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British Thoracic Society

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Peer review report

Castle Hill Hospital Adult Cystic Fibrosis Centre, Hull

8 October 2015

Contents

1. Executive summary

Overview of the service

Castle Hill Hospital, Hull, is a small, geographically isolated clinic in an area with a high deprivation index. It has a small paediatric feeder clinic, is situated in a teaching hospital with all the appropriate specialties necessary for the management of cystic fibrosis (CF) and has good links to the Newcastle Transplant Centre. However, despite the clinic's longevity and the length of service of some of the team, because of its small size and slow incremental growth there is relatively little clinical experience across the multidisciplinary team (MDT) when compared with other clinics. The plan to appoint an internal candidate with only three months experience of major CF centre care will only partially alleviate this. Due to the limited patient growth it is unlikely it will ever achieve viability as a standalone centre, hence recent discussions with York. Despite this, there is strong motivation and obvious passion within the team, some considerable burden of responsibility, and a willingness to learn. The facilities are reasonable with a promising outpatient development, although the en suite inpatient facilities are at a different hospital, which may pose logistical problems, and are not fully equipped for young patients' needs. Due to the low level of inpatient care need, the ward nurses also have limited cumulative experience.

Good practice examples:

- Innovative attempts to utilise video for MDT and joint clinics with York, with discussions around joint management based on pooled experience.
- Sterling effort to provide 24-hour cover by a diminutive team via the CF phone. Patients comment 'access is good' and they carry contact number cards and the mobile numbers of the team members.
- Huge commitments and breadth of responsibility falls upon the CF nurse, who clearly strives to provide high-quality care and without whom there would be no CF service.

Key recommendations:

- The Peer Review team feels that the level of care currently provided does not meet the Standards of Care, 2011.
- In particular the service fails to meet the Standards of Care in the majority of care disciplines. The Peer Review team recommends that the service needs to address the shortfalls in staffing in the following disciplines in order to meet the standards of medical, physiotherapy, nursing, pharmacy and social work. Psychology appears to be well provided for and a good service is provided.
- The service appears to be predominantly CF nurse led, including the on-call commitments, and is unsustainable; significant training is required at senior medical level. A sustainable on-call model is required.
- Based on current staffing numbers, skill mix, experience and current practices we cannot recommend Hull as a standalone specialist centre, despite its location within a teaching hospital with appropriate specialties.
- Should the Commissioners approve it, York should be approached to be the lead centre of a joint York–Hull CF centre, with services for local patients provided at Castle Hill by the current Hull staff overseen by the joint MDT.
- While new medical, social work, pharmacy, and possibly nursing appointments are urgently needed at Hull, staffing requirements should be reviewed in conjunction with a proposed joint team with York to best suit long-term strategic development.

- Accelerated training of all core specialist staff members by sending to regional centres for weeks at a time or consider seconding a senior specialist clinician from another centre.
- Patients should be formally reviewed by the joint MDT for optimisation of their care.
- The model of care should be developed on a collaborative basis with the Hull and York teams embedding a continuing process of Quality Assurance that can be externally validated.

Areas for further consideration:

- Urgent review of job plans of all staff members currently in post to facilitate dedicated time for CF, attendance at regional special interest groups, regional and national meetings and international meetings and perhaps to attend comprehensive teaching courses, eg the Brompton or Cardiff CF courses.
- Significant up-skilling of the physiotherapy team to include use of all nebulised drugs, equipment, Non-Invasive Ventilation equipment, oxygen etc; the management of this is currently with the specialist nurse.

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

Models of care

Summary

Patients on average have poor lung function and nutritional indices and high Pseudomonas infection rates compared with the national averages, despite a young clinic age. This may be due to a low uptake of mucolytic and nebulised antibiotic use, compatible with the social deprivation index of the patient population. If the data is correct, there are three hours per week of consultant time in CF (recently increased to six hours) and decision making is led by a Specialist Nurse who has many years of experience. There are inconsistencies in the matrix and some MDT members have suggested that the responses may be aspirational.

Multidisciplinary care

Summary

According to the risk matrix there is currently inadequate consultant input, inadequate review by the MDT, and an insufficient capacity for effective delivery of the service. Although the assessment suggests green for Personal Development Plan and attendance at meetings in the last twelve months, discussion with individuals suggests this may be aspirational in some cases.

