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Peer review report

Hull Royal Infirmary
Cystic Fibrosis Centre
Paediatrics
09 July 2013

1. Executive summary

1.1 Overview of the service

The paediatric cystic fibrosis unit at Hull Royal Infirmary delivers multidisciplinary full care for 29 children all aged less than 16 years, over a 25-mile radius.

This unit is not linked to a regional specialist centre, nor does it provide a shared-care or outreach service.

Clinicians and management team are keen to develop services for patients of Hull. Their nearest specialist CF centre (Leeds) is 60 miles away and is currently running at full capacity.

Parent/patient survey and interviews with parents on the day have given a very positive feedback.

1.2 Good practice examples

1. All members of the team work cohesively and are fully dedicated to providing a good level of individualised care.
2. The team is supported by experienced and well-trained core Allied Health Professionals (AHPs). The CF clinical nurse specialist (CNS) has independent prescriber status. Physiotherapist provides home visits.
3. Pre-prepared intravenous antibiotics and delivery via homecare have been a good new development.

1.3 Key recommendations

1. Hull CF unit should consider network care linked to Leeds specialist CF centre due to its relatively small size and little prospect of increasing patient numbers within the catchment area.
2. Network care arrangement with Leeds to be facilitated by lead clinicians and commissioners of Hull and Leeds.
3. Under network care arrangement, patients will continue to receive the majority of their routine outpatient and inpatient care at Hull.This link will provide a larger pool of expertise and ensure that cross-cover can be provided for all members of the multidisciplinary team (MDT).
4. Urgent addition of a social worker to the team is required to improve support and quality of care.

1.4 Areas for further consideration

1. Treatment should be maximised during IVABs.
2. Transition process needs refining.
3. Recommendation to consider specialist pharmacist input for annual review and homecare work.
4. Addressing current shortfalls of MDT especially within pharmacy and psychology, and improving cover for holidays or sickness.

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.

Recommended that the annual review process should be formalised to fully meet the Cystic Fibrosis Trust's 'Standards of Care (2011)'. Provision of a formal post-annual review discussion between parents and consultant to formulate a management plan for the coming year should help achieve this.

2.2 Multidisciplinary care

Summary

For continued safe and effective delivery of care the MDT staff need to consider provision of cover for annual leave and sickness. Although there are informal referral arrangements with other specialities, this needs to be formalised into referral pathways.

2.3 Principles of care

Summary

All inpatients are cared for in single rooms, however there are no en suite facilities. This reflects the nature of the building and will be addressed as the inpatient facility is due to be relocated.

The Trust's current 'Standards of Care (2011)', state that the screening for reduced bone mineral density (BMD) using a bone density DEXA scan should be initiated by 10 years of age. At present this standard is not achieved and the team is attempting to incorporate this as soon as possible.

2.4 Delivery of care

Summary

Inpatient review by consultant – The apparent lack of review by the CF team during inpatient stays can be addressed by providing dedicated CF MDT ward rounds with improved documentation.

Issues about lack of CNS, physiotherapist, dietitian and psychologist review on ward and in clinic have been qualified. Improved inpatient documentation and appropriate leave cover would address this issue. These members of the MDT are accessible at all times except during annual or sickness leave.

Social work – CF service has no social worker.

Communication – All clinic letters are sent in a timely fashion. No letter for annual assessments written currently.

2.5 Commissioning

Summary

Hull specialist commissioner, senior clinical team and service manager to look at achievements in comparison with service specification.

Future commissioning arrangements for the CF service at Hull Royal Infirmary will be based on a decision made between specialist commissioners in the north and senior clinical and management team of Hull and Leeds. Service needs to be developed in conjunction with commissioning. Please see Appendix 8 for full commissioning report.

3. UK CF Registry data

Body mass index (BMI)	Paediatric sites	Patients with a BMI percentile <10th centile on supplemental feeding	6 (100%)

				Male	Female
FEV_1	Paediatric sites	Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
			4–7 years	1	0
			8–11 years	0	1
			12–15 years	4	0
			16–19 years	1	2

Data input	Number of complete annual data sets taken from verified dataset	35

Pseudomonas Chronic PA is 3+ isolates between two annual data sets	Paediatric sites	Number and % of patients with chronic PA infection on inhaled antibiotics by age group	0–3 years	0
			4–7 years	0
			8–11 years	0
			12–15 years	0
			16–19 years	0

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	0
	Number and % of patients on chronic macrolide without chronic PA infection	2 (6%) on macrolide without chronic PA

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

1. Job plan: There are two consultants with 0.325 whole time equivalent (WTE) for 29 patients. This is in line with the Cystic Fibrosis Trust 'Standards of Care (2011)' recommendations (0.8/75).
2. Training/Experience: The two consultants are new to the CF team. Lead consultant is experienced in respiratory paediatrics and appointed as lead of CF service since March 2013. The second consultant is newly appointed in April 2013, has CF experience but was not a grid trainee. There is no specialist registrar (SpR) allocated to the service.

