and necessity for prioritisation of airway clearance across all areas of acute respiratory care), main focus of input is airway clearance. Supervised formal exercise sessions are therefore often limited, despite availability of good facilities/equipment.

Recommendations:

An additional 1.0 WTE of dedicated CF physiotherapy, would enable:

- More specialist input and increased supervised, formal exercise for inpatients;
- Consistent ward round attendance and review of outpatients outside clinic times; and
- Increased service development, eg proposed physiotherapy–led nebuliser and oxygen assessment services; further development of continence, musculoskeletal and lung transplant patient management; formalisation of transition process; potential development of a homecare service; increased involvement in audit/research.

4.4 Dietetics

The dietitian is a member of the UK Dietitians CF Interest Group and attends their meetings. She attends the weekly MDT meeting and ward rounds. Bleep cover for outpatients is provided by a band 7 nutritional support dietitian when the CF dietitian is on leave. The nutritional support dietitian will also review patients twice per week on the wards during the CF dietitian's leave. The dietitian attended the NACFC in 2009 and the Cystic Fibrosis Trust Medical Conference in 2012. The dietitian has been involved in audits. The dietitian's post is split between adult and paediatric CF patients. She attends the twice yearly transition clinics.

Good practice:

- Proactive dietitian who works hard within the current service to provide good 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 0.6 WTE is within current recommendations of 1.0 WTE dietitian for 150 patients. However, the CF dietitian helps out with some general dietetic work as part of this time. If the CF service expands in the future this current caseload will need to be reviewed.

4.5 Commissioner

Lewisham has a small but well established cystic fibrosis service providing care for adult patients. The centre is geographically located near to other CF centres, particularly Kings College Hospital in South London. There are many strengths in the existing service with a dedicated core team providing a personalised service to patients with opportunities for strong relationships to develop between the multidisciplinary team. There is good evidence of the Hospital Trust systematically recording and learning from incidents.

The small patient numbers create a number of challenges to the Hospital Trust when considering service development and planning, including:

- Access to the full multidisciplinary team.
- Small numbers in the paediatric service which is shared with Kings College Hospital mean that there is unlikely to be much, growth in the total adults service from patient transitions over the coming years.

Challenges which the Hospital Trust needs to consider going forward include:

- Establishing regular meetings with commissioners to review and plan the provision of specialised services within the Hospital Trust.
- Ensuring the provision of support services for patients with cystic fibrosis to include seven-day access to imaging and homecare delivery services.
- Monitoring the on-going sustainability of the service to ensure that the full service specification can be delivered, potentially including discussions with other CF centres as to how Lewisham could support them in addressing capacity issues for patients living in boroughs with good links to Lewisham.
- The Hospital Trust has been through a period of external challenge and review and now that its future appears more secured, the stated commitments to building and developing the CF service need embedding.

4.6 Pharmacy

As there is no provision for a dedicated CF pharmacist, the Cystic Fibrosis Trust recommendation of 0.5 WTE per 75 patients is not currently met. Inpatients are admitted to a respiratory ward, where a pharmacist provides the usual ward clinical pharmacy services (including level 2 medicines reconciliation and discharge planning) along with a MMT (though self-administration of medicines is currently not in place on the inpatient ward). The antimicrobial pharmacist reviews inpatient- outpatient- and homecare prescriptions for antibiotics.

- When available, the pharmacist attends the weekly MDT meeting, though not always. As there is no dedicated CF pharmacist, there is no formal pharmacy support for annual review or outpatient clinics although there is a pharmacist available for advice for complex outpatients – usually the antimicrobial or medicines information pharmacist as appropriate. There is no specific adherence support by a pharmacist.
- Support services provided by pharmacy include in- and outpatient dispensing, home IVs via homecare; medicines information; homecare for high cost drugs. Horizon scanning is undertaken as part of general pharmacy business planning; budget planning and homecare services/management of high cost drugs absorbed within pharmacy department (by clinical lead) as part of routine business.
- Guidelines concerning the use of medicines within the CF service are available, but not always approved by pharmacy.
- The Clinical Nurse Specialist currently fields calls from patients who are having difficulty obtaining medicines in the community, and arranges outpatient prescriptions for these. Over the next financial year this is likely to increase and the CNS would be well supported by a specialist CF pharmacist.

