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Peer review report

Sheffield Children's NHS Foundation Trust
8 May 2013

1. Executive summary

1.1 Overview of the service

The South Yorkshire and North Lincolnshire Paediatric cystic fibrosis (CF) network delivers multidisciplinary CF care for approximately 150 children and young people, with the majority of care being delivered at the Sheffield Children's Hospital NHS Trust. Some outpatient and inpatient activity takes place in a number of other hospitals around the area including Barnsley, Doncaster, Rotherham, Scunthorpe and Grimsby. Although this is not a managed clinical network there are many elements of a clinical association delivering care on a shared care basis. The cohesive multidisciplinary team at Sheffield provides an excellent foundation for delivery of CF care. The surveys of patients and parents have given mostly very positive feedback.

1.2 Good practice examples

1. Close working with all members of the extended multidisciplinary team (MDT), in particular, microbiologist and psychologists.
2. Pre-prepared intravenous antibiotics and delivery via homecare has been well developed.
3. The panel were particularly impressed by the MDT efforts in CF Week, eg trying out nasogastric feeding, insertion of cannulae, etc. This demonstrated the dedication of the team members and their empathy for their patients.

1.3 Key recommendations

1. Urgent review of consultant time to address the shortfall, which results in lack of appropriate cover for leave (study and annual), peer support, service development and out-of-hours/ weekend cover.
2. Rationalising the service provision in the shared care hospitals to provide improved care (particularly inpatient) for those patients who have less access to the full MDT team. This may be facilitated by the appointment of a service manager and development of service level agreements (SLA) with each clinic.
3. Review of the use of the CF Unit space for activities, which are not CF-related and result in a compromise in the attempts to achieve good segregation for CF patients, inability to rationalise clinic capacity and seeing patients on an ad hoc basis, as necessary.
4. Eliminating the insecurity around the physiotherapy provision by establishing a substantive Band 7 post and reconsidering the rotational nature of the band 6 post and increasing the existing physiotherapy time.

1.4 Areas for further consideration

1. Review of the CF bed allocation to ensure adequate bed provision in a timely manner, particularly if patients from outside Sheffield require admission to Sheffield.
2. Improvement in the car parking facilities and information to families about other ways to travel into the hospital.
3. Review of catering provision, as this was identified as a major issue by families.
4. Patient/parent involvement in review of the shared care network.
5. Increasing the MDT (clinical nurse specialist (CNS), physiotherapy and dietetics) provision to support the work of the shared care clinics.
6. Improve exercise facilities for the patients.
7. Recommendation to consider an increase in pharmacy service in whole-time equivalent (WTE), in line with the Cystic Fiborosis Trust's 'Standards of Care (2011)' in addition to the increased burden of homecare work**.**

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

2.1 Models of care

Summary

Generally performance in this area is good. Areas for particular attention include annual review and full MDT review for patients in the shared care centres.

Although this is not a managed clinical network, there are many elements of a clinical association delivering care on a shared care basis. A fully developed clinical network delivering the model of care described in the Cystic Fibrosis Trust's 'Standards of Care (2011)' needs further work and will be facilitated by close working between commissioners, senior managers and clinicians.

2.2 Multidisciplinary care

Summary

The key staff/personnel are present as members of the MDT (apart from database coordinator as indicated above and currently being undertaken by the staff grade doctor). It is encouraging that a social worker has been appointed.

A review of the numbers needs to be undertaken (in particular, for members of the MDT seeing patients in shared care clinics) and also the number of patients seeing a consultant on 50% of visits.

Provision of joint CF/diabetes clinics falls short of the recommendations. Although there are informal arrangements with other specialties this needs to be formalised into pathways as more members of the team are appointed, for consistency.

The ability of all staff members to undertake activities to enhance continued professional development (CPD) needs to be ensured and facilitated. This also applies to members of the MDT at the shared care clinics.

2.3 Principles of care

Summary

Although all inpatients are cared for in single rooms only 25% have en suite facilities. This reflects the nature of the building and will be addressed in the new build with all new medical ward single rooms having en suite facilities.

Microbiology advice and input is excellent. Segregation policies are in place although consideration needs to be made for potential contacts in weighing and measuring areas and lung function.

Male infertility – The cohort of patients reviewed included those with learning difficulties and does not reflect the usual practice of the team in this respect. It is important to ensure that even if the young person is not deemed fit to understand that the families are informed.

2.4 Delivery of care

Summary

Inpatient review by consultant at least twice a week – needs further work to increase consultant numbers.

Inpatient stay – there is lack of capacity in dietetic and pharmacy input and weekend physiotherapy cover.

Issues about lack of CNS review and physiotherapy review in clinic have been qualified. Although these MDT members are accessible at all times, they may not see a patient depending on needs.

Social work – recent appointment of 0.5 WTE social worker will ameliorate this issue.

Communication – not reaching targets for either letters or discharge summaries.

2.5 Commissioning

Summary

Commissioning of CF services is generally in a state of flux with CF being one of the prescribed specialised services within NHS England. The move to NHS England has resulted in significant changes to personnel and highlights the need for changes to service configurations in many areas, to meet the service specifications.

Following the completion of the peer review, the key recommendations from a commissioning perspective are that:

1. The commissioners, Senior Clinical Team and service managers work together to look at the achievements of the service in comparison with the service specification and to plan how to maintain and develop the existing strengths of the Sheffield service as the new build progresses.
2. The Hospital Trust ensures that the dedicated management support provided to the CF service (allocated Assistant Manager supported by the Associate Director) supports the team through a time of transition, both within the hospital and the wider network.
3. Existing network arrangements and provision are strategically reviewed from both inpatient and outreach perspectives.
4. Transparent budgets and reporting arrangements are established for the cystic fibrosis service and shared with local commissioners.

