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Cystic Fibrosis why we're here

British Thoracic Society

BIPRS

Peer review report

University Hospital of South Manchester NHS Foundation Trust – Wythenshawe Hospital

26 June 2014

1. Executive summary

1.1 Overview of the service

The Manchester Adult Cystic Fibrosis (CF) Centre is recognised nationally and internationally as a centre of clinical excellence. Four hundred and twenty adults currently attend the centre and the service is highly valued by its users. The multidisciplinary team (MDT) is extremely dedicated and its staff are experts in their respective fields, while the centre offers enviable outpatient and inpatient facilities. The centre also has a good track record in innovative service development, with examples including the fully integrated CF-related diabetes service, CF satellite pharmacy, bespoke CF ward kitchen and state-of-the-art musculoskeletal service. A review of the centre's UK CF Registry data did not raise any clinical concerns, although the prevalence of chronic *Pseudomonas aeruginosa* infection was noted to be relatively high. The Manchester Adult CF Centre has a very strong track record in training and in advancing clinical practice through research and guideline development.

The urgent priority for University Hospital of South Manchester Trust, the clinical team and the specialist commissioner is to work collaboratively to address immediate capacity issues, which are compounded by the high dependency of the patients admitted to the ward at Wythenshawe Hospital, while also implementing a strategy to develop a new adult service in the region.

1.2 Good practice examples

1. A highly expert and dedicated MDT that delivers exceptional clinical care.
2. Enviable outpatient and inpatient facilities.
3. Excellent track record in training, research and guideline development.

1.3 Key recommendations

- University Hospital of South Manchester Trust, the clinical team and the specialist commissioner need to work collaboratively to implement a strategy to develop a new adult service in the region.
- There is an urgent requirement to review staffing and skill mix on the CF ward.
- To meet the recommended staffing levels outlined in the Cystic Fibrosis Trust's 'Standards of Care (2011)' and to address immediate capacity issues, the following additional MDT members are required: 0.55 whole time equivalent (WTE) consultant; 6.1 WTE nurse specialists; 0.34 WTE dietitian; and.1.6 WTE psychologists. The staffing shortfalls in this review suggest that full compliance has not been met and requires derogation via an action plan approved by the local specialised commissioner.
- Provide sufficient support for the MDT to participate in continuing professional development (CPD), audit and research.

1.4 Areas for further consideration

- Expand nurse-led triage service – consider advanced nurse practitioner.
- Further develop the home intravenous antibiotic and homecare programmes.
- Enhance access to peripherally inserted central catheter (PICC) and totally implantable venous access device (TIVAD) insertion.

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

2.1 Models of care

Summary

420 adults currently attend the adult CF centre in Manchester for full care.

73% of patients were offered an annual review and 66% attended, all of whom had a follow-up discussion with a consultant to develop an action plan for the year ahead.

95% of patients are registered on the Cystic Fibrosis Trust's patient registry.

2.2 Multidisciplinary care

Summary

The centre has an experienced and dedicated MDT that provides highly expert care to its patients.

2.3 Principles of care

Summary

As a consequence of the increasing number of adults with cystic fibrosis and the increasing complexity of care required by an ageing population, the Manchester Adult CF Centre has reached capacity. This is reflected in the unacceptable waiting time for inpatient admission and the relatively low number of patients that have an annual review, and therefore annual oral glucose tolerance tests (OGTTs).

2.4 Delivery of care

Summary

The MDT delivers an exceptional level of care to its patients.

2.5 Commissioning

Summary

The urgent priority for University Hospital of South Manchester Trust, the clinical team and the specialist commissioner is to work collaboratively to address immediate capacity issues at Wythenshawe Hospital, while implementing a strategy to develop a new adult service in the region.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	369

			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	81.5 (22.5–110.6)	51.07 (24.5–122.5)
		20–23 years	77.6 (22.4–111.5)	67.9 (22.1–120.9)
		24–27 years	66.7 (27.9–108.7)	60.3 (19.4–116.0)
		28–31 years	60.2 (30.8–106.9)	60.8 (20.3–121.5)
		32–35 years	70.9 (29.5–106.2)	54.9 (22.3–77.3)
		36–39 years	76.8 (25.8–119.2)	42.9 (26.7–74.4)
		40–44 years	62.0 (17.3–81.4)	56.0 (22.6–97.2)
		45–49 years	44.6 (28.0–85.5)	41.9 (28.1–98.5)
		50+ years	47.7 (40.0–113.4)	41.6 (26.5–75.8)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=221) 90 (41%)	(n=148) 43 (29%)
	Number of patients and % with BMI <19 split by sex	33 (15%)	39 (26%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	242 (66%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	231 (96%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	204 (84%)
	Number and % of patients on chronic macrolide without chronic PA infection	93 (73%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

Staffing:

- The CF service is staffed by 3.65 WTE respiratory consultants.
- This represents a 0.55 WTE shortfall based on the recommendations of the Cystic Fibrosis Trust's Standards of Care.

Areas of good practice:

- The consultants are hugely experienced and provide an expert level of care to their patients. They are highly respected by their peers nationally and internationally, and demonstrate exceptional clinical leadership within their centre and beyond.
- The consultant team provides a 24/7 CF consultant on-call service, frequent in-depth ward rounds of inpatients and a comprehensive outpatient service. The consultants also have oversight of the annual review programme.
- The consultant team has made major contributions to CF research in areas such as exercise, bone health, diabetes, cardiac complications, lung physiology and microbiology/cross-infection prevention, and have contributed significantly to national guideline development.
- Patient feedback on the CF consultant team is extremely complimentary.
- The consultants attend at least one international specialist CF meeting each year.

Areas for improvement:

- There is an urgent need to address the shortfall in consultant staffing to enable the consultant team to deal with the immediate capacity issues faced by the centre.

Recommendations:

- To address the 0.55 WTE shortfall in consultant staffing. University Hospital of South Manchester Trust, the clinical team and the specialist commissioner need to work collaboratively to implement a strategy to develop a new adult service in the region.