Areas of good practice:

- Ward manager reports good level of general pharmacy service to inpatient ward.
- Home IV antibiotic service is available.

Areas for consideration

- Review of pharmacy service with consideration of formalising the pharmacist support to CF team with appointment of dedicated 0.3–0.4 WTE Band 8a specialist CF pharmacist for the current cohort of 52 patients. This is required to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)', and Pharmacy Standards of Care (2011).
- This would ensure that patients are reviewed by a specialist CF pharmacist at least annually, at annual review, and have direct access to a CF specialist pharmacist during outpatient appointments and inpatient episodes. The development of this post would also support attendance at ward rounds and team meetings; support adherence to commissioning policy, and homecare delivery of high-cost drugs such as ivacaftor; development of guidelines; support self-administration and adherence programmes; and support transition of patients from paediatric to adult services.

4.7 Psychology

- There is no clinical psychologist and so it is not possible to comment on best practice or areas of improvement.
- The service has good links with a liaison psychiatrist. Patients are referred by CF MDT according to perceived need for assessment and/or psychological intervention. Inpatient referrals are seen within 48 hours and then offered follow-up outpatient sessions as necessary. Outpatients are seen within two weeks. Between four and six patients per year are referred. Patients may also self-refer to a counselling service.
- Roles that are not currently fulfilled (as outlined by the Cystic Fibrosis Trust's Standards of Care 2011) include clinical psychologist participation in ward rounds and MDT meetings, screening for psychosocial problems in the annual review process, 'gate keeping' for onward referrals and liaising with other agencies, providing consultation, supervision and support for other CF team professionals, providing training for the team, and research and audit roles.
- There is no psychological input at key stages such as transition, adult diagnosis, end of life or transplantation unless a patient is referred to the liaison psychiatrist.
- Recommended clinical psychology staffing in the Cystic Fibrosis Trust's Standards of Care for this patient population is between 0.3–0.4 WTE.

4.8 Social work

In the absence of a social worker on the team, many of the areas requested re practice and development cannot be directly commented on. The National CF Standards in Social Work would require there to be a social work post of approximately 0.3–0.4 WTE. There are currently no specific plans to recruit a social worker, but there is acceptance that it is a reasonable expectation.

The CF CNS in the team has tended to offer support with benefits, housing, university and employment. Patients make some use of the welfare adviser at the Cystic Fibrosis Trust National Office which is local. Some patients receive emotional support from a local psychiatrist and from a counselling service which accepts self referrals.

Gaps in provision are: a multi-agency approach in complex cases and gatekeeping for onward referral; provision of casework routinely, at times of crisis, and at difficult times in the disease trajectory; anyone in the team with a psychosocial focus, who can promote a social model of care in the team, and normalise contact with psychosocial professionals for the patients and their families.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	0	3	2	1	1	0
Female	0	2	7	0	1	0	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	18	1	0	0
From the ward staff	4	7	3	0
From the hospital	10	8	1	0

Areas of excellence

1. CF team – communication
2. CF team – access
3. Outpatient – availability

Areas for improvement

1. Car parking
2. Inpatient – food
3. Inpatient – exercise

6. Appendices

Appendix 1

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

Reported and actual compliance below follows a Red, Amber, Green rating defined as the following:

Green = Meeting all the Trust's 'Standards of Care (2011)'

Amber = Failing to meet all the Trust's 'Standards of Care (2011)' with improvements required

Red = Failing to meet the Trust's 'Standards of Care (2011)' with urgent action required

Hospital name

University Hospital Lewisham

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% patients seen at least once a year by the specialist centre for an annual review	90%	Green	89% Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	87% Green	45/52 patients
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	N/A	Not a network clinic.