3. UK CF Registry data

BMI	Paediatric sites	Patients with a BMI percentile <10th centile on supplemental feeding	(n=14) < 10th centiled; 2 not on supplemental feeding

			Male	Female
FEV_1	Paediatric sites	Number of patients and % with FEV_1 <85% by sex	(n=60) 13 (22%)	(n=65) 17 (26%)

Data input	Number of complete annual data sets taken from verified data set	125

Pseudomonas Chronic PA is 3+ isolates between two annual data sets	Number and % of patients with chronic PA infection	7 (12%)
	Number and % of patients in that cohort on anti- pseudomonal antibiotics	7 (100%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	25 (20%)
	Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	25 (100%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

Medical staffing consists of 1 consultant (0.6 WTE), with consultant sessions from another (0.15 WTE). A third consultant (who would be 0.2 WTE) is currently off. There is a staff grade (0.7 WTE) who undertakes much of the day-to-day clinical work with some junior doctor cover (shared with the respiratory service). A microbiology consultant attends the MDT meeting every week.

The clinical service provision consists of outpatient clinics, annual reviews, ad hoc reviews and inpatient care at Sheffield Children's Hospital with joint clinics run at several of the shared care hospitals. Some of these hospitals also admit children with CF for inpatient care. While these hospitals have a general paediatrician with an interest in CF, some are off sick or due to retire.

There is research activity supported by the paediatric Clinical Research Fellow and time in the staff grade's job plan.

There are many excellent and positive aspects of the medical provision of the service:

- There is an enthusiastic, cohesive medical team.
- The lead consultant, who demonstrates excellent leadership of the MDT team.
- The regular presence of a microbiologist at the MDT.
- A staff grade doctor working within the team, who provides excellent continuity of care.

Areas that require attention include:

- Inadequate consultant numbers/time to allow cross-cover for annual leave/study leave (this will also allow peer support, currently partly provided by the microbiologist).
- Informal out-of-hours cover/advice for CF inpatients (by one consultant when available) which needs formalising and improving.
- Shared care clinics with no local consultant presence.
- Increasing support for the shared care clinics/any reduction in inpatient provision in these clinics will result in the need for increased medical capacity in Sheffield.
- Lack of formal pathways for referrals to other specialties (particularly important when consultant numbers increase).
- Increasing demands on junior doctor time which reduce their exposure to – training and involvement with CF patients.

4.2 Specialist nursing

Staffing

- 2 WTE band 7 clinical Nurse Specialists (CNS).
- 1WTE band 5 senior staff nurse.
- 1 WTE administration assistant.

Areas of good practice

- Established, knowledgeable and enthusiastic band 7 CNS.
- Achieve required continued professional development (CPD) for CF CNS post.
- Achieves recommended targets for CF CNS inpatient and outpatient support/review for patients cared for at Sheffield Children's Hospital (SCH).
- Excellent co-ordination, implementation and support for SCH patients receiving home IVs.
- Excellent co-ordination and implementation of new born screening referral pathway for all patients across the Sheffield network.
- Available to attend joint network clinics where they are provided.
- Very good insight into the current limitations in nursing service and ways to develop to improve this service.

Areas for improvement

- CF CNS input/support for Sheffield network patients not equitable to patients solely cared for by SCH due to lack of CNS time and CF link nurses in networks.
- Current band 5 post manages the CF unit at the level of a band 6 nurse and as such also could cross-cover the CNS role. This post is now vacant so new appointment will not have the skills to achieve that of their predecessors.
- CF unit space not prioritised for CF for whole week – difficulties co-ordinating timely patient reviews.
- No dedicated CF beds on medical ward – delays in admissions and increased time coordinating admissions due to this.

Recommendations

- Increase band 5 CF unit nurse to a band 6 – As well as managing CF unit can take on some CNS roles to increase CNS available time.
- Increased CNS time – Establish CF link nurses on wards and community settings (SCH & networks) and provide regular communication, support and education to improve standard and level of nursing input, so care is equitable through whole CF patient group.
- Carry out inpatient bed "supply and demand" audit to establish dedicated/priority beds for CF use.
- Work to develop network to SCH communication, regarding inpatient and home intravenous antibiotics (IVs), so SCH home IV programme and specialist input/review, during IVs, can be extended to network patients.
- CNS to have opportunity to visit other CF centres to aid development of their current nursing service.

4.3 Physiotherapy

Staffing

0.75 WTE band 7 is a permanent post, currently being covered by a secondment until end of October 2013, 0.75 WTE band 6 rotational (due to rotate at the end of June), 0.5 WTE band 3 due to have to reduce hours in June.

For 150 patients across the specialist centre and network centres there should be 3 WTE physiotherapists, therefore there is a shortfall in the current numbers.

Areas of good practice

The current team is enthusiastic, dedicated and provides good care to the paediatric CF patients at the specialist centre within the limits of current resources.

The band 7 has worked to improve communication and support for network centre physios by providing electronic feedback of annual reviews and by starting an annual study day.

The band 7 has recently undertaken the role of Yorkshire representative for the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) committee.

The team are based on the CF unit, which facilitates effective MDT working and flexibility for seeing patients regularly.

Good support for study leave to attend national and international conferences for the band 7, and training programme established to disseminate knowledge to staff who provide care to CF patients.

Areas for improvement

The present arrangement of a dual purpose physiotherapy office and gym does not provide adequate space and facilities to be able to exercise patients sufficiently.

The lack of stability resulting from the band 7 post being covered by a secondment as well as the static band 6 post becoming a rotational post has compromised continuity of care for patients and families as well as the ability to develop the service.

The non-CF respiratory physiotherapy work impacts on the ability of the physiotherapists to deliver the CF work. The whole respiratory service should be adequately resourced with attention paid to cover for absence

Physiotherapy provision for patients in network centres is often substandard.

Recommendations

With new building work planned, improved space and facilities for exercising patients should be established. This should be sufficient to allow daily access for inpatients, as well as the undertaking of annual exercise testing.

The current staffing structure should be addressed. A combination of protecting current roles for CF care, increased band 3 and static band 6 hours, and establishing a permanent band 7 position would allow better and more consistent standards of care across inpatients, clinic and community, and for joint working with network centre physiotherapists, as well as for developing the CF service and undertaking research projects.