   Clinical experiences of uncommon complications are inevitably limited due to the small size of unit with a young patient cohort (26/29 are under 10 years of age). They have one patient with CF-related diabetes (CFRD), none with Non-Tuberculosis Mycobacterium (NTM), Allergic bronchopulmonary aspergillosis (ABPA) or Meticillin-resistant staphylococcus aureus (MRSA) and have in the past had one patient with *Burkholderia cepacia.* This means that it is now important to have a strong link with a larger specialist centre.
3. Cover for annual leave: The two consultants cover each other. Both not permitted to be on leave concurrently except in exceptional circumstances; this would only be problematic if one consultant had sick leave while the other was on annual leave.
4. On-call cover: On-call cover is provided by two consultants and one CF nurse for families and ward teams. There is no formal rota. The two consultants provide a 1:7 paediatric ward cover, the rest of the weeks are covered by general paediatricians with an informal 'phone-a-CF friend' system in place between consultants out-of-hours.
5. Inpatients: Elective admissions for IVAB or surgical procedures are seen by a CF consultant daily. Long lines are done by CF nurse; consultant or paediatric SpR. Providing CF MDT ward rounds with improved documentation by the team could address the apparent lack of review by CF MDT.

   Internal notification of acute admissions to CF team can be unreliable and it is being addressed.
6. Consultant ward round twice a week: Majority of patients have received home IVAB as the norm. These children are not seen by consultant twice a week. Those having regular IVAB are usually the sicker patients or those not receiving consistent treatment at home and often the ones needing the closest supervision.
7. Outpatients: All patients seen by CF consultant. All have had annual reviews but not held within a formal MDT annual review clinic. Action plans are discussed within MDT and currently in the process of including feedback and discussions with family.
8. Learning/networking: Consultants have attended national CF meetings but have not attended European Cystic Fibrosis Society (ECFS) or North American Cystic Fibrosis Conference (NACFC). Lead consultant to attend this year's Cystic Fibrosis Trust meeting.

   The lead consultant would like to establish links with Leeds specialist CF centre and is in the process of attending their MDT clinic/ward round.
9. Newborn screening: Positive screen results are conveyed directly by screening laboratory to Hull and Leeds. Hull practice is to contact family via telephone to inform that cystic fibrosis is likely and a visit to Hull has been organised for the following day. New diagnosis is seen at Hull by the CF consultant and available MDT. Sweat test done only on fixed day of the week.
10. Transition: No fixed formal transition process/clinics held. Patients are usually transitioned to their adult service.

11.Miscellaneous:

- Bone density (DEXA) scans not done on cystic fibrosis patients. Clinical lead addressing the issue.
- No flexible bronchoscopy service. Clinical lead would like to establish links with Leeds specialist centre.
- Annual review process to be formalised; have review discussion with parent/patient and formulate management plan for the following year. The report should be available in a timely fashion.

4.2 Specialist nursing

The CNS (Band 7) is well qualified (RGN, RSCN, BSc Hons ++) and extremely experienced in nursing, as well as cystic fibrosis and education. She is a nurse prescriber. She is a member of Cystic Fibrosis Nurses Association (CFNA) and attends relevant local, national meetings and conferences.

She is funded full time for CF nursing, though approximately 25% of her work load is covering other complicated respiratory patients. This is a ratio of 0.75 WTE for 35 patients (recommendation 1:50). Her CF time is divided evenly between hospital and community-based care. The service is nurse-led take over for home IVs and patient reviews outside CF clinic (ad hoc nurse clinics) and she aims to review inpatients on a daily basis. Expenses for the community part of the job are fully funded by the hospital trust. Leave is covered by other disciplines within the CF MDT. There is no formal nursing cover but nursing-specific issues will be picked up by clinic nurses or another CNS. Space to review outpatients and start treatments is becoming increasingly difficult due to changes and pressures from within the paediatric unit.

The nurse carries a work phone for out-of-hours cover. This is informal and if she is not available one of the other MDT members will be contactable via the CF phone. Again, this cover is informal.

There are medical links with Leeds CF specialist centre for advice and support with complex issues or procedures that are not available locally. The nurse-to-nurse support is limited.

She is involved in research and audit – recent involvement in TIDES study, parent satisfaction audit and nebuliser audit. Recent developments include updating of clinic forms, continued development of a transition programme and a Paediatric Continual Medical Education (CME) meeting including education on cystic fibrosis. She has been involved in securing pre-packed home IV treatment and the introduction of this over the last year.

Good practice

The CNS is extremely experienced in her field and abilities in cystic fibrosis and nursing in general and therefore offers a high level of service which is well organised. She knows her patients well (an advantage of a smaller case load). Guidelines and protocols are clear and concise.

Areas of improvement

CNS does a lot of social sorting, Disability Living Allowance (DLA) applications etc, which should be supported by social work input. The lack of admin support means she does some of her own letters and takes minutes of meetings. If the appropriate disciplines were in place this would allow her to do more nursing.

There is a general lack of ward staff involvement with all CNSs. The CNSs are keen to do more education for ward staff but there is difficulty with them being released from the ward to attend.