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include annual review.)	95%	Green	88% Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Amber	Delivery of care would be greatly enhanced by adding the additional MDT members required to meet the service specification for a specialist CF centre.
	% of MDT who receive an annual appraisal	100%	Green	80% Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	100% Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	100% Green	

2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green	Yes Green	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Yes Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	100% Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	86% Green	
	% patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	85% Green	

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	100% Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	100% Green	Segregated by room and clinic time. However, this system would not work if patient numbers increase.

3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* in the previous 12 months	100%	Green	100% Green	
	% 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	66% Green	Although prescription is limited to days when results can be received promptly.
3.4 CFRD	% patients >12 years of age screened annually for CFRD	100%	Green	97% Green	
3.5 Liver disease	% patients >5 years of age with a recorded abdominal ultrasound in the last three years	100%	Green	96% Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Amber	60% Amber	Needs to be addressed in the paediatric clinic.
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded BMD (DEXA) scan in the last three years	100%	Green	84% Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Amber	75% Amber	Insufficient
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/ shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	95% Green	
	% dictated discharge summaries completed within 10 days of discharge	100%	Green	95% Green	
	% patients reviewed by a CF clinical nurse specialist at each clinic visit	100%	Green	100% Green	
	% patients with access to a CF CNS during admission (excluding weekends)	100%	Green	100% Green	
	% patients reviewed by a CF physiotherapist at each clinic visit	100%	Amber	66% Amber	Additional physio support required.
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	71% Amber	Additional physio support required.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
	% availability of a CF specialist dietitian at clinic	100%	Green	92% Green	
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	100% Green	
	% availability of clinical psychology at clinic	100%	Red None in clinic.	None Red	Clinical psychologist input required.
	% availability of clinical psychology for inpatients	100%	Red Referred to Maypole.	Referral to hospital psychiatric service. Red	Clinical psychologist input required.
	% availability of social worker for at clinic	100%	Red	None Red	Social worker input required.
	% availability of social worker for inpatients	100%	Green	Available Green	
	% availability of pharmacist at clinic	100%	Green Available if requested.	Available if requested. Green	Patients and hospital would benefit from regular CF – specific pharmacy input.
	% availability of pharmacist for inpatients	100%	Green	Available Green	Patients and hospital would benefit from regular CF specific pharmacy input.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	100% Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	66% Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	1 complaint	1	
5.2	Number of clinical incidents reported within the past 12 months	<1%	9 incidents	9	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service Level Agreements (SLA) in place for all	100%	N/A	N/A	

Appendix 2

Staffing levels (Adult)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	University Hospital Lewisham 52 patients
Consultant 1	0.5	1	1	0.3
Consultant 2	0.3	0.5	1	0.3
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.4	0.8	1	0.3
Specialist nurse	2	3	5	1
Physiotherapist	2	4	6	0.5
Dietitian	0.5	1	2	0.6
Clinical psychologist	0.5	1	2	0
Social worker	0.5	1	2	0
Pharmacist	0.5	1	1	available
Secretary	0.5	1	2	0.3
Database coordinator	0.4	0.8	1	0

Appendix 3

Registry data

CF Registry data 2012	
Demographics of centre University Hospital Lewisham	
Number of active patients (active being patients within the last two years) registered	52
Number of complete annual data sets taken from verified data set (used for production of the Annual Data Report 2011)	45
Median age in years of active patients	24
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (Ref: 1.6 'Annual Data Report 2011')		
Number in age categories	16–19 years	5 (11%)
	20–23 years	14 (31%)
	24–27 years	12 (27%)
	28–31 years	5 (11%)
	32–35 years	2 (4%)
	36–39 years	1 (2.5%)
	40–44 years	1 (2.5%)
	45–49 years	3 (7%)
	50+ years	2 (4%)

Genetics	
Number of patients and % of unknown genetics	4 (9%)

Body Mass Index (BMI) (Ref: 1.13 Annual Data Report 2012)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	19 (35%)	26 (35%)
Number of patients and % with BMI <19 split by sex	3 (16%)	8 (31%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	3 (100%)	5 (63%)