4.4 Dietetics

Full time band 7 Clinical Specialist Paediatric CF Dietitian in post for 3½ years and has undertaken additional specialist CF training, completing the masters module on 'CF and Nutrition' at Leeds Metropolitan University in 2012.

Attends all CF MDT meetings, ward rounds and clinics and carries out annual reviews on the majority of CF children. Reports good ability to provide specialist CF service except limited cover available during leave/illness, when only urgent cases can be seen by a covering band 7 dietitian.

Member of the UK dietitians CF interest group and attends national CF dietitians meetings once a year (50%). Evidence provided for attendance at local regional CF meetings and European CF Conference in Valencia in 2010.

Clinical workload limits time for participation in audit, however plans for service evaluation/audit and service improvements for CF patients, such as an audit of infant feeding practices.

Active role in critical life stages/increased nutritional needs such as new diagnosis; cystic fibrosis related diabetes (CFRD), tube feeding and preparation for transplantation. CF team has an established transition process in place, including joint clinics with adult CF team counterparts.

Hospital is able to provide other specialist services pertinent to CF care, notably neonatal surgery for infants with meconium ileus and gastrostomy insertion.

Areas of good practice

- Dietetic management guidelines in place
- Specialist CF training undertaken
- Dietitian present at clinics and ward rounds to see all patients
- Dietetic assistant available Monday, Tuesday, Wednesday to support inpatients to obtain extra snacks, vouchers for hot breakfast.

Areas for improvement

- Cover for absence/leave (1.25 WTE is normally required to cover a whole-time post).
- Care for patients seen at network clinics – Little if any dietetic support is available in between visits from the Sheffield team and there is no travel budget for the specialist dietitian to attend the clinics (currently relies on travelling with colleagues in the CF MDT). There are other constraints such as CF dietitians time demands. Discussion included the fact that 1 WTE post is not sufficient to cover 52 weeks a year with the same lever of cover (around 42 weeks allowing for annual leave, sick leave, and study leave) for any post. This would require around 1.25 WTE.
- Catering for the increased nutritional needs of children with CF as inpatients. "Hospital food is universally hated" and food availability is limited in the evenings, which is a particularly a problem for teenagers. See Appendix 8 for more detailed notes regarding the catering service.

4.5 Pharmacy

Sheffield has 150 patients and 0.2 WTE specialist pharmacist time funded.

The Cystic Fibrosis Trust's 'Standards of Care (2011)' state 0.5 WTE highly specialist pharmacist per 75 patients and 1 WTE for 150 patients.

Standard: All patients should see a pharmacist at annual review. The pharmacist here is only able to see a proportion of patients at annual review, not all.

The pharmacist is able to see some inpatients but not all, attends approximately 50% of the CF team business meetings and is available to answer queries at other times. There is no cover for annual leave or other absences.

The pharmacist is responsible for arranging homecare IVs (IV – Bupa, oral (one patient on Kalydeco) and inhaled) for full care patients. Shared care patients are not able to access homecare for their home IVs, leading to inequity across the network.

There has not been any additional support provided for the work that homecare necessitates.

The Pharmacist is an active member of the cystic fibrosis pharmacist group (CFPG), attending annual study days and also teaches on the postgraduate pharmacy clinical diploma.

A high quality service is provided, but is very limited by lack of time and does not currently meet minimum standards.

Recommendations

- Increase funded pharmacist time to minimum standard of 1.0 WTE highly specialist pharmacist (8a).
- Arrangement of homecare medicines supply for shared care patients needs to be addressed.

4.6 Psychology

The clinical psychology (CP) service is 1.0 WTE (split 0.5 WTE band 8c and 0.5 WTE band 7) service. Compared to other disciplines within the MDT CF team, the CP service is well resourced (the shortfall is 0.25 WTE). Having 2 CPs allows them to offer each other cover for annual leave and study leave. CP services appear well respected, managed and supported both at the children's hospital (there is a large and thriving paediatric clinical psychology service) and within the CF team.

The entire review panel identified the hard work and commitment to their work offered by both CF CPs. Both are members of UK Psychiatry and Psychology – cystic fibrosis (UKPP-CF), with one being on the committee. Particular areas of good practice include the responsiveness to referrals from the team, offering a flexible and reactive approach to referrals and ongoing patient caseload.

Direct clinical work is a priority for the CPs, including involvement in all key life stages. All CP referrals are considered by need and opportunity, eg appointment is offered when the patient is next in outpatient clinic. No new referral waits longer that one month to be offered a first appointment. There is 100% attendance at team ward rounds/team meetings. There is also a monthly psychosocial ward round facilitated by the CPs. Ongoing consultation/support to other MDT team members (eg, accompanying consultant when informing a family of their baby's CF diagnosis) and teaching is offered as requested.

As reflected by the CF team, these strengths are for those patients and families prepared to access the services at Sheffield. Network clinics are never attended by CPs and although home visits could be offered to those patients seen in these areas, ongoing therapeutic work is not really feasible unless the family are prepared to travel into Sheffield. There are some links with local child and adolescent mental health services (CAMHs) – the level of this service is patchy and there do not appear to be formal processes of communication/consultation from the CF centre.

There have been some changes in Band 7 personnel with gaps in service and as such there is room to improve the number of patients offered a CP annual review, consider using audit/outcome measures and to review and improve written information given to the children and their families. Research would also be an identified goal for the CPs, as would attendance at national and international conferences, along with other members of the MDT (and funding provided without the huge amount of time and effort involved in sourcing it).

There is no dedicated, confidential space for CPs to meet with inpatients (they are seen at the bedside and/or in a room such as the 'adolescents' room' if available). There is a room five minutes walk away, but this is not really satisfactory for those patients on active treatment (eg, IVs) and/or wheelchair/pram users and this could be considered, at least when the new build space is allocated. Outpatients are seen either in the CF unit or in the more 'child/therapeutic friendly environment' in the CP department. Again, this area is not wheelchair friendly (eg, the toilet is up steep stairs).