4.2 Specialist nursing

Staffing:

- CF clinical nurse specialists (CNSs): 2.3 WTE Band 7s.
- CF diabetes CNS: 1.43 WTE Band 7.
- Clinic nurses: 2.7 WTE (one Band 6 and two Band 5s)
- In accordance with the Cystic Fibrosis Trust's Standards of Care, the specialist nurse team is currently 6.1 WTE understaffed for 420 patients.

Areas of good practice:

- The implementation and management of a triage system for all medical telephone calls Monday–Friday.
- All key life stages are well supported by the CNS team. There is a named lead for the transition service. They work closely with patients undergoing the transplant process and have close links with their local transplant team. They support patients throughout the whole of their obstetric care.
- An enthusiastic team that has worked together closely for 20 years and is keen to develop new clinical skills, ie performing sweat tests.

Areas for improvement:

- The CNS team tries to attend the Cystic Fibrosis Nursing Association (CFNA) conference and other educational meetings, but this is not always possible due to time constraints. They have not attended the European/North American cystic fibrosis conferences for 10 years.
- Further develop the current homecare service to ensure it is equitable for all patients receiving home IVS.
- Undertake and develop nursing research.
- Improve service for patients admitted to other wards in the hospital outside the CF unit.

Diabetes service:

- The diabetes service is comprehensive. It has a dedicated diabetic consultant who is an integral part of the CF team and attends MDT ward rounds and clinics.
- The team would like to further develop joint CF/obstetric care.

Clinic staff/UK CF Registry:

- The centre benefits from experienced clinic staff who work closely with the CNS team and wider MDT. A coordinator helps with patient throughput in clinic.
- There is a well-organised system in place for the collection and input of UK CF Registry data.

Recommendations:

- Succession planning ahead of the impending retirement of several senior nursing staff – Band 6 CNS training post.
- Additional 1.0 WTE Band 7 CNS or advanced nurse practitioner to further develop and manage the telephone triage service.
- Additional 1.0 WTE CNS to develop and improve the current homecare service.
- Consider an additional 1.0 WTE Band 6 or 7 CF diabetes CNS to meet the needs of the service.

4.3 Cystic fibrosis ward

Staffing:

- 24.22 WTE nursing staff.
- Ward benefits from a dedicated and experienced ward manager.

Areas of good practice:

- Dedicated CF ward with excellent facilities.

Areas for improvement:

- The CF ward is overstretched due to the increasing dependency of patients. The AUKUH Acuity Dependency Tool at University Hospital of South Manchester Trust identified a large number of high dependency patients on ward. The number of single rooms available and the ward geography impact safe nursing.
- Complex and prolonged nurse transfers for procedures require adequate cover.
- The current daytime nurse-to-patient ratio of 1:6 is very challenging, and at 1:11 the night ratio is unsafe.
- The skill mix of nursing staff on the ward needs careful consideration in order to match patient complexity.
- The high dependency of patients requires appropriately skilled physiotherapy, seven days per week.
- Effective junior doctor cover is vital.

Recommendations:

- Urgently review an increase in the nurse-to-patient ratio. The AUKUH Acuity Dependency Tool recommends 30 WTE nurses on ward.
- Introduce a comprehensive physiotherapy service.

4.4 Physiotherapy

Staffing:

- The specialist CF physiotherapy service is outstanding and considered to be a truly individualised, comprehensive service that many centres across the UK aspire to. It should be commended for the strong team structure in place, which is led by the consultant physiotherapist, and for taking into account all aspects of the physiotherapy management of CF – including an enviable expert musculo-skeletal service.
- Staffing levels are appropriate according to the Cystic Fibrosis Trust's Standards of Care for a unit of this size and a five-day week service, although it is acknowledged that increased patient complexity and the recent development of a CF-specific seven-day physiotherapy service has challenged the daily staffing levels and skill mix. Therefore, further evaluation of an appropriate model of working is recommended. As the service is so comprehensive, there may also be scope to consider the use of some Band 4 assistant practitioners to free up specialist physiotherapy time for more complex patients.

- Consideration needs to be given to the equity of CPD across the Trust, and recognition that specialist posts require annual CF-specific CPD, such as attending national study days, regional CF groups and national and international conferences.

Areas of good practice:

- Outstanding, fully comprehensive, inclusive, individualised CF physiotherapy service.
- Expert practice, e.g. musculo-skeletal service, non-invasive ventilation, inhalation therapy, exercise.

Areas for improvement:

- Evaluation of an appropriate seven-day working model and of staff skill mix of at weekends.
- Considering the leadership and seniority of the specialist staff, a greater research/audit output would be expected from this service.
- Equity of CPD provision across the Trust, recognising specialist staff requirements.

Recommendations:

- Consider at least 3.0 WTE staff working at the weekend and bank holidays (could be achieved by including Band 8 staff on the rota if paid on Agenda for Change, as Band 7 at weekends or as Band 8 for on-call or as unsociable hours payments). Alternatively, explore other seven-day working models, eg shift system comprising of longer days, fully rostered.
- Consider using some Band 4 assistant practitioner roles to free up specialist physiotherapy time.
- Consider developing a day-case service for more patients starting home intravenous antibiotics, with a specialist physiotherapist review on commencement or during the course (could be linked to the homecare service) to aid admission waiting times.

4.5 Dietetics

Staffing:

- Actual staffing: 3.02 WTE
- Breakdown: 1 x WTE Band 7, 1 x WTE Band 6, 2 x 0.6 WTE Band 6, 1 x 0.5 WTE Band 6 term time.
- The Cystic Fibrosis Trust's Standards of Care recommend 3.36 WTE, therefore it is 0.34 WTE understaffed.

Areas of good practice:

- Excellent specialist care provided by a very experienced team.
- All team members attend specialist dietetic meetings and/or the European CF conference.
- Good channels of communication between team members. Good cross-cover and leave cover among the team.
- Evidence of excellent dietetic team coordination to enable thorough and complete cover of workload for inpatients and outpatients.

- Excellent food choice provision for patients, with dedicated CF unit chefs.