	FEV1 (Ref:1.14 Annual Data Report 2012)		
		Male	Female
Median FEV_1% pred at age 16 years split by sex		0	0
Number and median (range) FEV_1 % pred by age range and sex	16–19 years	3, 104.2% (66.9-113.7)	2, 70.1% (62.02-73.11)
	20–23 years	6, 78.9% (48.5-95.5)	8, 56.6% (25.6-87.5)
	24–27 years	4, 64.3% (19.1-104.2)	8, 67.8% (45.5-90.9)
	28–31 years	1, 41.2%	4, 58.1% (41.2-65.8)
	32–35 years	1, 35.6%	1, 54.1%
	36–39 years	0	1, 45%
	40–44 years	0	1, 28.9%
	45–49 years	2, 52.9 % (22.8-83)	1, 37.1%
	50+ years	2, 52.4% (28.9-76)	0

Lung Infection (Ref 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	5
	20–23 years	14
	24–27 years	12
	28–31 years	5
	32–35 years	2
	36–39 years	1
	40–44 years	1
	45–49 years	3
	50+ years	2
Number of patients with chronic PA by age group	16–19 years	2
	20–23 years	8
	24–27 years	5
	28–31 years	3
	32–35 years	2
	36–39 years	1
	40–44 years	1
	45–49 years	1
	50+ years	1

Burkholderia cepacia (BC)	
Number and % of total cohort with chronic infection with BC complex	2 (4%)
Number and % of *cenocepacia*	0
Meticillin-resistant staphylococcus aureus (MRSA)	
Number and % of total cohort with chronic infection with MRSA	2 (4%)
Non–tuberculosis mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complication (Ref 1.16 Annual Data Report 2012)	
ABPA (Allergic Bronchopulmonary Aspergillosis)	
Number and % total cohort identified in reporting year with ABPA	4 (9%)
Cystic fibrosis related diabetes (CFRD)	
Number and % total cohort requiring chronic insulin therapy	11 (24%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	4 (9%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (2%) with PH 1 (2%) without PH

Transplantation (Ref: 1.18 Annual Data Report)	
Number of patients referred for transplantion assessment in reporting year	5
Number of patients referred for transplantion assessment in previous three years	5
Number of patients receiving lung, liver, kidney transplants in last three years	3

IV therapy (Ref:1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	44
	20–23 years	194
	24–27 years	147
	28–31 years	28
	32–35 years	7
	36–39 years	0
	40–44 years	27
	45–49 years	24
	50+ years	0
Number of days of home IV therapy in reporting year split by age group	16–19 years	36
	20–23 years	285
	24–27 years	88
	28–31 years	42
	32–35 years	140
	36–39 years	28
	40–44 years	66
	45–49 years	0
	50+ years	0
Total number of IV days split by age group	16–19 years	80
	20–23 years	479
	24–27 years	235
	28–31 years	70
	32–35 years	147
	36–39 years	28
	40–44 years	93
	45–49 years	24
	50+ years	0

Chronic DNase therapy (Ref 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged >16 years FEV1, % predicted <85% (ie below normal) on DNase	(n=37) 28 (76%)
If not on DNase % on hypertonic saline	3 (8%)

Chronic antibiotic therapy (Ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	24 (53%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	21 (88%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	16 (67%) with PA 8 (38%) without PA

Appendix 4

Patient survey

University Hospital Lewisham

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	0	3	2	1	1	0
Female	0	2	7	0	1	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	18	1	0	0
Communication	18	1	0	0
Out-of-hours access	9	9	0	0
Homecare/community support	14	1	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	17	2	0	0
Waiting times	17	1	0	0
Cross-infection/segregation	14	4	1	0
Cleanliness	11	6	0	0
Annual review process	17	2	0	0
Transition	15	11	1	0

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor
Admission waiting times	7	6	1	0
Cleanliness	9	2	3	0
Cross-infection/segregation	11	3	0	0
Food	4	3	5	1
Exercise	6	6	2	0

How would you rate:

	Excellent	Good	Fair	Poor
Home intravenous (IVs) antibiotic service	13	1	0	0
Availability of equipment	11	6	1	0
Car parking	2	5	3	6

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	18	1	0	0
Of the ward staff	4	7	3	0
Of the hospital	10	8	1	0

Comments about CF team/hospital

"I have always been looked after well. CF nurse is fantastic."