4.7 Social work

At the time of the visit there was no social worker in post. There has however been a 0.5 WTE social worker (SW) appointed (starting date 15 June 2013).

This appointment is greatly welcomed and anticipated by the CF team (and should relieve some of the responsibilities currently undertaken by the CNSs and CPs, as well as offering the other discrete skills offered by a SW colleague).

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	6	8	4	0
Female	5	5	6	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	19	13	2	0
From the ward staff	11	15	1	4
From the hospital	13	17	3	0

Areas of excellence

1. CF team – supportive
2. Cleanliness – outpatients
3. Accessibility – appts/advice

Areas for improvement

1. Segregation
2. Car parking
3. Food

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 (RAG) rating defined as the following:

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

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

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

Hospital name

Sheffield Children's NHS Foundation Trust

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	Green	
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	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include AR).	95%	Amber	Amber	Good arrangements for Sheffield patients but not for those going also to other clinics
	Do staffing levels allow for safe and effective delivery of service?	Y/N	N	N	
	% of MDT who receive an annual appraisal.	100%	Green	Green	
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red	Red	Informal arrangements in a small Trust
	Are there local operational guidelines/policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust standards.	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Amber	Amber	
	% patients with CFRD reviewed at a joint CF/ Diabetes clinic.	100%	Amber	Amber	

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%	Red	Red	All are single rooms but only 25% have ensuite facilities
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Red	Red	Particular concerns raised by patients with respect to weight/height and lung function areas.
3.2 Monitoring of disease	% attempted eradication of 1st isolates *Pseudomonas Aeruginosa* in the previous 12 months.	100%	Green	Green	
	% patients admitted within 7 days of the decision to admit and treat.	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours.	60%	Green	Green	
3.4 CFRD	% patients > 12 years of age screened annually for CFRD.	100%	Green	Green	
3.5 Liver disease	% patients > 5 years of age with a recorded abdominal ultrasound in the last three years.	100%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Red	Red	Reasons given for not discussing
3.7 Reduced BMD	% patients >10years of age with a recorded DEXA scan in the last three years.	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% patients seen by a CF consultant a minimum of twice a week while inpatient.	100%	Amber	Amber	Minimal consultant cross-cover available
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/shared care consultant/patient or carer, within 10 days of consultation.	100%	Amber	Amber	
	% dictated discharge summaries completed within 10 days of discharge.	100%	Red	Red	Need to address
	% patients reviewed by a CF CNS at each clinic visit.	100%	Red	Green	"meet and greet" all patients
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Green	Green	
4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Red	Red	Access to but not seen every visit – care is targeted. Priority area in recommenda-tions
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Priority area in recommenda-tions
	% availability of a CF specialist dietitian at clinic.	100%	Green		
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Amber	Amber	Cover required for absence/ leave
	% availability of clinical psychology for inpatients and at clinic.	100%	Green	Green	
	% availability of social worker for inpatients and at clinic.	100%	Red	Red	0.5 WTE appointed – starting 15 June 2013
	% availability of pharmacist for inpatients and at clinic.	100%	Amber	Amber	Insufficient pharmacist time so spread very thinly
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	

4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life.	75%	N/A	N/A	

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	1	
5.2	Number of clinical incidents reported within the past 12 months.	<1%	7	7	
5.3	User survey undertaken a minimum of every three years.	100%	Red	Red	Done for this peer review
5.4	SLA in place for all	100%	Amber	Amber	Some SLA in place and further discussions in place, tentative financial arrangements made which will need review in the light of discussions about the services

Appendix 2

Staffing levels (in WTE)

	75 patients	150 patients	250 patients	Sheffield Children's NHS Foundation Trust 151 patients
Consultant 1	0.5	1	1	0.6
Consultant 2	0.3	0.5	1	0.2 currently off work
Consultant 3			0.5	0.15
Staff grade/Fellow	0.5	1	1	0.7
Specialist registrar	0.3	0.5	1	0.2
Specialist nurse	2	3	4	2
Physiotherapist	2	3	4	1.5 band 7 and rotational band 6
Physiotherapy assistant				0.35 currently off work
Dietitian	0.5	1	1.5	1
Clinical psychologist	0.5	1	1.5	1
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.2
Clinicians assistant				
Secretary	0.5	1	2	0.8
Admin assistant				0.8
Database coordinator	0.4	0.8	1	
CF unit manager				

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the 'UK CF Registry Annual Data Report 2011', available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2011	
Demographics of centre: Sheffield Children's NHS Foundation Trust	
Number of active patients (active being patients with data within the last two years) registered	133
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2011')	125
Median age in years of active patients	9
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 and % in age categories	0–3 years	19 (15%)
	4–7 years	35 (28%)
	8–11 years	28 (22%)
	12–15 years	37 (30%)
	16–19 years	6 (5%)

Genetics	
Number of patients and % of unknown genetics	15 (12%) with unidentified mutation on 1 allele; 2 (2%) with unidentified mutations on both alleles

BMI (Ref: 1.13 'Annual Data Report 2011')	
Patients with a BMI percentile <10th centile on supplemental feeding	(n=14) <10th centile; 2 not on supplemental feeding

FEV^1 (Ref: Figure 1.14 'Annual Data Report 2011')		
Number of patients and % with FEV_1 <85% by sex	Male	Female
	(n=60) 13(22%)	(n=65) 17(26%)

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas Aeruginosa* (PA)		
Number of patients in each age band	0–3 years	19
	4–7 years	35
	8–11 years	28
	12–15 years	37
	16–19 years	6
Number of patients with chronic PA by age band	0–3 years	1
	4–7 years	4
	8–11 years	9
	12–15 years	8
	16–19 years	3
***Burkholderia Cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	3 (2%)	
Number and % of cenocepacia	1 (1%)	
MRSA		
Number and % of total cohort with chronic infection with MRSA	6 (5%)	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	7 (6%)	