Principles of care

Summary

There is clearly an aspiration to manage the service correctly and the managerial support to grow the service and develop facilities shows this. There is also an appreciation that much needs to be done to achieve these outcomes.

Delivery of care

Summary

Although the matrix suggests a physiotherapist sees the patients in clinic, this was not confirmed at interview. The absence of a CF social worker and pharmacist is noted and needs to be addressed as a matter of urgency from the perspective of the pharmacist and as soon as possible from a social work perspective, not least to unburden the specialist nurse from social work-related issues.

While there are strengths in individuals, if that individual is off, there is no depth in medical, nursing, physiotherapy, pharmacy, or social work so there is little resilience. Despite the level of morbidity reported from the UK patient registry, the service model of care is primarily outpatient-based which reflects patient choice.

Out-of-hours cover cannot be sustainably delivered and falls to the specialist nurse with telephone back-up, and a robust system to involve the team and cover for out-of-hours periods in a sustainable way needs to be developed.

Commissioning

Summary

The Hull adult service is small (less than 50 patients) and as such, is unable to meet the requirements of the NHS England service specification. This service specification reflects Cystic Fibrosis Trust 'Standards of Care, 2011' which recommend that, typically, a service will have approximately 100 patients, and not less than 50. As a consequence, the Hull adult service is viewed by commissioners as being unsustainable as an independent CF centre. Low patient numbers does not generate sufficient tariff income to allow the service to resource the full MDT, as required by the Standards of Care.

Areas of good practice:

- There is a strong commitment from both the clinical team and Trust management, to work with potential partners at the York Teaching Hospital NHS Foundation Trust and NHS England commissioners, to fully test and implement a new service model that would strengthen the service in Hull, whilst still providing local access to high quality care for CF patients. Work is already underway in this respect.
- The clinical team is clearly committed to providing the highest possible standards of care, under very challenging circumstances. This commitment has been recognised by patients who responded to the survey.
- Members of the clinical team are keen to secure opportunities for professional development, working with peers in other services and organisations, with the support of the Trust.

Areas for improvement:

- There is unacceptable pressure on some members of the clinical team, which urgently needs to be addressed.
- Planned new outpatient facilities need to become fully operational at the earliest opportunity. Current arrangements are unsatisfactory.
- The service needs to be clinically led, by medical staff trained and experienced in the comprehensive care of patients with cystic fibrosis.

Commissioner recommendations – a new model of care:

- There is clear recognition within the service in Hull, that a new model of adult CF care is required, in order to address all the issues identified in this report, whilst maintaining local services for patients.
- NHS England has confirmed its agreement to commission a merged CF service between York (which is also a small adult service) and Hull, to be clinically and contractually led by the York Trust, subject to a planned assurance process, to be undertaken early in the new calendar year.
- Comprehensive, evidenced plans for a merged, fully compliant service, which improves the quality of care for patients in Hull and meets the needs of all patients with CF in the North & East Yorkshire area, need to be completed, as soon as possible.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	38

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and median(range) FEV_1 % pred by age range and sex	16–19 years	6 (96.28%) 19.3–108.41	1 (41.74%)
		20–23 years	4 (39.21%) 21.39–98.48	4 (40.1%) 27.58–58.22
		24–27 years	3 (68.9%) 67.01–93.44	3 (59.16%) 34.29–125.8
		28–31 years	4 (34.41%) 15.95–56.03	3 (54%) 13.16–61.16
		32–35 years	2 (51.55%) 43.35–57.74	n/a
		36–39 years	2 (88.02%) 72.9–103.14	n/a
		40–44 years	1 (51.68%)	2 (32.31%) 31.6–33.02
		45–49 years	n/a	n/a
		50+ years	3 (32.82%) 22.87–79.74	n/a

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=25); 11(44%)	(n=13); 1(8%)
	Number of patients and % with BMI <19 split by sex	7 (28%)	8 (62%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	23 (61%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	16 (70%)

Macrolides	Number and % of patients on chronic macrolide with chronic *Pseudomonas aeruginosa* infection	20 (87%)
	Number and % of patients on chronic macrolide without chronic *Pseudomonas aeruginosa* infection	10 (67%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

There appear to be two hours of Professor Morice's time and just over an hour with a non-specialist consultant making <0.1 whole time equivalent (WTE). There is no staff grade and very little registrar input officially on the rota, although the current registrar's interest in CF and commitment to continue is noted. This is inadequate and does not meet the standards of care. It has been generally and generously noted by the consultants that the work load predominantly falls upon the specialist nurse; thus leadership is at a nursing level, not medical level, and is inappropriate.