The out-of-hours cover needs formalising.

Links with other nurses in the field are lacking.

Succession planning is lacking. It would be difficult to replace the patient knowledge and expertise of the current CNS.

4.3 Physiotherapy

- Physiotherapy service provision is managed by a clinical lead Band 7 physiotherapist, 0.7 WTE. She has been in post 4/5 years and works from 8.30am–2.30pm daily; designated CF time 0.4 WTE with the rest of her time allocated between paediatric medical respiratory inpatients, cystic fibrosis (which always takes priority) and adult critical care. She covers CF inpatients, outpatients, annual reviews and provides home visits for those patients having home IVABs. She is responsible for teaching and training Band 6 and 5 physiotherapists in cystic fibrosis management and treatment. She is also responsible for on-call training of physiotherapists as well as educating medical staff.
- This physiotherapist is a member of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and Association of Chartered Physiotherapists in Respiratory Care (ACPRC) special interest groups, as well as the Yorkshire regional physiotherapy specialist interest group, which meets regularly throughout the year.
- She attends the annual ACPCF study days, the Royal Society of Medicine (RSM) meetings and the Cystic Fibrosis Trust conference each year.
- Annual assessments are booked in with her in advance for a Tuesday morning. Review of physiotherapy techniques, equipment and an exercise test are performed, using the modified shuttle test if the patient is over six years of age. She is also responsible for lung function testing, and postural assessment and incontinence are also discussed with referral on to either the orthopaedic team or women's health team as appropriate, for those with problems.
- Patients are seen during an inpatient admission by the lead physiotherapist predominantly with help from a Band 6 or 5 physiotherapist, dependent on clinical need. Annual leave/sickness cover is provided by the critical care team. Most courses of IVABs are given at home with few patients being admitted. She supports these patients at home with a visit halfway through the course of IVAB treatment, with follow up as needed or is seen in clinic. Patients have access to 24-hour emergency cover and have physiotherapy treatment over the weekends. The paediatric gym is accessible to inpatients; trampet and pedals used in cubicles.
- The lead physiotherapist has protected time to attend CF clinic each week on Friday morning where she would assess the patient, perform spirometry and obtain samples for bacteriology; there is no cover for annual leave or sickness in clinic. Respiratory samples and spirometry would be collected/performed by the specialist nurse in her absence. Frequency of appointments is dependent on patient's condition. If routine, then six-to-eight weekly, for those with more advanced disease monthly and the new born screened infants bi-weekly initially.
- The initial contact for a family needing support or advice outside clinic would be the specialist nurse, who would then contact the lead physiotherapist to arrange an outpatient visit.
- This physiotherapist would see newly diagnosed screened infants when the MDT is introduced to the new family and a follow-up outpatient visit would then be arranged to see her independently, to commence physiotherapy treatment and plan management.
- She attends the MDT meeting following each clinic to discuss inpatients, outpatients and annual reviews. She also attends the monthly MDT CF business meeting with the team.
- Her research and audit includes 'the patient home visit physiotherapy survey' which she plans to revisit and update.
- Service improvements include the introduction of home visits into the physiotherapy service in the last 12 months and the commencement of exercise testing with dedicated space in which

to perform testing. A recent addition is the opportunistic collection of respiratory samples for testing, by the physiotherapist, during anaesthetic induction on patients having elective surgery.

- The nebuliser service is predominantly led by the specialist nurse but the lead physiotherapist has increasingly been involved in the I-neb set up and downloads. The Pari system or the I-neb is used (not the e-flow). There are no patients colonised at present with pseudomonas; all have eradicated pseudomonas with treatment. Patients are segregated at clinic for infection control.
- All physiotherapy and nebuliser equipment is funded through the paediatric fund eg acapellas, PEP devices etc. Hypertonic saline is used for treatment as well as for use in induced sputum sampling.
- Unfortunately, due to the small number of patients attending this clinic, the physiotherapist's experience with key life changes is limited but she has overcome this by establishing close contacts with Leeds, contacting their specialist CF physiotherapist, with any concerns, or for advice.
- There is a shortfall in the protocols and patient handouts; however this will be addressed in the near future with the availability of the ACPCF documents as they are completed. The Cystic Fibrosis Trust factsheet is used for newly diagnosed patients.
- The referral system for identifying new admissions needs addressing as patients have been missed and have consequently had their physiotherapy delayed or missed completely during a short admission.
- Overall, the lead physiotherapist is dedicated and committed to the cystic fibrosis patients and families and provides a very good, comprehensive physiotherapy service.

4.4 Dietetics

Dietetic support is provided by a very experienced Band 7 dietitian who has supported patients with cystic fibrosis for many years. Her time is split between CF and diabetes, with 0.2 WTE of her time allocated to cystic fibrosis.

She provides a service to outpatients predominantly, as inpatients are rarely in hospital for more than a few days at a time, and these patients do not receive a dietetic review. The only exception to this is patients admitted for enteral feeding (often called tube feeding), and surgical neonates (newborn child; especially a child less than a month old) who are reviewed by this dietitian regularly while on the ward.