Areas for improvement:

- Research and audit lacking, considering the staffing and level of experience.
- The team is looking to develop a home service involving dietetic home visits.

Recommendations:

- The grading of the dietetic team is not in line with their level of experience/expertise or in line with other UK specialist centres. In terms of succession planning, and in the context of the current grading structure, it would not be possible to recruit to the same level of expertise at the current Band 6, as specialist dietitians with significant CF experience should be Band 7.
- More audit activity and dietetic-initiated research would further enhance the service.

4.6 Pharmacy

Staffing:

- Actual staffing: 1.75 WTE pharmacists (0.75 Band 8a + one Band 7).
- Pharmacist allocation to the CF service at Wythenhawe Hospital is within the recommendations of the Cystic Fibrosis Trust's Standards of Care.
- However, no cover is provided when either of the pharmacists is on leave, and the Band 8a pharmacist is increasingly being pulled from CF to provide cover to other wards as a result of vacancies and annual leave among the wider pharmacy team.
- The pharmacy benefits from a dedicated WTE Band 5 pharmacy technician. There are currently no recommendations for pharmacy technicians or other pharmacy support staff numbers in the Cystic Fibrosis Trust's Standards of Care. This should not be considered an 'extra', as in most trusts these staff groups would be part of the main pharmacy staff pool, working within the main pharmacy.

Areas of good practice:

- Having an integrated pharmacy within the unit is an excellent feature that benefits both patients and the MDT. It should be the gold standard for all CF centres.
- The pharmacy team actively contributes to service improvement through regular audit and research. The specialist pharmacist is an active member of the UK's Cystic Fibrosis Pharmacists Group and attends national/international CF meetings.
- Inpatients are always reviewed by a pharmacist and receive at least level 2 medicines reconciliation. A pharmacist is present on all MDT ward rounds and at annual review. They do not formally see each patient during clinic, but are available within the unit while the clinic is running. The pharmacy team provides a comprehensive specialised medicines information service to patients and the MDT.

Areas for improvement:

- More formalised cover for annual leave.

Recommendations:

- Homecare is in place for the newer high-cost inhaled therapies/Ivacaftor, but has created a significant amount of additional work for the pharmacy team. Consideration needs to be given to the additional work that will be created when the high-cost nebulised therapies currently provided by GPs are re-patriated to secondary care. It would be useful to discuss the workload implications with NHS England to see if funding is available for additional staff to support CF homecare. Unless additional staff are made available to support homecare, the current CF pharmacy service will suffer significantly.
- The Band 8a pharmacist will soon become an independent prescriber. The whole CF team should think carefully about how this new role can be fully exploited within their team.

4.7 Psychology

Staffing:

- A consultant (0.8 WTE) and a Band 8a (1.0 WTE) clinical psychologist provide psychological support for the patients in this large service.
- The current staffing shortfall based on the Cystic Fibrosis Trust's Standards of Care is 1.6 WTE. However, should patient numbers further increase, it is recommended that this team increase by 2.0 WTE in order to maintain the effective service that is currently offered.
- The psychologists provide cover for each other during periods of leave, which stretches the capacity of the service during those periods.

Areas of good practice:

- Well integrated into the MDT.
- Wide range of innovative service development, with broad service offered to patients.
- In addition to attendance at national and international CPD events, research keeps this small team at the cutting edge of psychological thinking and intervention for patients with CF.

Areas for improvement:

- Training for staff members on the ward to support ward staff in reflection and keep them up-to-date with psychological care.
- Due to capacity problems, inpatients are often not seen by a psychologist within one week of referral to the psychology team.
- Due to timetable congestion, it is not always possible to attend some key meetings. It would be helpful if this could be reviewed.

Recommendations:

- This is a dedicated and thoughtful team that provides excellent patient care, but the service has reached capacity.
- An additional 1.6 WTE psychologists are needed to meet the requirements outlined in the Cystic Fibrosis Trust's Standards of Care.

4.8 Social work

Staffing:

- The unit has four social workers, (one is currently on maternity leave) who work exclusively for the CF service.
- The team is very knowledgeable and experienced, and all members are registered with the Health and Care Professions Council and are members of the UK Psychosocial Professionals in Cystic Fibrosis Group.
- The team all attended their regional CF meeting, with representatives at the annual social work meeting, the 2013 European CF Conference and the psycho-social day. The team is proactive when it comes to presenting at these meetings.
- Currently, three of the social workers are employed by an agency, having left Manchester City Council, and are negotiating their contracts with the NHS. The worker on maternity leave will lead this process on her return to work.
- There is no cover provided when one of the workers is absent.
- The unit meets the Cystic Fibrosis Trust's Standards of Care requirements for staffing.

At least one of the social workers will attend the team meeting, MDT meeting and ward round. Each patient is allocated a dedicated social worker as soon as the team is aware of the referral, and there is no waiting list. Each social worker manages their own caseload. The majority of their cases come via transition, and the allocated social worker will attend an initial home visit with the specialist nurse. The social workers are involved with annual reviews and, if not available on the day, they arrange to see the patient separately. It is decided on a case-by-case basis when to transfer patients to the transplant social worker, who then generally retains the case. The social workers provide support on end-of-life and bereavement issues as appropriate, supporting families after death if required.

Areas of good practice:

- As each patient has a dedicated social worker, the social workers get to know their patients well and patients are offered a very comprehensive service.
- The social workers have sufficient flexibility to see patients at home, in clinic or on the ward.
- There are excellent communication channels and working relationships between the social work team and the wider MDT.

Areas for improvement:

- Consider additional community support for patients who do not have a car and live a long distance from the hospital.

Recommendations:

- As above.

4.9 Commissioner

The adult CF service at Wythenshawe Hospital is large, looking after 420 patients. The service is impressive with regard to the dedication and skill of its clinical staff, and its purpose-built facilities. However, there are concerns about future capacity, staffing levels, and the operational connection between the service and trust management.

Areas of good commissioning practice:

- The service is funded via national PbR year of care tariffs.
- Good working relationship with local specialised commissioner.
- Willingness to engage in the review and possible reconfiguration of adult CF services in Greater Manchester and Lancashire and South Cumbria.