"They are brilliant."

"The care and support I receive from my CF team go above and beyond the call of duty. They make me feel safe when I am in their care and truly take the everyday pressures off, of having cystic fibrosis. I can relax in the knowledge that they will do all they can to make my stay in hospital or on home IVs comfortable and always there to reassure me and answer any questions I have. They are a truly invaluable team."

"The CF team are excellent, friendly and always there for us if we need anything in or out of hospital."

"My CF team are very supportive they make you feel like you are their only patient. They work so hard and I'm so grateful. There appears to be a lot of damp on the ceilings (in outpatients). (Inpatients) CF patients are always kept apart and have their own rooms which is good. However, sometimes the rooms haven't been cleaned properly before I go in them. Also have had issues with nurses not being sterile whilst doing IVs. The CF team I have are excellent but I feel they are over stretched. There are too many patients for them to look after."

"Need to give patients more choice of when appointments are made."

"Cannot rate the CF team highly enough, superb care."

"The CF outpatients team are outstanding, the CF specialist nurse, dietitian and doctors. However the inpatient staff are inconsistent and less knowledgeable than the fantastic outpatient team in there cleanliness care and cross infection knowledge."

"Because the majority of team members have known me for a long time we have a really strong relationship and level of trust which I believe is incredibly important in the delivery of care I receive and why I think it's so good."

"CF team are the best."

"Never had any problems with my CF team/hospital."

Appendix 5

Patient/parent interviews

Lewisham Hospital

Patient 1

Female, aged 21. Diagnosed at birth. Attended Lewisham Hospital since she was born, has had no problems.

Areas of good practice

- The staff are excellent and very dedicated especially the CNS. Staff are strict regarding cross–infection. The two doctors are approachable.
- The clinic and all facilities are very tidy and clean, she never has to wait for a bed on the ward.
- Transitioned at 16 years old, she wanted to transition as soon as possible. She didn't want to be on a ward with young children.
- She stated that the hospital food is not very good. She goes home and comes back to hospital so normally eats at home or brings food in and uses the microwave. She likes the snack boxes and the dietitian is approachable and always easy to find.
- She attends the gym every day at home and uses the gym in hospital although prefers to use the stairs.
- She likes the personal service at Lewisham and feels comfortable with the staff.

Areas for improvement

- The parking can be issue but she will get dropped off and her family will find a parking space, although she can always get a disabled parking space.
- She doesn't think a social worker or psychologist would be helpful for her but would be helpful for other patients.

Patient 2

Male, aged 48 years, diagnosed CF aged 28. Transplant, 2011. Lives with partner, two children aged 20 and 17 years both with CF and grandchild, without cystic fibrosis. Carpenter and HGV driver not working at present due to hip fracture, awaiting hip replacement after high dose steroids and osteoporosis.

Areas of good practice

- Staff all great from cleaners to consultants.
- He feels understood and totally trusts the CF team.
- The CF nurse specialist in particular goes beyond the call of duty at all times.
- The physiotherapy team pushed him pre transplant to exercise and he now totally appreciates all of their care.