Out-of-hours cover seems to be predominantly provided by nursing as well, or by non-specialist consultants, although Professor Morice has given phone numbers to patients and would be available on call for any member of the CF team or any of his non-specialist colleagues who called him. This is only sustainable with the relatively small numbers and a formal on-call rota should be considered.

Areas of excellence

- A commitment to drive management to develop the service for adults in Hull and willingness to 'think outside the box' by developing links with York.
- Potential of availability via mobile phone.

Areas for improvement:

- Up-to-date knowledge of CF management.
- Clinical lead responsibility delivered by medical rather than nursing staff.

Recommendation:

- To actively recruit a CF specialist to take the service forward.
- Job plan sufficient time to clinically (as opposed to managerially) lead the team forward.
- Thoroughly review the management strategy of all patients.
- Advertise, promote and generally encourage all patients to attend at least three-monthly clinics, more often if they are poorly, and come to the new hub at Castle Hill with no patient option for outpatients at Hull Royal where the team will no longer be based.

Specialist nursing

40 CF patients 2 WTE (one currently on maternity leave).

110 Bronchiectasis patients.

The clinical nurse specialist (CNS) facilitates the care and management of patients with CF and non-CF bronchiectasis. The split and commitment required to undertake this is not clear at this stage. The CNS has worked independently for a year while a colleague has been on leave. She is clearly a hardworking and enthusiastic member of the team. She has been integral to all aspects of patient care and appears pivotal in the management of the CF service. However, she has now found herself being in a position of being overstretched and under extreme pressure. The commitments the CNS has undertaken within the team have started to compromise her being able to undertake the nursing role as she would clearly like to do. Attendance on days for education has been limited; however the nurses are members of the Cystic Fibrosis Nurses Association (CFNA), meeting with the Trans Pennine Group twice a year.

Areas of excellence:

- The CNS communicates well and is passionate and dedicated to her role.
- The CNS provides a prompt day-casing service for patients able to undertake home intravenous (IV) antibiotics (IVABs).
- Participates in monthly MDT meeting with York via video conference.

Areas of improvement:

- Identify a clear channel of communication and medical decision making; there is access to respiratory consultants but not always a CF consultant. On the day of the Peer Review it was clear that 24:7 attendance by the CF consultant could not be maintained.
- Clearly identify roles within the MDT – a multidisciplinary approach to decision making needs to be encouraged rather than having the responsibility being with the CNS.
- Currently there is no provision for community care for the CF patients. The CNS feels she would like to recommence the homecare service in order to support patients, especially in light of limited clinic and day review facilities. This will be possible upon the return of nursing colleagues from maternity leave.

Recommendations:

- Nurse manager support has been limited. This can help to identify the nursing agenda and responsibilities within the CF team.
- Job planning needs to occur in light of a colleague returning to work and reducing their hours.
- A review of the CNS's responsibilities needs be undertaken to establish the appropriateness of some of her duties and ensure her time is best spent in direct patient care and ward education. An example of this is that the CNS currently manages the inhalation service; this needs to be physio led in order for the nurse to commit more to her nursing role. The nurse currently holds a phone 24:7 for patient contact for advice and the appropriateness of this needs urgent review. With the creation of a pool of skilled ward nurses they can then become the first point of contact out of hours.

Physiotherapy

There has only been a dedicated CF clinical lead physiotherapist for the service since May 2015 (1 WTE, band 7) when dedicated CF physiotherapy funding was identified, although this post was only truly 'up and running' from August 2015. Prior to this, physiotherapy was provided from the general inpatient respiratory team and an audit in August 2014 internally, showed many significant gaps in the CF physiotherapy service. A dedicated CF Band 7 physiotherapist was appointed in May 2014 but left the post in November 2014. Therefore, as the CF clinical lead physio has only been in post since May, many aspects of the proposed service are still in development. However, good progress has been made and the clinical lead is very enthusiastic with regards to her role and future plans are consistent with national standards and comprehensive physiotherapy care. There is also good support from the physiotherapy manager.