The dietetic team at Hull is small, and no cover is provided for annual leave, sickness or study leave. Dietetic support is provided by the MDT in Anne's absence.

The CF dietitian's time is split as follows:

- One outpatient clinic per week, followed by a post-clinic meeting.
- Annual reviews – one patient per week.
- A monthly MDT meeting, which includes clinical discussions in preparation for the annual reviews, discussion about any patients of concern, and education.
- Ad hoc calls from families in between clinic visits.
- Support for newly diagnosed infants in next day MDT clinics.
- Attendance at transition clinics.

The CF dietitian monitors blood vitamin levels and tracks changes in body mass index (BMI) at clinic visits and discusses trends with families at annual review.

There has been an increased awareness of blood vitamin levels recently, and the dietitian has taken responsibility herself for monitoring levels and actioning changes in prescriptions.

There has also been an increased awareness of the need to manage low BMIs with new personnel in the team, and the dietitian believes this will facilitate improvements in BMI in future.

The hospital has a Cook Chill meal service, with meals produced off-site. High energy meals and snacks are available, and a choice of meals is provided for children, including access to the staff restaurant if required.

The hospital stocks a full range of enteral feeds (tube feeds), specialised infant feeds and oral nutritional supplements.

The dietian's expertise as a diabetes dietitian is advantageous in her management of CF-related diabetes (CFRD), and she has been instrumental in the diagnosis of CFRD in some patients.

Patients over the age of 12 years are given an annual Oral Glucose Tolerance Test (OGTT) and routine blood glucose monitoring is done for inpatients. There are no joint CFRD clinics, however as numbers are small, a flexible approach is used and the diabetes team will often attend the CF clinic appointments.

Patients with more complex problems such as CF liver disease attend Leeds, and are not seen by the CF dietitian at Hull.

4.5 Pharmacy

Hull paediatric service has no funded specialist pharmacist time.

Inpatients are seen by the regular general ward pharmacist who will undertake medicines reconciliation at the time of admission.

A general pharmacist will screen homecare prescriptions for home IVABs provided by Willow and inhaled or oral treatment provided through Healthcare at Home.

The pharmacists have not received any specific training in cystic fibrosis and are not members of the CF Pharmacists Group. Outpatients are not seen by a pharmacist at annual review or when they attend clinic.

In order to meet the pharmacist-related standards of care, a business case will need to be developed for a 0.5 WTE highly specialist pharmacist.

4.6 Psychology

- The psychologist has attended every annual UK Psychosocial Professional Group CF (UKPP-CF) meeting for over five years, including 2013.
- The psychologist attends all clinical and business meetings, but not ward rounds as the CF service does not routinely provide inpatient care.
- There is no cover for the psychologist. The lack of a social worker further limits broader psychosocial support and places additional demands on the psychologist's time.
- The psychologist has attended the UK CF Pyschosocial Professional Group (UKPP-CF) study day annually; Royal Society of Medicine (RSM) symposium most years, plus European CF Society (ECFS) conference in 2005.
- Local coordinator for TIDES (International Depression Study). Provided consultation and support

to MDT and patient adviser re audits of physiotherapy, clinic etc.

- Psychologist sees newly diagnosed patients/families at first or second clinic visit; is actively involved in joint paediatric/adult transition clinics, MDT review and transition summary. Works as part of palliative care team which is routinely involved when patients are listed for transplant.

Good practice includes the psychologists' timetabled routine and integral involvement in outpatient clinics, transition and MDT business meetings.

It would be helpful to set up arrangements to *routinely* inform the psychologist on the rare occasions that CF patients are admitted; both for acute and elective reasons (eg port insertion).

In March 2013, Humber Foundation Trust, which hosts the post, considered terminating the CF psychology role. Although the immediate threat to the post has apparently passed, it is important that the funding of this post is formalised and protected through discussion between Hull Royal Infirmary, Humber Foundation NHS Trust and commissioners.

4.7 Social work

Good practice

- The team's commitment to their patients' welfare is clear.
- The existing team work in a psychosocially aware way and prioritise the specific needs of their patients who are largely from a deprived community. The ability of the staff to work in the community despite huge time pressures is commendable.
- The team actively wants a social worker service and recognises the benefits social work can offer its patients.

Areas for improvement

- Obtaining and funding specialist social work services – This is part of a larger problem for the team: being able to meet a full range of patient needs 24 hours a day, year-round, when numbers of staff and patients are currently small.
- This may be best done initially by working in partnership with a larger service after careful negotiation, to retain the good practice of the existing service.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	10	5	2	0
Female	8	2	1	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	21	1	0	0
From the ward staff	12	3	1	3
From the hospital	12	5	2	0

Areas of excellence

1. Availability of MDT – advice and assistance
2. Accessibility – always there for anything
3. Homecare/community support

Areas for improvement

1. Food (quality/quantity)
2. Inpatient cleanliness (cubicle/bathroom)
3. Car parking

6. Appendices

Appendix 1

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

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

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

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

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

Hospital name

Hull Royal Infirmary

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	Amber	Formal post-annual review discussion between parents and the consultant, to formulate a management plan for the coming year.