Areas for improvement

- Food is average.
- Increased psychological help for those who require it.
- Free Wi-Fi, internet and TV access for all inpatients.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Hospital Name	University Hospital Lewisham
	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	8/9 patients per clinic. 5 clinic rooms. Bed, desk, chairs, sink.
Do patients spend any time in waiting room?	No	Check in and go straight to a room.
Is there easy access to toilets?	Yes	2 toilets staff and patients, patients would all use same toilet facility.
Where do height and weight measurements take place? Is this appropriate?		Weight in clinic room. Height at annual review only.
Where are lung function tests done for each visit?		Yes – in each individual clinic room.
Are clinic rooms appropriately sized?	Yes	Spacious and airy.
For annual review patients, are any distractions provided?	No	Don't have time. Start at 8.30 finish at 11am. Only 2 patients per annual review clinic. Can use their own phones.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Dedicated clinic	Generally seen in the chest clinic or in diabetes clinic.
Transition patients – can they get tour of outpatient facilities?	Yes	In/outpatients.
Transition/new patients – do they get information pack?		Information leaflet. CNS does a transition clinic – twice a year.

Additional comments

- New facilities – clean and spacious. One CF clinic a week.
- One annual review clinic once every two weeks.

Environmental walkthrough: ward
Ward name: Mulberry
Microbiology status: All

		Hospital name	University Hospital Lewisham
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		No	Mulberry – all on same ward. However no more than two inpatients at a time, housed in different areas. It is suitable – generally very good facility.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	Excellent, spacious, clean, well decorated and well thought-out facilities.
Number of side rooms?		11	11 side rooms, 1 or 2 patients on ward and housed in separate areas.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	All rooms have lockers and fridge for medication.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	3 portable TVs.
If no, are there any concessions for CF patients?		No	Multiday prices for all patients however, this is still expensive.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	2 zed beds.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Flexible hours.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	Fridge in room, microwave in room.
What facilities are provided for teenagers?			They can bring in their own laptops, dongle and phones etc.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	2 gyms – 1 main gym in physiotherapy department and 1 satellite gym.
What facilities are there to help with school and further studies?		Laptops – schools and college will email work over.
Is there a relatives' room?	Yes	On ward day sitting room.
What internet access is there?	None	No Wi-Fi however, bring in dongles.
What facilities are there to enable students to continue work and study?		
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in each room.
What facilities are provided for those with MRSA?		Separate rooms in different areas of ward. Gloves and apron for treatments.
What facilities are provided for those with *B. cepacia*?		Separate rooms in different areas of ward.
What facilities are provided for those with other complex microbiology?		Separate rooms in different areas of ward.
Are patient information leaflets readily available on ward?	Yes	CF noticeboard.
Transition patients – can they get tour of ward facilities?	Yes	

Additional comments

- Ward nurses being trained by Clinical Nurse Specialist and can access ports out of hours as required.

	Hospital name	University Hospital Lewisham
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	Disabled parking available. Excellent public transport links. Reasonable parking spaces. No other concessions for patients.
Other hospital areas		
Clear signage to CF unit and/or ward.		Clearly labelled by colour zone. However, not a CF–specific ward or clinic as used for all respiratory patients, therefore no CF signage.
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?		Small area for pharmacy. Different waiting areas. Only 2 patients a time at annual review and maximum of 9 at any clinic.
Do patients have to wait at pharmacy for prescriptions?		Patients drop off prescription and come back to collect it.
Patient information		
Is patient advice and liaison service (PALS) well-advertised - leaflets, posters?	Yes	British Lung Foundation notice board in clinic PALS posters all over the hospital.
Are there patient comment/ feedback boxes?	Yes	Comments box at reception.

Additional comments

Close by are a park and riverside walks making for a very pleasant environment. Patients exercise in the park with and without physiotherapist.

Appendix 7

Panel members

Charles Haworth*	Consultant	Papworth Hospital
Sarah Collins	Dietitian	Royal Brompton Hospital
Catherine O'Leary	Psychologist	Wales Adult CF Centre
Keith Thompson	Pharmacist	Royal Brompton Hospital
Sarah Cameron	Physiotherapist	Birmingham Heartlands Hospital
Ruth Davies	Nurse	Birmingham Heartlands Hospital
Sarah Freeman	Commissioner	Shrewsbury & Telford
Eileen Reynolds	Social Worker	Kings College Hospital
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust

*Clinical lead for peer review panel

Appendix 8

Other information

cysticfibrosis.org.uk