A significant improvement has led to the clinical lead post being almost fully dedicated to CF (still includes a small part of respiratory inpatient cover) and cover is now provided by a rotational physio who has been trained in CF as well. The service benefits from a consistent, CF-experienced small team which covers across the seven-day period for inpatients, and only respiratory physiotherapists now see CF patients at weekends. During any vacancy periods though this team will find it difficult to provide a seven-day service, and recently there have been vacancies in other areas of the respiratory physio team, which has created pressure on this small team. Since the dedicated CF service started in May, focus has been given to generating an inpatient physiotherapy pathway, which includes the patient being assessed by a CF physio within 24 hours of admission and including a comprehensive physiotherapy assessment, including: airway clearance, inhalation therapy, exercise, oxygen review as appropriate, musculoskeletal (MSK) and urinary incontinence screening. An outpatient pathway has been created, although the physiotherapist has so far been unable to see any outpatients or attend any CF clinics. This needs to be addressed immediately. There is full physiotherapy attendance and assessment at annual review (AR).

The Registry report for 2014 shows very low figures for inhalation therapy use (DNase, hypertonic saline, and lower than expected inhaled antibiotics rates). The CNS currently leads the inhalation therapy service and the physiotherapist should look to be directly involved in/lead this service, as in other centres in the UK. Training will be required in this area, with particular emphasis on inhalation techniques, individual treatment strategies and optimisation of inhaled therapies, plus an acknowledgement of the evidence base, particularly around mucolytics and best practice.

Areas of good practice:

- The service now has a dedicated CF clinical lead physiotherapist, with cover from a CF-trained Band 6 physiotherapist.
- The CF service benefits from a consistent, small, CF-experienced physiotherapy team who provide a seven-day service.
- Comprehensive physiotherapy assessment at AR, including airway clearance advice and review, exercise testing, exercise programmes and screening for MSK and continence issues, with onward referral as appropriate.

Areas of improvement:

- Current focus has been on seeing inpatients and AR only. Need to establish a regular specialist CF physiotherapy presence in all outpatient CF clinics and to review all patients attending.
- Physiotherapy should lead the inhalation therapy service, including first test dose assessments, inhalation technique, adherence issues, advice and education, as well as provision of efficient delivery devices, eg eflow. A thorough understanding of inhalation therapy needs to be achieved in order to improve the inhaled therapies at this clinic.

Recommendation:

- To become a member of the ACPCF and establish contact with the local ACPCF regional group and members and to attend regional meetings and national ACPCF study day. In addition, to establish some local networking with regards to peer support at other CF centres, eg York, Leeds. The clinical lead should consider undertaking some specialist CF education or courses within the next 6–12 months.
- To ensure the CF physiotherapy service is comprehensive in enabling CF physiotherapists to see all inpatients and outpatients and annual reviews. The physiotherapist must have a thorough understanding of all aspects of CF physiotherapy care, including airway clearance techniques (including competence in each technique), inhalation therapy, use of NIV (to include use for airway clearance and exercise), exercise, MSK and continence issues.
- To ensure that all patients are advised on appropriate exercise therapy programmes, including aerobic and strength training programmes as inpatients, for home use, for optimisation of lung function (in conjunction with airway clearance technique regimes, inhalation therapy strategies).
- The CF lead physiotherapist's time needs to be protected for CF work and not to cover shortages in the inpatient respiratory service. This is particularly important to allow her to establish the outpatient service.

Dietetics

There is a very experienced Band 7 dietitian providing nutritional and dietetic cover for the CF service. There is also cover provided by a Band 6 dietitian who has CF experience.
Dietetic cover is protected for 15 hours a week. However, with the increasing numbers in the adult service, the dietitian's role is ever extending and there may need to be a review of the structure and potential of Band 5 to help.

Cystic fibrosis-related diabetes (CFRD) is increasing and the current arrangement in place is excellent but relies solely on the personal links the dietitian and the diabetic specialist nurse have. Should either one of them move then the service has the potential to be limited.

Meeting the nutritional needs of 40 patients is being attempted with a variety of options available – snacks provided on the ward, access to different trust catering menus and a voucher scheme to use in the staff canteen.

Video conferencing monthly with another centre has proved invaluable in developing resources and ongoing support; a good use of current technology.