Areas for improvement:

- Shortfall in recommended staffing levels.
- Despite a self-assessment of full compliance against the national service specification, the staffing shortfall suggests that full compliance has not been ensured and requires derogation via an action plan approved by the local specialised commissioner.
- The service's understanding of financial and contractual arrangements, eg the difference between income and budget, requires improvement. There also needs to be an acceptance that increases in income derived from increased activity and the shift to a more complex case mix are the source of funding to meet additional demands on the service.

Recommendations:

- The most pressing need is to address the increase in demand and capacity limitations at Wythenshawe Hospital. The Cheshire, Warrington and Wirral area team has initiated a project to review capacity and consider possible service configurations, and the trust must continue to be fully involved in this project.
- The service needs to reconsider its assertion that it is fully compliant with the service specification and, if non-compliant, needs to submit an action plan to the local specialised commissioner in accordance with the derogation process.
- While the service affirmed a close working relationship with the Trust management team, the trust management and clinical team are encouraged to work together more closely to address the financial challenges and capacity issues they both face.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	4	20	12	12	2	3
Female	2	7	11	13	9	1	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	90	6	2	2
From the ward staff	73	8	2	2
From the hospital	74	15	4	1

Areas of excellence:

1 CF team – accessibility/communication, “supportive”, “treated as individual”, “excellent team”

2 Pharmacy experience – since dedicated CF pharmacy, all delivered to patients in room.

3 Inpatient – own chef caters for “whatever we like”.

Areas for improvement:

1 Inpatient admission times – from several days up to six to eight weeks for a bed (even though 22 beds, need another floor).

2 Outpatient waiting times – “quite lengthy”, and have to wait in communal waiting area before going into own rooms.

6. Appendices

Appendix 1

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

University Hospital of South Manchester NHS Foundation Trust – Wythenshawe 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	Amber	73% offered an annual review and 66% attended the appointment.
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%	Green	Green	

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	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	Note staffing recommendations in report.
	% 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	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%	Green	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	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	The service has an action plan to address this.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	Appropriate systems in place to identify and treat new growths of PA.
	% of patients admitted within seven days of the decision to admit and treat	100%	Amber	Red	62%

3.3 Complications	% 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	OGTT offered to 73% of patients without CFRD, and 70% tested.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	N/A	N/A	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A	N/A	
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%

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% 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	

4.2 Inpatients/ outpatients	% 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%	Green	Green	
	% 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 clinical psychology at clinic	100%	Amber	Green	
	% availability of clinical psychology for inpatients	100%	Green	Green	
	% availability of social worker for at clinic	100%	Green	Green	
	% availability of social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of 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	75%

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%	None	None	
5.2	Number of clinical incidents reported within the past 12 months	<1%	28 incidents	28 incidents	Evidence on matrix.
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	

Appendix 2

Staffing levels (adult)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Wythenshawe Hospital 420 patients
Consultant 1	0.5	1	1	1
Consultant 2	0.3	0.5	1	1
Consultant 3			0.5	0.9
Consultant 4				0.75
Staff grade/fellow	0.5	1	1	2
Specialist registrar	0.4	0.8	1	1
Specialist nurse	2	3	5	2.3
Diabetes nurse				1.43
Physiotherapist	2	4	6	11 (includes 1 consultant physiotherapist)
Dietitian	0.5	1	2	3.02
Clinical psychologist	0.5	1	2	1.8
Social worker	0.5	1	2	4
Pharmacist	0.5	1	1	1.75
Pharmacy technician				1
Secretary	0.5	1	2	1.84
Database coordinator	0.4	0.8	1	1
Admin and clerical				3.54

Appendix 3

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)

CF Registry data 2012	
Demographics of centre – Wythenshawe Hospital	
Number of active patients (active being patients within the last two years) registered	379
Number of complete annual data sets taken from verified data set (used for production of the Annual Data Report 2012)	369
Median age in years of active patients	28
Number of deaths in reporting year	6
Median age at death in reporting year	30.5

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number in age categories	16–19 years	21 (6%)
	20–23 years	76 (21%)
	24–27 years	85 (23%)
	28–31 years	62 (17%)
	32–35 years	34 (9%)
	36–39 years	18 (5%)
	40–44 years	44 (12%)
	45–49 years	16 (4%)
	50+ years	13 (3%)

Genetics	
Number of patients and % of unknown genetics	27 (7%)

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	(n=221) 90 (41%)	(n=148) 43 (29%)
Number of patients and % with BMI <19 split by sex	33 (15%)	39 (26%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	23 (70%)	29 (74%)

FEV_1 (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	81.5 (22.5–110.6)	51.07 (24.5–122.5)
	20–23 years	77.6 (22.4–111.5)	67.9 (22.1–120.9)
	24–27 years	66.7 (27.9–108.7)	60.3 (19.4–116.0)
	28–31 years	60.2 (30.8–106.9)	60.8 (20.3–121.5)
	32–35 years	70.9 (29.5–106.2)	54.9 (22.3–77.3)
	36–39 years	76.8 (25.8–119.2)	42.9 (26.7–74.4)
	40–44 years	62.0 (17.3–81.4)	56.0 (22.6–97.2)
	45–49 years	44.6 (28.0–85.5)	41.9 (28.1–98.5)
	50+ years	47.7 (40.0–113.4)	41.6 (26.5–75.8)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	21
	20–23 years	76
	24–27 years	85
	28–31 years	62
	32–35 years	34
	36–39 years	18
	40–44 years	44
	45–49 years	16
	50+ years	13
Number of patients with chronic PA by age group	16–19 years	12
	20–23 years	46
	24–27 years	50
	28–31 years	44
	32–35 years	28
	36–39 years	12
	40–44 years	30
	45–49 years	13
	50+ years	7
***Burkholderia cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	33 (9%)	
Number and % of *cenocepacia*	33 (9%)	
***Meticillin-resistant staphylococcus aureus* (MRSA)**		
Number and % of total cohort with chronic infection with MRSA	19 (5%)	
***Non-tuberculosis mycobacterium* (NTM)**		
Number and % of total cohort with chronic infection with NTM	17 (5%)	