2 Multi-disciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	N	No cover for A/L or S/L	
	% 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 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 Not documented, informal arrangements.	Red	Although there are informal arrangements with other specialities, this needs to be formalised into referral pathways.
	Are there local operational guidelines/policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's standards	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% patients with cystic fibrosis-related diabetes (CFRD) reviewed at a joint CF/diabetes clinic	100%	Green	Green	There is no fixed joint CFRD clinic as numbers are small, but a flexible approach is used to see patients as necessary.

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 – single room x10 hand washing only	Red	Patients are admitted to single rooms, but there are no en suite facilities.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of 1st isolates ***Pseudomonas aeruginosa*** in the previous 12 months	100%	Green	Green	
	% patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 CFRD	%patients >12 years of age screened annually for CFRD.	100%	Red	Green	Annual Oral Glucose Tolerance Test (OGTT) for patients over 12 years.
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%	Green	Green	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded bone density (DEXA) scan in the last three years	100%	Red – not currently done	Red	Bone density (DEXA) scan not currently done. Need to address.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Amber	Amber	Dedicated MDT ward rounds needed, with improved documentation.
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/shared care consultant, patient or carer, within 10 days of consultation.	100%	Green	Green	Clinic letters all completed in a timely fashion. However annual review report needs to be discussed with family and to include the treatment plan agreed.
	% dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% patients reviewed by a CF CNS at each clinic visit	100%	Green	Amber	Need to cover annual leave and sickness.
	% patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	Although accessible at all times except during weekends, annual leave and sickness, documentation needs to reflect this. Introduce an admission pack to improve documentation.

4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Green	Green	No cover for annual leave and sickness.
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Cover required for absence and leave.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	Cover required for absence and leave.
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	Cover required for absence and 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	No social worker available.
	% availability of pharmacist for inpatients and at clinic.	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	% 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%	None	None	
5.2	Number of clinical incidents reported within the past 12 months	<1%	1	0	Delayed notification of acute admission to CF team.

5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreement (SLA) in place for all shared care services	100%	N/A	N/A	

Appendix 2

Staffing levels

	75 patients	150 patients	250 patients	Hull Royal Infirmary
Consultant 1	0.5	1	1	2 PAs
Consultant 2	0.3	0.5	1	1.25 PA
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	1 WTE
Physiotherapist	2	3	4	0.4 WTE
Physiotherapy assistant				0
Dietitian	0.5	1	1.5	0.2 WTE
Clinical psychologist	0.5	1	1.5	0.1 WTE
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Clinician's assistant				
Secretary	0.5	1	2	0.8 WTE
Admin assistant				
Database coordinator	0.4	0.8	1	0
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: Hull Royal Infirmary	
Number of active patients (active being patients with data within the last two years) registered	38
Number of complete annual data sets taken from verified data set (used for production of National Report)	35
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	15
	4–7 years	8
	8–11 years	3
	12–15 years	5
	16–19 years	4

Genetics	
Number of patients and % of unknown genetics	1 patient with unidentified mutations on 2 alleles; 1 patient with unidentified mutation on 1 allele

Body Mass Index (BMI) (Ref: 1.13 'Annual Data Report 2011')	
Patients with BMI percentile <10th centile on supplemental feeding	6 (100%)

FEV_1 (Ref: Figure 1.14 'Annual Data Report 2011')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	1	0
	8–11 years	0	1
	12–15 years	4	0
	16–19 years	1	2

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age band	0–3 years	15
	4–7 years	8
	8–11 years	3
	12–15 years	5
	16–19 years	4
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	1 (3%)	
Number and % of cenocepacia	0	
Meticillin-resistant staphylococcus aureus (MRSA)		
Number and % of total cohort with chronic infection with MRSA	1 (3%)	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	0	

Complications (Ref: 1.16 'Annual Data Report 2011')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis-related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	3 (9%)
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 with PH; 0 without PH

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	34
	4–7 years	15
	8–11 years	16
	12–15 years	18
	16–19 years	1
Number of days of home IV therapy in reporting year split by age groups	0–3 years	127
	4–7 years	256
	8–11 years	133
	12–15 years	108
	16–19 years	70
Total number of IV days split by age groups	0–3 years	161
	4–7 years	271
	8–11 years	149
	12–15 years	126
	16–19 years	71

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	13 (37%)
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	N/A
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	2 (6%) on macrolide without chronic PA

Appendix 4

Paediatric survey: Hull Royal Infirmary

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	10	5	2	0
Female	8	2	1	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	22	3	0	0	0
Communication (verbal/written)	21	4	0	0	0
Out-of-hours access (via phone or ward)	21	2	1	0	1
Homecare/community support (appointments/advice)	20	2	0	0	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	22	3	0	0	0
Waiting times	17	6	1	0	0
Cross-infection/segregation	19	6	0	0	0
Cleanliness (room)	18	6	0	0	0
Annual review process	18	6	0	0	0
Transition (paediatric to adult)	12	3	0	0	8