Complications (Ref: 1.16 'Annual Data Report 2011')	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	7 (6%)
CFRD	
Number and % of total cohort requiring chronic insulin therapy	5 (4%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	2 (2%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis with no portal hypertension	0 patients with PH; 1 (1%) without PH

Transplantation (Ref:1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	1
Number of patients referred for transplant assessment in previous three years	1
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (Ref:1.21 'Annual Data Report 2011')		
Number of days of hospital IV therapy in reporting year split by age groups	0–3 years	237
	4–7 years	273
	8–11 years	133
	12–15 years	395
	16–19 years	82
Number of days of home IV therapy in reporting year split by age groups	0–3 years	24
	4–7 years	180
	8–11 years	73
	12–15 years	590
	16–19 years	92
Total number of IV days split by age groups	0–3 years	261
	4–7 years	453
	8–11 years	206
	12–15 years	985
	16–19 years	174

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	42 (34%)
If not on DNase % on hypertonic saline	15 (12%)

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	25 (20%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	25 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	16 (64%) with chronic PA; 16 (16%) without chronic PA

UK CF Registry data

UK CF Registry data 2011	
Demographics of centre: Barnsley District General Hospital	
Number of active patients (active being patients with data within the last two years) registered	7
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2011')	6
Median age in years of active patients	5
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 and % in age categories	0–3 years	1 (17%)
	4–7 years	4 (67%)
	8–11 years	1 (17%)
	12–15 years	0
	16–19 years	0

Genetics	
Number of patients and % of unknown genetics	1 (17%) patient with unidentified mutations on both alleles

BMI (Ref: 1.13 'Annual Data Report 2011')	
Patients with a BMI percentile <10th centile on supplemental feeding	0

FEV_1 (Ref: Figure 1.14 'Annual Data Report 2011')		
Number of patients and % with FEV_1 <85% by sex	Male	Female
	(n=3) 0	(n=3) 0

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas Aeruginosa* (PA)		
Number of patients in each age band	0–3 years	1
	4–7 years	4
	8–11 years	1
	12–15 years	0
	16–19 years	1
Number of patients with chronic PA by age band	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16–19 years	0
Burkholderia Cepacia (BC)		
Number and % of total cohort with chronic infection with BC complex	0	
Number and % of cenocepacia	0	
MRSA		
Number and % of total cohort with chronic infection with MRSA	0	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	0	

Complications (Ref: 1.16 'Annual Data Report 2011')	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	0
CFRD	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis with no portal hypertension	0

Transplantation (Ref: 1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	0
Number of patients referred for transplant assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (Ref: 1.21 'Annual Data Report 2011')		
Number of days of hospital IV therapy in reporting year split by age groups	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16–19 years	0
Number of days of home IV therapy in reporting year split by age groups	0–3 years	0
	4–7 years	14
	8–11 years	0
	12–15 years	0
	16–19 years	0
Total number of IV days split by age groups	0–3 years	0
	4–7 years	14
	8–11 years	0
	12–15 years	0
	16–19 years	0

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	0
If not on DNase % on hypertonic saline	0

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	0
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 1 patient without chronic PA (17%)

Appendix 4

Patient/parent survey: Sheffield Children's NHS Trust

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	6	8	4	0
Female	5	5	6	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	18	15	1	0	0
Communication (verbal/written)	15	14	5	0	0
Out-of-hours access (via phone or ward)	9	12	8	1	0
Homecare/community support (appointments/advice)	15	10	7	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	16	14	4	0	0
Waiting times	12	11	6	0	0
Cross-infection/segregation	15	12	7	0	0
Cleanliness (room)	17	14	3	0	0
Annual review process	16	11	2	0	3
Transition (paediatric to adult)	1	1	0	1	28

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	10	10	2	0	12
Cleanliness (cubicle/bathroom)	9	12	0	2	10
Cross-infection/segregation	10	8	2	1	10
Food (quality/quantity)	4	8	5	5	11
Exercise (gym equipment/facilities)	5	5	1	2	19

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	11	5	0	0	14
Availability of equipment (physiotherapy aids/nebuliser parts)	14	9	2	1	8
Car parking (availability/ease of reach)	0	2	1	25	4

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	19	13	2	0	0
Of the ward staff	11	15	1	4	0
Of the hospital	13	17	3	0	0

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	0	0	1	0
Female	0	1	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	2	0	0	0	0
Communication (verbal/written)	2	0	0	0	0
Out-of-hours access (via phone or ward)	2	0	0	0	0
Homecare/community support (appointments/advice)	0	2	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	2	0	0	0	0
Waiting times	2	0	0	0	0
Cross-infection/segregation	0	0	2	0	0
Cleanliness (room)	0	2	0	0	0
Annual review process	0	0	0	0	2
Transition (paediatric to adult)	0	0	0	0	2

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	0	0	0	0	2
Cleanliness (cubicle/bathroom)	0	0	0	0	2
Cross-infection/segregation	0	0	0	0	2
Food (quality/quantity)	0	0	0	0	2
Exercise (gym equipment/facilities)	0	0	0	0	2

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	0	0	0	0	2
Availability of equipment (physiotherapy aids/nebuliser parts)	0	0	0	0	2
Car parking (availability/ease of reach)	2	0	0	0	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	2	0	0	0	0
Of the ward staff	0	0	0	0	2
Of the hospital	0	2	0	0	0

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	0	1	0	0
Female	0	1	1	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	2	0	1	0	0
Communication (verbal/written)	1	2	0	0	0
Out-of-hours access (via phone or ward)	1	0	2	0	0
Homecare/community support (appointments/advice)	2	1	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	0	2	1	0	0
Waiting times	1	2	0	0	0
Cross-infection/segregation	1	0	1	1	0
Cleanliness (room)	0	1	0	0	1
Annual review process	1	0	0	0	2
Transition (paediatric to adult)	0	0	0	0	2