Complication (ref: 1.16 Annual Data Report 2012)	
***Allergic bronchopulmonary aspergillosis* (ABPA)**	
Number and % of total cohort identified in reporting year with ABPA	61 (17%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	119 (32%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	86 (23%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without portal hypertension	17 (5%) with PH/ and 12 (3%) with no without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	13
Number of patients referred for transplantion assessment in previous three years	37
Number of patients receiving lung, liver, kidney transplants in previous three years	9

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	497
	20–23 years	1387
	24–27 years	1050
	28–31 years	1483
	32–35 years	577
	36–39 years	230
	40–44 years	469
	45–49 years	286
	50+ years	311
Number of days of home IV therapy in reporting year split by age group	16–19 years	67
	20–23 years	283
	24–27 years	628
	28–31 years	349
	32–35 years	182
	36–39 years	81
	40–44 years	265
	45–49 years	147
	50+ years	28
Total number of IV days split by age group	16–19 years	564
	20–23 years	1670
	24–27 years	1678
	28–31 years	1832
	32–35 years	759
	36–39 years	311
	40–44 years	734
	45–49 years	433
	50+ years	339

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged >16 years FEV_1% predicted <85% (i.e. below normal) on DNase	(n=286); 131 (46%)
If not on DNase, % on hypertonic saline	24 (8%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	242 (66%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	231 (96%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	204 (84%) with chronic PA and 93 (73%) without chronic PA

Appendix 4

Patient survey

Wythenshawe Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	2	4	20	12	12	2	3
Female	2	7	11	13	9	1	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	85	12	2	
Communication	81	14	4	1
Out-of-hours access	54	21	6	1
Homecare/community support	41	10	2	3

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	79	14	4	
Waiting times	41	38	11	3
Cross-infection/segregation	71	19	4	2
Cleanliness	81	17	2	0
Annual review process	63	23	8	1
Transition	47	5	1	3

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	34	23	18	6
Cleanliness	62	17	2	1
Cross-infection/segregation	62	16	2	2
Food	47	22	7	6
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	66	11	2	1
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	49	19	8	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	38	8	0	2
Availability of equipment	64	16	1	1
Car parking	52	30	6	4

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	90	6	2	2
Of the ward staff	73	8	2	2
Of the hospital	74	15	4	1

Comments about CF team/hospital

"Fantastic care, as a patient I cannot see any room for improvement. Although I'm sure the staff will have ideas given their closer proximity to the way the centre is run."

"All very friendly and nice. Food could be improved (not all fried)."

"Concerns over waiting lists for in-stay treatment has seen greater increase recently on the Facebook group. Whilst the staff are great, – I think perhaps more could be done to reduce the rate of patients needing to come in."

"The care I receive is fantastic, they are all angels each and every one of them. I don't know where I would be without them."

"An excellent service all round, informal and friendly."

"The musculoskeletal physiotherapy team is excellent as well. The CF team is very understanding and proactive in patient's care which I think is very important."

"Excellent centre with excellent helpful staff."

"A fantastic, dedicated team. The pride of the NHS!"

"The MACFC at Wythenshawe is the best place I could be at! The team there are amazing and I don't have anything bad to say about them!"

"Very friendly. Easy to talk to. Great support. Model of how a CF unit should be run."

"I can't speak highly enough of the care I have received and continue to receive from consultant and team; they have my full trust and confidence."

"At first the lack of communication was poor. I went in to have my first ever portacath, spent the night in hospital, had an IV line put in (which I have anxiety about), only to turn up to theatre for them to tell me they didn't have the port in for me. I was very upset and stressed about all the mental preparation and unnecessary time wasted for no reason at all."

"The CF team is superb. My health would not be as good as it is now without them. They are very supportive of patients and work as a great team."

"Very happy, always at hand to help, nothing too much trouble, they have made a big difference to my health."

"Cleanliness – decreased in standards with new contract. I have formed such a working relationship with my current team, which is a testament to their attitude, doggedness and good care. Other centres were happy to let me self-destruct, but not here."

"They are amazing. Cannot praise them enough. Consultant should be 'sir', he should be knighted."

"Excellent staff doing an excellent job. Food still poor despite best efforts. Apart from breakfast (which is brilliant and should be every meal.)"

"They are the best; I feel that they care about me as well care for my condition. I do not think they could do better as they are already at an excellent standard, but they continue to strive to improve everything. I have had a double lung transplant on 27/6/13, my 'CF' family/team – they supported my family and I, so much love, time, resources was offered at a difficult time in my life. I will never be able to thank them enough."

"Very supportive team. Excellent team!"

"The entire CF team at Wythenshawe are like extended family to me. Thanks and keep up the good work."

"I wish I'd have had the same care throughout my childhood, as I probably wouldn't be as poorly now. Blackpool Victoria Hospital has a lot to answer to."

"Manchester adult CF ward is a credit. Keep up the good work."

"The staff in the outpatients are all lovely and make me feel I can be honest with them of any issues, when I can sometimes find this hard."

"I am happy with the care I receive at Wythenshawe. Prof Webb is awesome."

"The staff all go above and beyond, which makes all the difference."

"I have visited and worked in other hospitals, but find Wythenshawe excellent. The CF team is fantastic and deliver outstanding patient care in all aspects! Thank you."

"Waiting time in clinics is quite lengthy."

"Very good service."

"Really happy with the team, can't fault them!"

"The only thing I would say is I want more information about my CF, ie on the internet, having two CF genes what it all means, the doctors have told me about it which was great, it's just taking it all in. I haven't got full blown CF."

"Excellent."

"Excellent team, staff friendly and welcoming. I have really valued the approach and attitude of the CF team and I feel I am cared for as a person and not just a patient with CF."

"They are fantastic and really do take good care of their patients."

"It's a great, friendly team at Wythenshawe. The main disappointment is that, from my perspective, patients are treated through policies as opposed to tailoring treatment and policies to patients."