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	8	5	3	1	6
Cleanliness (cubicle/bathroom)	8	5	4	0	4
Cross-infection/segregation	3	5	2	1	5
Food (quality/quantity)	5	5	4	0	7
Exercise (gym equipment/facilities)	6	1	2	0	8

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	11	2	0	0	10
Availability of equipment (physiotherapy aids/nebuliser parts)	12	3	0	0	5
Car parking (availability/ease of reach)	5	2	3	3	8

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	21	1	0	0	0
Of the ward staff	12	3	1	3	0
Of the hospital	12	5	2	0	0

Comments about CF team/hospital

Hull Royal Infirmary (Paediatrics)

"They have always been great with any help and great at doing their jobs."

"The CF team is fantastic, caring, always there for anything."

"The CF team that deals with my son is very understanding and very patient. This team is wonderful."

"Hull Royal Infirmary CF team is fantastic. They have helped our family a lot and really taken care of our son from day one of knowing he had CF and they continue to do this every day/every visit to the clinic and if we have any worries they're also happy to help and reassure us."

"Keep up the good work."

"Very happy with the care my daughter receives from the team/hospital."

"CF team provide excellent care and advice. During appointments and via telephone. My son's care is utmost priority to staff."

"The help and assistance from the CF team has been second to none, including advice and assistance with planning second child and the risks. Couldn't want for anything else from the team."

"My CF team have been fantastic with my child and myself."

"Always there when needed; so helpful – brilliant team."

Appendix 5

Patient/parent interviews

Hull Royal Infirmary Paediatrics 9 July 2013

Parent 1

- The mother of a seven-year-old male with cystic fibrosis. She works within the hospital on the Labour & Delivery Ward in the Catering Department. The family helps with childcare by picking up the son from school and also looking after her three-year-old daughter who does not have cystic fibrosis.
- The family lives 10 minutes away and walks to the hospital for appointments.
- The mother has a mobile number to call the hospital nurse/team, which she can call at any time of the day or night for advice.
- The son was last admitted to hospital a couple of weeks ago when he had a chest infection. He stayed in hospital for six days. The mother said that the overnight facilities for parents are acceptable. There is no issue with the food, as he is not a fussy eater. There are lots of snacks available. They have snacks at 10am followed by lunch at 12pm, more snacks are available during the afternoon and tea is served at 4.45pm, then afterwards evening snacks are available, if required.

Areas of excellence

- Staff are always available for questions 24/7.
- The relationship with the staff feels like an extended family.

Areas of improvements

- The location of the ward – 13th floor can only be reached by lifts or 26 flights of stairs.

Parent 2

- The mother of a 17-year-old daughter, without cystic fibrosis, who lives at home. She has two other children who both have cystic fibrosis, a son of eight years and a daughter of seven years – there are 15 months between them in age.
- The mother takes an active part in the ‘Chief’ charity which raises funds for the Royal Infirmary and also Castle Hill Hospital to buy equipment. The charity is run by mothers of children with cystic fibrosis and is a great way to meet other mothers for social meetings and also provide advice for new mums, or even a shoulder to cry on.
- The family lives a 15-minute journey away by car. There has never been an issue with the parking facilities; there are always spaces available.
- The son went to hospital two weeks ago complaining of reflux, but was not admitted. The last time he stayed in hospital was three years ago. Her daughter was last admitted to hospital five years ago.
- The appointment times are a strict 30 minutes apart, if they arrive early they will be either sent away, or ushered into a room. The children are not fussy eaters, therefore she does not remember there being an issue with the hospital food.
- The mother has a mobile number to contact the nurse 24/7.

Areas of excellence

- The backing of the team is more than 100% and feels like ‘extra family’. The doctors and team are very supportive, they communicate well.

Areas of improvements

- Lifts to ward on 13th floor. The grandmother does not like to use the lifts; therefore she would have to walk up 26 flights to get there. This is not acceptable.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Hull Royal Infirmary	
	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)		Clinic times are staggered, 30 minutes apart, strict appointment time keeping. However, it was noted for a patient to see all MDT would actually take longer then 30 mins.
Do patients spend any time in waiting room?	No	Patients are taken immediately to the height and weight room on arrival.
Is there easy access to toilets?	Yes	4
Where does height and weight measurements take place? Is this appropriate?		There is a separate height and weight room, a large room well equipped with toys available. However, it was suggested that height and weight equipment in every clinic room would prevent risk of cross-infection.
Where are lung function tests done for each visit?		These are carried out in the cubicles. Mobile trolley with spirometers, using new heads each time. Spirometry equipment in all rooms may be considered.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	There are toys/mat available. Patients can bring their own. All toys are cleaned after use.
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?		Joint clinic. The dietitians are part of the diabetic team.
Transition patients – can they get tour of outpatient facilities?	N/A	
Transition/new patients – do they get information pack?		