Recommendations:

- To develop robust CFRD clinical pathways with ongoing diabetic services to the CF population is an essential part of CF care.
- It is strongly recommended that at least two nurses and a dietitian be trained and skilled-up in passing nasogastric (NG) tubes and supporting patients with NG tube feeding for their use in hospital and their own homes. There is a need for the dietitian to support regimes and help monitor glucose levels.

Pharmacy

There is currently no designated pharmacy support for the CF centre, which means the service fails to meet CF service standards of care. According to centre size (40 patients), the service should be funded for a 0.27 WTE pharmacist to support the service and meet Cystic Fibrosis Trust 'Standards of Care, 2011' required staffing levels. As a result, the service fails to meet the Peer Review standards, as set by the CF pharmacists group (CFPG). Despite the lack of current funding for pharmacy support, there is informal support from an experienced respiratory pharmacist on a limited basis due to staffing, workload and funding constraints. The pharmacist is a member of the CFPG, but due to other commitments has not had time to attend the group's study day or attend CF-related continuous professional development (CPD) events or conferences, although hopes to in the future. As a result of the lack of dedicated CF pharmacist, as identified in the service risk matrix, no patients are seen at AR for a pharmacy assessment. There is no pharmacy representation on CF MDT ward rounds or meetings. There has not been pharmacy involvement in CF team audit/research or service improvements and no involvement at key life stages from pharmacy, due to no funding being in place to allow for this. All CF inpatients are reviewed daily by the respiratory pharmacist who also completes medicines reconciliation in accordance with Trust guidelines, is available to provide medicine information to nursing staff on inpatient wards and can provide medication counselling or training on inpatient wards to patients if able, meeting some CFPG standards. However, the respiratory pharmacist with an interest in CF is not involved in services such as horizon scanning for CF, evaluating treatments, advice on budget planning, the cost-effective use of medicines and offering support to patients with difficulty adhering to medicines; resulting in a lack of specialist input in these areas. These are all identified by the Pharmacy Standards in CF Care as important for good pharmaceutical care practice and areas a funded CF pharmacist would support.

Areas of Good Practice:

- CF inpatients are reviewed regularly by a respiratory pharmacist who undertakes medicines reconciliation.
- Pharmaceutical advice provided to ward staff and patients when required.

Areas for improvement:

- Development of a specialist CF pharmacist role within the centre.
- CF pharmacist review for patients at AR and availability to attend outpatient clinics (currently only available by phone) and attend MDT ward rounds/meetings.

Recommendations:

- Funding for specialised pharmacy support is made available to enable pharmacy standards of care to be met.

Psychology

Input is provided by a 0.4 WTE clinical psychologist; extrapolation from standards suggests this service meets staffing requirements for clinical psychology. The psychologist is an active member of the UK Psychology Professionals CF Group (UKPP-CF), and attends annual meetings. She has attended regional CF meetings but has yet to attend an international CF meeting.
The clinical psychologist meets standards of care in offering appointments to refered inpatients and outpatients. All patients are offered a clinical psychology annual review. As with other CF centres, this is partly achieved by the use of questionnaire-based reviews, although all patients have the option of requesting a face-to-face review. This is a small clinic so procedures are not required to ensure psychology input at set stages of the journey through CF care; the psychologist is well aware of patients' circumstances through attending MDT meetings and offers appropriate responses when need is identified. The psychologist is part of a wider Clinical Health Psychology service and has access to excellent support and supervision. Good arrangements are in place for accessing appropriate services should patients present with risk issues or psychological difficulties requiring specialist intervention (eg eating disorders). There is good communication between the psychologist and the CF team and all relevant team and MDT meetings are attended. During short periods of leave there is access to psychological services for emergencies. Arrangements are in place to ensure any non-urgent needs identified in the psychologist's absence are met on their return. This is commensurate with national practice in CF centres. Robust plans are made to arrange cover during longer periods of absence, and this process is being followed during the psychologist's maternity leave.

Areas of good practice:

- This centre meets recommendations for clinical psychology staffing and service delivery; the psychology service is well embedded within the team. Good arrangements are in place to access services in case of urgent/risk issues or complex psychological problems.

Areas of improvement and recommendations:

- Psychology provision in this centre meets national standards. The psychology service could be enhanced by the psychologist undertaking research and/or audit, jointly with other centres if small numbers preclude such opportunities within the clinic. Now that the psychologist is established within the team, further skill sharing (training, joint working, psychological consultation) could enhance service delivery by the MDT.