"Keep up the good work!"

"I am always treated as an individual. Staff are always pleasant and efficient. Nothing is too much trouble for them. Excellent."

"Maybe this response should be ignored, I do not and have not suffered from CF it was discovered that I am a carrier. This shed some light on 1 or 2 mysteries but did not involve treatment."

"Fair for cross infection – because waiting room small and waiting times seem to have got longer over last 12–18 months. I wait in the corridor instead."

"All the staff at the unit are my extended family, they go out of their way to help in any way. Love them all!"

"Excellent, especially Prof Webb! Friendly, matter- of- fact manner!"

"The staff at Wythenshawe CF unit, both the clinical staff and Pearce Ward, are absolutely fantastic."

"Couldn't ask for more. Very understanding and helpful."

"All friendly, informative and helpful. Thank you."

"The CF team are fantastic in every way. They provide a holistic approach to their care which is very appropriate to me as I have twin boys to consider when being an inpatient etc. Nothing short of being marvellous!!"

"The CF team are fantastic."

"It's alright sometimes in hospital when you get the right nurse and doctor who knows what they're doing, has time for you and access your medical notes."

"Very helpful staff. Always able to deal with queries quickly and efficiently."

"Overall I am extremely satisfied with my care from the CF team. I always feel I can approach any member of the team if I have concerns. They are excellent."

"I have never been let down or experienced anything but care, consideration and support from the CF team at Wythenshawe."

"The service has improved over the years. Staff are very friendly and supportive. My care is genuinely a partnership and incorporates my views. Excellent."

Appendix 5

Patient interviews

Patient A

- **Outpatient clinic:**

On arrival at clinic, patient is directed more or less straight away to a consultancy room where patient then stays, sees each member of the MDT and has spirometry conducted (new computerised spiro – patient/staff use hand gel). She explained that weight was measured "in a private area, down the corridor". Patient sees each member of the MDT at outpatient clinic (appointments needed to see psychologist and social worker). She feels happy that the CF team makes decisions regarding treatments with her.

She explained that hospital pharmacy experience used to be "a nightmare", but is now much better with own CF pharmacy within the CF unit and medications brought from pharmacy to patient in clinic consultancy room.

- **Annual review:**

She last had an annual review (AR) in November 2013 and is offered an AR each year. She sees each of the MDT at the AR, and all assessments take place at the same hospital – the DEXA scan is on a different day though. Outcome of her AR is fed back verbally to patient at next clinic apptointment, "but team ask me if I'd like it in writing".

- **Inpatient care:**

Patient can usually be admitted within two days, always to an en-suite side room. She feels the more experienced ward staff are "more up-to-date" on CF and her specific needs. She feels that all treatments are given on time. She is not sure about the amount of equipment on the ward and whether it's sufficient. Patient is very happy with the ward food/catering – "caters for whatever we like, with its own kitchen."

- **Homecare:**

She mixes home IVs herself, administered via portacath. Her port is flushed every four weeks at the CF Centre, or the CNS can visit her at home to do this (patient lives in Blackpool).

- **Areas of good practice:**

"The CF centre is clean."

"Staff are nice and helpful – both CF team and ward team."

"Food on ward."

- **Areas for improvement:**

"Waiting room at outpatient clinic is too small (ie the open waiting area, before patient is ushered into consultancy room)."

Patient B

- **Outpatient clinic:**

On arrival at (pseudomonas) clinic, patient usually waits five to 10 mins in a small communal waiting area before being directed to a single consultancy room for spirometry and to see each of the MDT. His weight is measured in the corridor at the side of pharmacy. The patient feels that staying in the consultancy room while the MDT rotate is a "brilliant idea". He explained that spirometry is "done electronically, plugs straight into USB port" and that he's encouraged to use antibacterial hand gel. He sees all of the MDT (social worker "occasionally pops in" and "psychologist is there if needed"). He feels that the CF team is good at discussing treatment decisions with him.

The patient explained that the pharmacy is now based in the CF unit, that medications are brought to him in the consultancy room within 10–15 mins, and that the prescription is double-checked with him.

- **Annual review:**

The patient last had an annual review (AR) in December 2013 and is offered an AR each year. He sees nearly everyone (in the MDT) at the AR; he can be referred to a psychologist if needed and a social worker "pops in" on the day or at the beginning of the next clinic appointment. He explained that all his assessments take place at the same hospital, on the same day. His AR report is fed back to him verbally at the next outpatient clinic. He seemed a little unsure whether a written report is offered.

- **Inpatient care:**

The wait for hospital admission was this patient's main concern – "sometimes wait for six to eight weeks for a bed. The 22 beds on the ward are usually full. Unit needs a third floor… sometimes CF patients are put on Doyle or Wilson non-CF wards)".

The patient always gets an en suite side room and feels ward staff are very knowledgeable about CF and his needs – "they all work purely on CF on the ward". He feels treatments/IVs are given on time and that there's sufficient equipment on the ward (ie IV pumps, drip stands, exercise equipment).

The patient explained that ward catering is very good – "own kitchen and own chef" – and that "there's great variety on the menu".

- **Homecare:**

The patient always has inpatient IVs. He doesn't require supplementary parenteral feeds.

- **Areas of good practice:**

"Can always ring someone in the CF team to get things resolved."

"Separate outpatient consultancy rooms (ie patients segregated)."

"CF team and ward team very knowledgeable and approachable."

- **Areas for improvement:**

"Not enough beds on the CF ward."

"Communal waiting room at outpatient clinic ie before patients directed to consultancy room."

Patient C

- **Outpatient clinic:**

On arrival at clinic, patient C either has to wait a short while in the waiting area, or be directed straight to a consultancy room ("it depends how busy it is – on the whole I go straight into a side room"). The patient explained that "there's strict segregation in place". If she turns up for an urgent clinic appointment, she has to ring from the car park to ensure her arrival doesn't compromise cross-infection safety.