Additional comments

All areas were clean and very pleasant with bright, child-friendly decoration.

For patients transitioning to adults there is a process in place. At the age of 13 years the child is seen without the parents present at beginning of consultation, then parents come in later. Then the adult team nurse from Castle Hill will meet the patient several times. The adult team consultant will come to discuss the patient and meet them once prior to transition to Castle Hill Hospital – adults. The teenagers can visit adult centre and get an information pack from there. It was suggested that it would be useful to further improve what appears a smooth transition by the adult physician and team meeting the patients on more than one occasion prior to transition.

There is an additional ‘day case’ room; two large well-equipped rooms and a treatment room, these are used to start IVs/port flush etc.

Environmental walkthrough: ward
Ward name: 130 West Ward (13th floor) All wards are general paediatric wards
Microbiology status: Medical Ward – all microbiology

		Hull Royal Infirmary	
		Yes/no/ number/ N/A	**Notes/comments**
Is ward a dedicated CF ward or ward suitable for CF care?		No	Unsuitable due to no en suites and only two toilets for the whole ward.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		10	41 cubicles for CF patients
Do the en suites have:	**Toilets?**	No	There is a commode for use if staff feel there is a risk. Shared two toilets only for all general paediatric patients.
	Wash basins?	Yes	In all cubicles.
	Bath or shower?	No	One bath/two showers for all of ward patients.
Do CF patients have to share any bathroom facilities?		Yes	Bath, showers and toilets.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Paeds	All medications are stored centrally.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	7am–7pm only.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	All rooms have a pull-down bed or Z beds available.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Open hours	Restricted at night as appropriate.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	Two cubicles have fridges but there is no microwave use.
Are there appropriate play facilities available?		Yes	There is a play therapist. Large bright, well-equipped play areas.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		There is no Wi-Fi available for patients at present. Computer available with a dongle. Patients can bring in own IT equipment if checked beforehand by electrical department.
Is there access to a gym or exercise equipment in the rooms?	Yes	Small gym, static bike available.
What facilities are there to help with school and further studies?		School room. Two local authority teachers to give one-to-one tuition, who also liaise with the schools.
Is there a relatives' room?		There is access to a room on Ward 130 East.
What internet access is there?		No Wi-Fi. However access to internet via computer dongle in school room.
What facilities are there to enable students to continue work and study?	Two local authority teachers who liaise with the schools. Computer access in the school room.	
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Milton tank. If admitted urgently would use disposable nebuliser parts.
What facilities are provided for those with MRSA?		Do not have any MRSA patients.
What facilities are provided for those with *B.cepacia*?		Do not have any *B.cepacia* patients.
What facilities are provided for those with other complex microbiology?		No patients with complex microbiology. Would be segregated on same ward and accomodate individually with commode and barrier nursed if appropriate. There are negative pressure rooms; however these have not been working for many years.
Are patient information leaflets readily available on ward?	Yes	On large display board, can also request from nurses.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

On Floor 12 – Ward 120 – Assessment Unit only.

There are five cubicles. This ward is used for assessment only; the patients are then admitted to West Ward (130). There is a parents sitting/waiting room, equipped with basic tea/coffee facilities.

Floor 2 – Ward 200 – Children's Critical Care unit – two cubicles. Well-equipped play area.

Floor 13 – 130 – East Ward – Surgical Ward. Six cubicles, all rooms have a sink only. Shared toilet/ shower and bath in a separate area. Large, bright, well-equipped play area.

Parents sitting room – basic, has fridge use, tea/coffee facility.

All areas are clean and bright.

	Hull Royal Infirmary	
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?		If admitted, patients' parents can buy a pass for £10 per month.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To ward/unit yes, however, no signs to state CF centre as all areas are general paediatric and shared.
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 density DEXA scan?	Pharmacy – No Radiology	Small, busy, cramped, closed-in area with limited seating. Parents can collect prescriptions, nurse will also collect. Suggested volunteer or Band 2 nurse to collect to avoid risk of cross-infection and free up CNS. Radiology is a small area, although there is unlikely to be more than one CF patient there at any one time. This requires consideration.
Do patients have to wait at pharmacy for prescriptions?	Yes	Risk of cross-infection if more than one parent and CF child at any one time or within short time of each other.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?		Are piloting own Friends and Family Service. This appears a very useful service with good feedback to date. Depending on feedback can direct to PALS if required.
Are there patients' comments/ feedback boxes?		Have used in past but found that they were filled with sweet wrappers. Can now feedback online.

Additional comments

Friends and Family pilot scheme – Forms are given to patients on discharge. The questions asked:

1. How likely are you to recommend our ward to friends and family if they needed similar care/treatment?
2. What was good about your care? What could be improved? All comments go to the Ward Manager.

There is a 'you said, we did' notice displayed on the ward board.

Physiotherapy – paeds: Annual assessment in a room called 'chest treatment'. No more than one patient attends annual assessment on any one day.

In the physiotherapy department there is a large gym, equipped with cross trainers/bikes/mats etc.