Social work

At present there is no CF social worker in post at Castle Hill Hospital. The team has recently approached Hull and East Riding Social Services about the provision of a 0.5 WTE CF social worker, which would more than cover the needs of the service's 40 patients.

Feedback from users of the service and discussion with the CF nurse specialist indicate that the team is very supportive and flexible. As the most established member of the team, the nurse specialist is very skilled at getting the best from extensive multi-agency networks, for support, information and services within the Health Trust and beyond for those in need of them.

In the absence of a specialist CF social worker, the team utilises local Social Services provision when necessary, and has established links with the Learning Disabilities Team in order to care for a number of patients who are living with multiple conditions. The generic hospital social work team offers support to inpatients during hospital admissions.

The CF psychologist (0.5 WTE), in post from October 2014, provides invaluable emotional and psychosocial support to patients, alongside the less formal emotional support provided by the wider team in the course of carrying out their more specific duties.

Support needs more traditionally carried out by a CF social worker are currently carried out by the nurse specialist. While the skills, commitment, drive and dedication of the nurse specialist are beyond doubt, she and the wider CF team recognise that it is not possible to fully and consistently bridge the gap left by the absence of an appropriately qualified and registered specialist social worker.

Encouraging discussions with local authority social work providers are being followed up within the Trust with the aim of at very least securing the 0.3 WTE CF social worker that would meet the CF Trust Standards of Care for a service of its size.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	0	1	1	0	1	3	1
Female	0	0	4	1	2	0	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	10	1	1	1
From the ward staff	5	4	1	0
From the hospital	6	4	2	0

Areas of excellence:

1. CF team, ward team and hospital all considered good/excellent.
2. CF team – accessibility, communication, out of hour's provision.
3. Outpatient care – availability of the team, waiting times, cross-infection measures, cleanliness, annual review – good/excellent.

Areas for improvement:

1. Transition programme
2. Home care
3. Inpatient food on ward

6. Appendices

Appendix 1

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

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

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

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

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

Hospital name

Castle Hill Hospital, Hull

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review.	90%	Green	Green 36/40	We understand did not attend (DNA) rates are high and some may be missed. This looks like four only.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry.	90%	Green	Green 36/40	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review.	90%	Red	Red 16/36	20/36 Discussed at MDT led by nurse – no Dr input.

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review).	95%	Red	Red 16/40	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	No	No	
	% 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	Amber	Interviews suggest that staff do not have time to attend meetings, so they cannot reach PDP or the PDP is not ambitious enough.
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Amber	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Amber/Red 16/40	High DNA rate, many patients seen ad hoc primarily by nurse. A third of medical consultant input is not CF trained.
	% of patients with cystic fibrosis-related diabetes reviewed at a joint CF diabetes clinic.	100%	Red	Red	Those that attend CF clinic see physician 'experienced in CF' but very small patient numbers.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission.	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months.	100%	N/A no isolates in this period	N/A	
	% of patients admitted within seven days of the decision to admit and treat.	100%	Green	Green	

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes	% of patients aged >12 years screened annually for cystic fibrosis-related diabetes	100%	Green	Green 90%	Question marks exist against eye testing and filament testing.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years.	100%	Green	Green 98%	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	N/A no transitions	N/A	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years.	100%	Amber	Amber 9/40 DNAs	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient.	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation.	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist at each clinic visit.	100%	Green	Green	No resilience in system or cover of annual leave or sick leave.
	% of patients with access to a CF clinical nurse specialist during admission (excluding weekends).	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit.	100%	Green	Red	The physio hadn't seen any patients in outpatient department at the time of review.
	% of patients reviewed by a physiotherapist twice daily, including weekends.	100%	Amber	Amber	
	% availability of a CF specialist dietitian at clinic.	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic.	100%	Green	Green	
	% availability of a clinical psychologist for inpatients.	100%	Green	Green	
	% availability of a social worker at clinic.	100%	Red	Red	No social worker.
	% availability of a social worker for inpatients.	100%	Green	Red	No dedicated CF social worker
	% availability of pharmacist at clinic.	100%	Red	Red	
	% availability of a pharmacist for inpatients.	100%	Green	Green	But no dedicated CF time

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

5 Commissioning

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

Appendix 2

Staffing levels (adult)