Her weight is measured in a separate area, but computerised spirometry takes place in a consultancy room. "We all use gel". Patient sees full MDT at the outpatient clinic, including the psychologist and social worker – MDT rotates so that the patient can stay in the same room. She's happy that decisions on treatments are "always made in consultation with me" and that the consultant and CF team appreciate she leads a busy life and make decisions holistically to best suit her.

The pharmacy is located within the CF unit; prescriptions are processed at the clinic and brought to the patient in the consultancy room.

- **Annual review:**

Patient C had an annual review (AR) in early 2014 and is offered one each year, where she sees the full MDT. All her AR assessments take place on the same day at the same hospital, but her ultrasound was done on a different day this year.

Her AR outcome is reported back to her verbally at her next clinic appointment (not offered a written report), but "if issues arise from the AR, the CF team act on this quickly".

- **Inpatient care:**

Patient C rarely has inpatient IVs. Her recent inpatient IVs resulted in her being admitted the same day; prior to that, 18 months ago she was admitted "next day". On each occasion she was in an en suite side room. She feels the ward staff "are very knowledgeable and will also ask what they don't know" (they'll also ask if the patient wants her door left open or not).

Timing of treatments – the patient felt this was "pretty good" and that sufficient equipment seems to be available on the ward.

Catering – she loves the CF ward food, explaining it has its own kitchen and chef. She likes the "home made cake" on the trolley most of all, and the fact that she doesn't have to cook.

- **Homecare:**

Patient C mixes her own home IVs, administered via a longline. The CNS visits her at home to check her Tobramycin levels. She doesn't PEG/NG feed.

- **Areas of good practice:**

"Really good CF team, ward staff and outpatient clinic staff."

- **Areas for improvement:**

The patient C was unable to give any suggestions here.

Patient D

- **Outpatient clinic:**

Patient D felt that there was "brilliant segregation" at the outpatient clinic – "no one sat in open seating area. Straight into clinic room from my experience". Her weight is measured in the corridor; and spirometry measured in consultancy room, where the patient is also seen by the full MDT (psychologist and social worker referrals available if necessary). Patient D remains in the consultancy room as the MDT rotates.

The patient feels that the CF team/consultant are very good at involving her in decisions on her treatment, compared with her experience at another CF centre she used to attend.

Pharmacy: the prescription is made at the start of clinic, so that the patient receives the prescribed meds in the consultancy room during the clinic. She feels this is very good.

- **Annual review:**

Her last annual review (AR) appointment was in January 2014. She's only been coming to the unit for one year so cannot refer to previous years. She sees the full MDT at AR and her assessments all take place at the same hospital, same day, apart from liver ultrasound and DEXA scan in the year where they're required.

- **Inpatient care:**

Patient D has not required inpatient treatment

- **Homecare:**

Patient D has not required homecare since joining the Manchester CF centre.

- **Areas of good practice:**

"The consultant/CF team involve me in decisions on my treatment."

"I feel extremely well cared for as a person and not just a patient – the team treats me holistically."

"Friendliness of the CF team; easy to get hold of – they never make me feel I'm a nuisance."

- **Areas for improvement:**

Mix-up of notes/cough swabs on a couple of occasions ("but this is only a small gripe"), but their response to these mix ups was impressive.

Patient E

Female patient, 33 years old. She has been a patient at Wythenshawe Hospital since the age of 15. She describes herself as a very proactive person and is a classically trained soprano and flutist. She works part time as a drama teacher. She has taken Kalydeco since January 2013, when her lung function was 82%. This is now 96%, and her energy levels are now high. She has not needed IVs for the last 10 years and has never been admitted as an inpatient.

- **Areas of good practice:**

"Excellent level of expertise available, day or night. Good communication and MDT working, forming good relationships with patients/family and partner."

"Holistic approach; physiotherapist very helpful and effective."

"Excellent outpatient appointments. Cleanliness is outstanding."

"Car parking excellent and free."

"Food smells good, however, never had chance to taste."

"Reception staff are excellent and experts."

"Artwork is much appreciated."

“Have the opportunity to take part in trials.”

“Team are transparent and share conference details and research findings.”

“Nursing triage respond very quickly and efficiently.”

“Email communication for non-urgent questions is good.”

- **Areas of for improvement:**

For patients who are new to staff, staff should consider face-to-face delivery of any new patient complication, such as diabetes, and not transmit information over the phone. However, this was a one-off situation.

Patient F

Male patient, 36 years old. His wife is his support. He has recently been on holiday to the Dominican Republic and on his return was admitted to hospital as he needed treatment. He lives approximately seven miles from the hospital and travels to the hospital by car. The patient referred to the hospital as ‘Costa del Wythenshawe’. He stated that the CF unit was fantastic and would be hard to fault.

- **Areas of good practice:**

“All staff, from the team to the cleaners, are very caring and listen to the patients”; he likened it to private care.

Food – he can order what he wants from the kitchen, when he wants, “food is freshly cooked on demand”.

“Sky and Wi-Fi facility is very up-to-date and useful.”

Patient has access to all members of staff. He has been issued with a card with staff contact details and he can call the nurses or physiotherapists any time, day or night.

“The snack trolley comes round once every evening, or you can buzz and request snacks. There is a snack cupboard available 24/7.”

For annual review, the appointment is for two to three hours; however, the patient does not feel that he is left waiting around – the whole team visits the patient in rotation.

“Parking is free to all CF patients and is near to the unit, so when feeling unwell, it is not far to walk to.”

- **Areas of for improvement:**

The wait for a bed can be up to two weeks for IVs. Alternatively, he can be admitted to another ward not specialising in CF care – however, the care there is not so good.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital name	Wythenshawe 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)	No	Seated area for 11. Different clinics for each microbiological group. Timings are staggered.
Do patients spend any time in waiting room?	Yes, sometimes.	There is a possibility that patients could mix with their own microbiological group.
Is there easy access to toilets?	Yes	Two unisex cubicles, these which are regularly cleaned. (Patients also use the staff toilets.)
Where do height and weight measurements take place? Is this appropriate?	Yes	Dedicated area. Equipment for use in clinic rooms is on order.
Where are the lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	All rooms are of a good size, bright and well equipped.
For annual review patients, are any distractions provided?	No	Patients can bring their own phones/laptops. The whole process only takes two to three hours, and staff from each discipline visit patients in rotation.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Dedicated clinic on Thursdays.
Transition patients – can they get tour of outpatients' facilities?	Yes	As required.
Transition/new patients – do they get information pack?		The pack contains a virtual tour of the facilities on DVD. (The DVD pack was funded by a BBC grant.)