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	1	0	1	0	0
Cleanliness (cubicle/bathroom)	1	1	0	0	0
Cross-infection/segregation	1	0	1	0	0
Food (quality/quantity)	1	1	0	0	0
Exercise (gym equipment/facilities)	1	1	0	0	0

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	0	1	0	0	0
Availability of equipment (physiotherapy aids/nebuliser parts)	1	1	0	0	0
Car parking (availability/ease of reach)	1	0	1	0	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	1	1	0	0	0
Of the ward staff	1	0	1	0	0
Of the hospital	1	0	1	0	0

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	1	0	1	0
Female	1	0	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	1	2	0	0	0
Communication (verbal/written)	1	2	0	0	0
Out-of-hours access (via phone or ward)	0	2	0	1	0
Homecare/community support (appointments/advice)	0	1	0	1	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	0	2	1	0	0
Waiting times	0	0	1	0	0
Cross-infection/segregation	0	0	2	1	0
Cleanliness (room)	0	3	0	0	0
Annual review process	0	1	0	0	2
Transition (paediatric to adult)	0	0	0	0	2

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	0	0	0	1	2
Cleanliness (cubicle/bathroom)	0	0	1	0	2
Cross-infection/segregation	0	0	0	0	2
Food (quality/quantity)	0	0	1	0	2
Exercise (gym equipment/facilities)	0	0	0	1	0

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	0	0	0	0	3
Availability of equipment (physiotherapy aids/nebuliser parts)	0	1	1	1	0
Car parking (availability/ease of reach)	0	1		1	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	0	2	1	0	0
Of the ward staff	0	1	0	1	0
Of the hospital	0	2	1	0	0

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	0	1	0	0
Female	0	0	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	1	0	0	0	0
Communication (verbal/written)	0	0	1	0	0
Out-of-hours access (via phone or ward)	0	1	0	0	0
Homecare/community support (appointments/advice)	1	0	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	0	1	0	0	0
Waiting times	0	1	0	0	0
Cross infection/segregation	0	1	0	0	0
Cleanliness (room)	0	1	0	0	0
Annual review process	0	0	0	0	1
Transition (paediatric to adult)	0	0	0	0	1

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	0	0	0	0	1
Cleanliness (cubicle/bathroom)	0	0	0	0	1
Cross-infection/segregation	0	0	0	0	1
Food (quality/quantity)	0	0	0	0	1
Exercise (gym equipment/facilities)	0	0	0	0	1

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	0	0	0	0	1
Availability of equipment (physiotherapy aids/nebuliser parts)	0	0	0	0	1
Car parking (availability/ease of reach)	0	0	0	1	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	0	0	1	0	0
Of the ward staff	0	0	1	0	0
Of the hospital	0	0	1	0	0

Comments about CF team/hospital

"I would prefer more parking spaces or change of times to the appointment. Everyone seems to be at clinic appointments at the same time, afternoon! Plus things could be better regarding weight and measures. We all sit together, but when in CF we are all apart – what's the point?! Parking is the biggest pain of all especially if you come from far and car is your only transport. I've had to come early due to parking issues. Waiting nearly an hour one day for a space. I think there should be more spaces, not less. Plus I have even seen people park in the disabled spaces! CF team could talk to each other more on regards of meds. Because one says do one thing and another says do this. I find that completely frustrating when you know your child is ill. To look at records and discuss before telling me what I should be doing. Checking is most important."

"Never able to get hold of CF nurse at Scunthorpe, doesn't respond to messages or get back with results quickly enough."

"The CF team is excellent. They provide top quality care for our son when required and strike a great balance, allowing us to incorporate CF into our family life. It genuinely is holistic support and they do an excellent job for our son and our family."

"Sheffield – good team, good support. Terrible accessibility… parking! Barnsley - as Sheffield, parking no problem."

"Both Sheffield and Scunthorpe hospitals have been great in their treatment of my child. I can easily speak to either team if I have any problems. My daughter trusts both Scunthorpe and Sheffield teams which means she is very happy to see them."

"Segregation on CF unit good – but at annual review you end up sat with other CF annual review patients in X-ray, growth and measurement etc. Parking is terrible even with a Blue Badge."

"The CF team at Sheffield is extremely supportive, professional and friendly. They make hospital visits a less stressful experience. As we live nearer Doncaster we sometimes are transferred nearer home for inpatient stays. In the past, we have bad, unpleasant and unhelpful experiences on change over which we found upsetting and stressful."

"Excellent service throughout, cannot fault the hospital and CF team. Only problem we find it's a nightmare to get parked anywhere."

"Both hospital staff are excellent to work with. Doncaster is just a lot easier for us to get to."

"We live in Lincoln but chose to be cared for by the Sheffield team after we moved from Grimsby, although we do not have the community care because of distance from Sheffield. All the team are excellent at helping us over the phone as well as at clinics. I think the team is above excellent and we would be lost without them."

"The CF team at Sheffield Children's Hospital are like an extended family. They are always there if we need them. The care is excellent."

"Great people and hospital always there when you need them."

"The CF team are a little bit distant nowadays, although friendly. It doesn't seem to be the same happy place it once was? The parking is a complete nightmare."

"The whole team at Sheffield are absolutely brilliant; nothing is too much trouble for them. We think they are all truly amazing."

"My son has always had excellent care from the CF team. He also has Asperger's and the CF team referred him for an assessment when school were not interested. They have been there to support the family's needs. I cannot fault them they are marvellous."

"I cannot fault our CF team. They are always friendly, kind and helpful. I wouldn't want my child in the care of anybody else. He is already in the best hands."

"The CF ward and staff are good for segregating patients. But sharing the lift and waiting outside growth and measurement doesn't separate them anyway, and pharmacy. Pharmacy estimated waiting time was 56 mins."

"Out of hours/contacts still a little battle. Sometimes messages taken by CF team at Sheffield and no one calls back. Upon first diagnosis at three weeks the service was 100% now at nine months it has slipped somewhat, but still Sheffield is better than Doncaster where we are from."