There is no spirometry laboratory. All spirometry performed by nurse or physiotherapist.

Appendix 7

Panel members

Dr Anu Shankar*	Consultant	Lewisham Hospital
Amanda Bevan	Pharmacist	University Hospital Southampton
Phil Brewin	Psychologist	Nottingham University Hospital
Sarah Elworthy	Clinical Nurse Specialist	Royal Devon and Exeter Hospital
Carolyn Patchell	Dietitian	Birmingham Children's Hospital
Pamela McCormack	Physiotherapist	Alder Hey Children's Hospital
Anne Dealtry	Social Worker	Nottingham University Hospital
Peter Dixon	Commissioning	Cumbria, Northumberland
Lynne O'Grady	Peer Review project lead	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust

*Panel Lead

Appendix 8

CF Service Peer Review
Hull Royal Infirmary (Paediatrics) – Visit date 9 July 2013
Commissioning report
Peter Dixon, Cumbria, Northumberland, Tyne and Wear Area Team, NHS England

1. Overview of the service

The service cohort is 29 children of which 26 are under 10 and 10 are under 2, with the oldest patient being 13. The gender split is 17 males to 12 females. The cohort is expected to increase by up to 2–3 patients per year, identified via newborn bloodspot screening.

The service generates circa £357,831 on the basis of the PbR year of care tariff within the HRG banded codes.

The service MDT is clearly dedicated and committed to the delivery of an effective and efficient service, and the team is fully supported by the management team.

Facilities are adequate but the inpatient ward on the top floor of the ward block needs refurbishing and is ill-served by an inadequate lift service.

2 Considerations

2.1 Cohort

The most obvious consideration is the size of the cohort, and 29 is little more than half of the recommended cohort determined within the second edition of the Cystic Fibrosis Trust's 'Standards of Care (2011)', which is clear that:

"A specialist CF centre has a minimum of 100 adults or children. In exceptional circumstances, the geographical location of a specialist CF centre may mean that the number of patients is less, although it should not be less than 50."

Clearly the Hull & East Yorkshire NHS Hospital Trust falls well short of the minimum cohort, and this raises significant concerns about the sustainability of the service, but does not reflect on the quality of the current service. There appears to be an unexplained gap in the cohort. Although six patients have transitioned into the adult service in the last 12 months, the oldest remaining patient is 13, and with a growth of 2–3 patients per year, it would appear that 15–18 (5–6 patients per year * 3 years) patients have chosen to receive treatment elsewhere.

Hull & East Yorkshire NHS Hospital Trust believes that the cohort can be increased by attracting patients back from other units, principally Leeds and Sheffield, increasing the take from north and north east Lincolnshire and by strengthening ties with York Hospitals NHS Foundation Trust.

1.2 Current commissioning arrangements

The service is contracted from the Hull & East Yorkshire NHS Hospital Trust by Yorkshire Specialised Commissioners and is funded via PbR year of care tariffs. Highly specialised services are bought in by the Hull & East Yorkshire NHS Hospital Trust from Leeds Teaching Hospitals NHS Trust. There was some uncertainty about the lead commissioner, and a misunderstanding about the difference between supplier managers and local service specialists, with supplier managers being responsible for contractual matters, and service specialists leading the commissioning function.

Hull & East Yorkshire NHS Hospital Trust was clear that a compliance statement in response to the service specification scheduled for adoption from 1 October 2013 has been successfully completed, together with the assessment template for compliance with the key requirements. This seems to be well ahead of other trusts and specialities, and copies of both documents were requested to assist in the Panel's deliberations.

There was a slight misunderstanding with the definition of shared care. The Panel defined shared care as the prime contract being held by the experienced provider who would sub-contract most of the care to the local and possibly less experienced provider. The Hull & East Yorkshire NHS Hospital Trust saw its model of role reversal ie the local and possibly less experienced provider buying in services from the more experienced provider.

The terminology is not important nor is the relationship between the two trusts, but it is essential that there is a clarity of understanding about the relationship, and this will invariably require a formal agreement/contract between the two collaborating trusts.

2. Recommendations

It is worth repeating that the panel was impressed by the dedication and skill of the clinical and nursing team and the clear leadership and support of the management team. Also the panel felt that the need for a service in Hull was clear, partly to allow services to be delivered closer to patients' homes and partly to relieve the capacity problems at other regional centres.

However, because of the limitations on the service, resulting from the small cohort of 29, which is well below the critical mass threshold of 50 patients set by the Cystic Fibrosis Trust, it is unlikely that the panel could recommend that the Hull service is designated as a paediatric CF centre. Instead, the recommendation from the commissioning representative on the panel concluded that:

- Hull & East Yorkshire NHS Hospital Trust should seek to be designated as a network care provider within a formal arrangement with a designated specialist CF centre.
- The choice of specialist CF centre to be a matter of the Trust's preference.
- Discussions/negotiations between Hull & East Yorkshire Hospital Trust and potential specialist CF centres should be conducted in conjunction with the commissioner.

cysticfibrosis.org.uk