Additional comments:

- The waiting area is equipped with a wall-mounted TV. Artwork on walls is by patients.
- The clinic nurse, fellows' and CNS offices are situated close by and are all of a high quality and good size.
- Pharmacy: The unit has its own fully functional pharmacy, which can quickly supply all CF drugs. The prescriptions can be delivered to patients' rooms and there is no need to wait in the general pharmacy.

- There is an interview room available, mainly for use by psychologists and social workers. This doubles up as a clinic room due to demand, and to prevent patients waiting together in the waiting room. There is a seminar room available for MDT meetings.
- Gym membership is available to all patients; this is funded by the centre.

Environmental walkthrough: ward

Ward name: Pearce Ward

Microbiology status: Non-Pseudomonas/Pseudomonas

		Hospital name	Wythenshawe Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Dedicated.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		22	
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 bed for adults? (Include in notes policy of ward)		Yes	Each room has lockable pod boxes.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	All rooms have free Sky TV.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Z beds are available for use and can be put in rooms.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Flexible as required.

Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?	Yes	Each room has two fridges – one for medication and another for food.
What facilities are provided for teenagers?		Wi-Fi in all rooms. Computers can be borrowed. Use of games and DVDs.
Is there access to a gym or exercise equipment in the rooms?	Yes	Three exercise rooms for sole use of CF patients. Equipment (bike, treadmill, exercise ball, music, TV) can be taken to rooms but is never left there for the duration of the stay. MRSA patients can exercise in the gym at the end of the day, after which the equipment is cleaned.
What facilities are there to help with school and further studies?		Wi-Fi. Teacher available. Connections with schools and college.
Is there a relatives' room?	Yes	TV, drinks and sofa bed.
What internet access is there?		Free Wi-Fi.
What facilities are there to enable students to continue work and study?		Wi-Fi. Teacher available. Connections with schools and college.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Each room has a hand sink and also an equipment sink.
What facilities are provided for those with MRSA?		Patients are barrier nursed within room.
What facilities are provided for those with *B. cepacia*?		Patients are barrier nursed within room.
What facilities are provided for those with other complex microbiology?		Patients are barrier nursed within room. Doors to rooms are kept closed at all times.
Are patient information leaflets readily available on ward?	Yes	Printed on demand.
Transition patients – can they get tour of ward facilities?	Yes	Pack contains DVD of virtual tour of inpatient and outpatient facilities.

Additional comments

- Large hospital grounds with many entrances to different areas, clearly signposted.
- Entrance 4: The CF unit was partly rebuilt and refurbished, reopening in early 2010. The unit has its own barrier-entry car park with 32 bays, for which the patients request a ticket from the staff to gain free parking and exit. The entrance to the unit is next to the car park. Outpatients is situated on the first floor and the ward is found on the ground floor. There is stair and lift access. Professional artwork adorns the walls, as well as artwork by patients. There are pictures of all staff, with names.
- Pearce Ward is the dedicated ward, with 22 side rooms available.

- Wilson and Doyle Wards are general respiratory wards. These can be used for overflow of patients; there are four additional side rooms available. These are fit for purpose, however, they are not to the same high standard as Pearce Ward.
- Pulmonary Oncology Unit (POU) can also be used for patient overflow, however, this is not ideal for staff rounds due to its geographical location.
- Pearce Ward – The side rooms are situated on a long passage. The rooms are extremely light, spacious and well equipped. All rooms have wall-mounted TV's with en suite/wet rooms. Due to the shape of the ward, staff are not able to see all patients at a glance and have to physically walk around the ward to check on rooms. There is a gloves and hand gel dispenser outside every side room.
- There are two negative pressure rooms.
- The physiotherapist and dietitian offices are of a good size and are light, with windows.
- Reception – There is a 'Friends and Family' comments box on wall.
- Laundry room – For patient use during stay. Contains washing machine, drier, iron and ironing board.
- Dedicated kitchen – Very large and well-equipped kitchen with two chefs working on rotation.
- Staff kitchen – All amenities, including a fridge, microwave, toaster and drinks facilities.
- Beverage bay – Well equipped for general use.
- Clinical room – Large room where supplies are stored.
- Outside garden area – Lovely area with plants, grass, tables and seating.

	Hospital name	Wythenshawe Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Very impressive 32-bay, barrier-protected car park for CF patients only. All CF patients get free parking. Staff issue exit tickets.
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?		Patients use the embedded pharmacy in outpatients, which supplies all CF drugs. Therefore no need to wait in general pharmacy. Medication is delivered to patients' rooms. Radiology – Staff call ahead and patients go down one at a time; inpatients are taken in the mornings. DEXA scans – Time slots booked.
Do patients have to wait at pharmacy for prescriptions?		Very occasionally at general pharmacy.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	PALS office and meeting room are located at the main entrance.
Are there patient comment/ feedback boxes?	Yes	'Friends and Family Boxes' located at the main entrance and outpatient reception.

Additional comments

- A light, airy and clean hospital.

Appendix 7

Panel members

Charles Haworth*	Consultant	Papworth Hospital
Helen Willimott	CF Pharmacist	Norfolk and Norwich Hospital
Sam Phillips	CF Specialist Psychologist	University Hospital Bristol
Christine Evans	CF Clinical Nurse Specialist	Birmingham Heartlands Hospital
Helen Watson	CF Specialist Dietitian	Papworth Hospital
Penny Agent	Director of Rehabilitation & Therapies	Royal Brompton Hospital
Sue Fenemore	Social Worker	Southampton General Hospital
Peter Dixon	Specialised Commissioning	Cumbria, Northumberland
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for peer review panel

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