Appendix 5

Patient/parent interviews

Parent – child 10

Sees MDT every 4–6wks in pseudomonas clinic books into reception and then put into cubicle stay in room then team come to him.

Port flush at same time by CF nurse.

Lung function done by CF team/CF nurses, but height and weight measurement is carried out in a separate area where there is no segregation and can be sat next to a CF patient.

Home IVs delivered and made up by Bupa

Prompt on starting IVs and in ward to have first two doses.

Inpatient facilities – fridge in parent's room. No snacks mum provided and doesn't eat from menu on ward so mum takes to canteen where she pays only once, as given a docket by CF nurse to pay for meal.

Physio came twice during inpatient stay and checked through pep techniques. Gym facilities on ward and can swap a physio session for a gym session.

Annual review – all done on one day. Fed back results verbally a couple of months later in clinic and then report to follow.

Areas of excellence

- Team always there for you
- Home visits when needed
- Don't feel like a number

Areas for improvement

- Segregation at height and weight measurement area
- Meals provided for at canteen

Sheffield Paediatric Peer Review 8 May 2013

Parent Interview

The parent of a 14-month-old baby girl with CF, who also has a non-CF son of four years old. The mother is an A&E nurse. She has a partner.

The baby was diagnosed at 2½ weeks after receiving a call from her GP to make an appointment, where she met the CF Nurse Specialist from Sheffield along with her GP. The parent said that the nurse explained CF to her; she was in shock at first as there was a lot of information to take in but she has had great support and help from the nurse and built a special bond between them.

The parent stated that she can call the nurse at any time for advice and has done so on the last bank holiday, where she was given friendly advice and told that the nurse would call her back the next day to see how the baby was getting on, which she did.

The parents are now moving to Mansfield, which is 40 miles away, as her partner's job will be nearer and also family members will be nearby for additional support. The parent is adamant that she still wants to travel for her care to Sheffield Hospital and not to transfer to Nottingham because of her bond with the nurse and the team. She actually stated that if it was not for the team her baby would not be alive.

The parent drives to the hospital which takes 20 minutes and then 10 minutes to find a parking space, she is aware that the parking is a real issue but does not find this a problem personally.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Hospital name	Sheffield Children's NHS Foundation Trust
	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	Patients are taken directly to cubicles on arrival 3 Cubicles and 3 Consultation rooms
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where does height and weight measurements take place? Is this appropriate?	No	Patients sent one at a time to Growth/ Measurement to prevent cross-infection risk. Patients arriving early for annual review in small waiting area (seating for 6) is a risk. One solution may be height and weight in each clinic room
Where are lung function tests done for each visit?		All are performed in Spirometry room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Xbox, free TV/Video library, colouring and toys
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?	Yes	Quarterly clinic (staff and space dependent)
Transition patients – can they get tour of outpatient facilities?	Yes	Patients seen at least twice in the joint clinic at the adult centre prior to transfer
Transition/new patients – do they get information pack?	N/A	

Additional comments

Timeslots for patients are given ½ hourly with one hour consultation time. Up to 18 patients seen in main clinic.

2 clinics weekly for non-Pseudomonas/Pseudomonas. Separate arrangements elsewhere for Burkholderia Cepacia patient.

Patient numbers – 150 patients. One hundred receive their full care in Sheffield and 50 also receive some care in peripheral hospitals.

Environmental walkthrough: ward
Ward name: M1 (0–4 years)
Microbiology status: General Paediatric Ward, all microbiology

		Hospital name	Sheffield Children's NHS Foundation Trust
		Yes/no/ number/ n/a	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Respiratory ward suitable for CF patients
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		8	Priority is given to CF patients
Do the en suites have:	**Toilets?**	No	
	Wash basins?	Yes	
	Bath or shower?	No	
Do CF patients have to share any bathroom facilities?		Yes	Facilities are allocated to patients for own use
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		No	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents / carers /partners to stay overnight?		Yes	There are camp beds. Treetops facility available which is situated on the floor above
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	Hot drink facility and use of fridge. No microwave use
What facilities are provided for teenagers?		N/A	

	Yes/no/ number/ n/a	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	N/A	0–4 yrs mainly play due to age
What facilities are there to help with school and further studies?		Play therapist and school teacher available
Is there a relative's room?		Parents room shared by Wards M1 and M3 and Treetops facility
What internet access is there?		Cable, no Wi-Fi
What facilities are there to enable students to continue work and study?	N/A	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Cleaned by the nurses in the kitchen in dishwasher
What facilities are provided for those with MRSA?		Would be in isolation in cubicle – none at present
What facilities are provided for those with *B.Cepacia*?		Admitted to Ward S3
What facilities are provided for those with other complex microbiology?		Admitted to Ward M2. Negative pressure cubicle
Are patient information leaflets readily available on ward?	Yes	Nurses distribute as appropriate
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

N/A

Environmental walkthrough: ward
Ward name: Ward M2 (4–16 years)
Microbiology status: General Medical (Not *B. Cepacia*).

		Hospital name	Sheffield Children's NHS Foundation Trust
		Yes/no/ number/ n/a	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Suitable for CF patients
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		12	6 Cubicles with en suite, 6 without en suite
Do the en suites have:	**Toilets?**	Yes	(6 en suite)
	Wash basins?	Yes	(6 en suite)
	Bath or shower?	Yes	(6 en suite)
Do CF patients have to share any bathroom facilities?		Yes	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		No	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Treetops and camp beds available
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	There is a fridge in parents' room shared with Ward M1, No use of a microwave
What facilities are provided for teenagers?			Teenagers' room, time slots for CF patients can be allocated, good range of facilities: Xbox, Playstation, Wii, large-screen TV, games, books and pool table. Can also bring in own equipment

	Yes/no/ number/ n/a	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is access to gym equipment in a room which is shared with three office staff. This is inappropriate
What facilities are there to help with school and further studies?		Schoolteacher
Is there a relative's room?	Yes	Treetops facility available
What internet access is there?		Cable, no Wi-Fi
What facilities are there to enable students to continue work and study?	Contact is made with the school and school work is arranged. Exams can be taken, (GCSEs), an assessor is sent to be present for the exam	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Can be cleaned in cubicles, there is use of dishwasher, for sterilisation or parents take home for cleaning
What facilities are provided for those with MRSA?		Barrier nursing.
What facilities are provided for those with *B.Cepacia*?		Admitted to Ward S3 (1 patient)
What facilities are provided for those with other complex microbiology?		Isolation cubicle, priority is given for negative pressure room (*M. Abcessus* – 5 patients)
Are patient information leaflets readily available on ward?	Yes	Nurses distribute
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

The treatment room is very small

Environmental walkthrough: ward
Ward name: Ward S3
Microbiology status: Orthopaedic (*B. Cepacia*)

		Hospital name	Sheffield Children's NHS Foundation Trust
		Yes/no/ number/ n/a	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Suitable for CF care
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		3	1 room has en suite
Do the en suites have:	**Toilets?**	Yes	1 room
	Wash basins?	Yes	1 room
	Bath or shower?	Yes	1 room
Do CF patients have to share any bathroom facilities?		Yes	Possibly
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		No	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Camp beds or Treetops facility on floor above ward
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open visiting hours
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?			Access to fridge but there is no microwave available
What facilities are provided for teenagers?			Xbox, Playstation and can also bring in own equipment

	Yes/no/ number/ n/a	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Access to gym equipment in office shared with 3 staff. Unsuitable for staff and patients
What facilities are there to help with school and further studies?		Teacher available and play therapist
Is there a relative's room?	Yes	And Treetops facility
What internet access is there?		Cable not Wi-Fi
What facilities are there to enable students to continue work and study?	School work can be brought in. Teacher available	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Nurses can sterilise in dishwasher which is also used for dishes separately
What facilities are provided for those with MRSA?		Side cubicle
What facilities are provided for those with *B.Cepacia*?		Side cubicle
What facilities are provided for those with other complex microbiology?		Side cubicle
Are patient information leaflets readily available on ward?	Yes	Nurses distribute
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

N/A

	Hospital name	Sheffield Children's NHS Foundation Trust
	Yes/no/ number/ n/a	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Parking is huge issue. There are only 24 spaces in total, of which 6 are for disabled patients. The cost is £8 per day. If a patient is admitted and stays over 4 days they can be issued a ticket, which enables them to park for a total of £10 and is valid for 3 months
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	The colour-coding system is not clear for the ward blocks
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, DEXA scan?	No	There could be a possible risk at the growth and measurement waiting area. Other areas are much more spacious. X-ray – large area, very busy
Do patients have to wait at pharmacy for prescriptions?	No	Pharmacy uses a bleep system where patients can collect their prescriptions once bleeped.
Patient information		
Is PALS well advertised – leaflets, posters?	Yes	PALS office in main reception area, clearly signed.
Are there patient comments/ feedback boxes?	Yes	The comment box is situated directly outside the PALS office

Additional comments

Home IVs are delivered to home; the CF unit carries out the first dose.

Action lab – A large, well-equipped room where annual reviews and detailed diagnostic exercise assessment can be carried out. Contains specialist equipment and offers lung-function testing service, including standard detailed lung-function measures.

The Spirometry room has no air conditioning.

Treatment room is shared with non-CF patients.

Appendix 7

Panel members

Dr Maya Desai	Consultant
Robyn Huggins	Dietitian
Charlie Dawson	Cystic Fibrosis Nurse Specialist
Amanda Bevan	Pharmacist
Marie Bolton	Physiotherapist
Michele Puckey	Psychologist
Sophie Lewis	Patient Adviser
Lynne O'Grady	Project Lead, Head of Clinical Programmes, Cystic Fibrosis Trust

Appendix 8

Other information

Dietetic Manager: Walkthrough 7 May 2013

- A patient/parent survey showed that the patients would prefer to have a light lunch and an evening meal and that the patients were not satisfied with the food.
- £6 is the daily allocation per patient for meals and snacks.
- The cooks cater for the patients and also the restaurant.
- The cooks try to make the food child orientated (pizza, beans and chips) but when the food is transported on a trolley to the ward, by the time it arrives, it is overcooked and unappetising.
- There is difficulty in providing adequate calories in the meals – patients require more calories in the evening meal.
- The time for the evening meal is 5pm which is too early for the CF patients, who would benefit from eating at 7pm.
- There are two cooks in the afternoon, of which one goes home at 4.30pm and the other leaves at 7pm.
- There is a snack trolley.
- A 'diet bay' was suggested. Although the dietetic manager had funding for extra staff, she informed that space was an issue. The available space may have to be utilised in an imaginative way to provide a diet bay.

Catering Manager and Dietetic Manager: Peer Review 8 May 2013

- Dietetics could work more closely with catering department.
- Trolley system (bulk delivery) – variable care is taken when dishing out meals, food not appealing to patients and overcooked on trolley.
- There should be more evening provision for teenagers especially, more substantial than just snacks.
- There are kitchens on wards, although there is no freezer storage and they are used by other staff during the day.
- The idea for a chef for oncology/CF was agreed a good idea in principle but in practice? Also that the trolleys are stored in the kitchens at meal times.

- Snack box contents for CF patients could be reviewed to include higher calorie yogurts/muffins etc.
- There could be changes to the menu, or a separate CF menu (fortified).
- There are six staff in the kitchen plus one agency staff, who in all cover a period of 12 hours (7am–7pm).
- On today's visit there are only two staff covering 120 patient meals and also 150/200 meals for the restaurant.
- Improved catering would mean less supplements taken, balancing budgets and healthier children.

Recommendations

- Could possibly utilise ward kitchen after 6pm.
- Consider diet bay/dedicated chef.
- Rotational chefs from kitchens to work in ward kitchen.
- Colourful crockery – would be more appealing and encourage larger portion size. Improve snack boxes.
- Separate food for CF patients containing higher calorific value/fortification.

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