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

***management confirms total of 1.5 PA = 0.15WE Consultant time in total**

	75 patients	150 patients	250 patients	Castle Hill Hospital 40 patients
Consultant 1	0.5	1	1	0.5 PA*
Consultant 2	0.3	0.5	1	0.33 PA* (non specialist)
Consultant 3			0.5	0
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.4	0.8	1	Variable/ sessional
Specialist nurse	2	3	5	1 WTE
Physiotherapist	2	4	6	1 WTE
Dietitian	0.5	1	2	0.40 WTE
Clinical psychologist	0.5	1	2	0.40 WTE
Social worker	0.5	1	2	0
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	0.49 WTE

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2014, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2014	
Demographics of centre – Castle Hill Hospital, Hull	
Number of active patients registered (active being patients within the last two years)	40
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2014')	38
Median age in years of active patients	24.5
Number of deaths in reporting year	2
Median age at death in reporting year	24.5

Age distribution (ref: 1.6 Annual Data Report 2014)		
Number and % in age categories	16–19 years	7 (18%)
	20–23 years	8 (21%)
	24–27 years	6 (17%)
	28–31 years	7 (18%)
	32–35 years	2 (5%)
	36–39 years	2 (5%)
	40–44 years	3 (8%)
	45–49 years	0
	50+ years	3 (8%)

Genetics	
Number of patients and % of unknown genetics	5 (13%) Have they been sent to Kennedy Galton Lab vs CF Trust initiative

Body mass index (BMI) (ref: 1.13 Annual Data Report 2014)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=25); 11 (44%)	(n=13); 1 (8%)
Number of patients and % with BMI <19 split by sex	7 (28%)	8 (62%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	3 (43%)	6 (75%)

FEV_1 (ref: 1.14 Annual Data Report 2014)			
		Male	Female
Medium FEV_1% predicted at age 16 year split by sex		0	0
Number and medium (range) FEV_1 %n predicted by age range and sex	16–19 years	6 (96.28%) 19.3–108.41	1 (41.74%)
	20–23 years	4 (39.21%) 21.39–98.48	4 (40.1%) 27.58–58.22
	24–27 years	3 (68.9%) 67.01–93.44	3 (59.16%) 34.29–125.8
	28–31 years	4 (34.41%) 15.95–56.03	3 (54%) 13.16–61.16
	32–35 years	2 (51.55%) 43.35–57.74	NA
	36–39 years	2 (88.02%) 72.9–103.14	NA
	40–44 years	1 (51.68%)	2 (32.31%) 31.6–33.02
	45–49 years	NA	NA
	50+ years	3 (32.82%) 22.87–79.74	NA

Lung infection (ref: 1.15 Annual Data Report 2014)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	7
	20–23 years	8
	24–27 years	6
	28–31 years	7
	32–35 years	2
	36–39 years	2
	40–44 years	3
	45–49 years	0
	50+ years	3
Number of patients with chronic *P. aeruginosa* by age group	16–19 years	2/7
	20–23 years	3/8
	24–27 years	2/6
	28–31 years	6/7
	32–35 years	2/2
	36–39 years	2/2
	40–44 years	3/3
	45–49 years	0/0
	50+ years	3/3

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	4 (11%) multivorans
Number and % of *B.Cenocepacia*	0
Meticillin-resistant *Staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	0
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	1 (3%) (not *M. abscessus*)

Complication (ref: 1.16 Annual Data Report 2014)	
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	9 (24%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	1 (3%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 (0%) with PH 0 (0%) without PH

Transplantation (ref: 1.18 Annual Data Report 2014)	
Number of patients referred for transplantion assessment in reporting year	2
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2014)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	0
	20–23 years	14
	24–27 years	0
	28–31 years	28
	32–35 years	0
	36–39 years	0
	40–44 years	6
	45–49 years	0
	50+ years	0
Number of days of home IV therapy in reporting year split by age group	16–19 years	84
	20–23 years	238 median FEV1 ~40%
	24–27 years	70
	28–31 years	362 all FEV1 <60%
	32–35 years	28
	36–39 years	28
	40–44 years	6
	45–49 years	0
	50+ years	0
Total number of IV days split by age group	16–19 years	84
	20–23 years	252
	24–27 years	70
	28–31 years	390
	32–35 years	28
	36–39 years	28
	40–44 years	12
	45–49 years	0
	50+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2014)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1, % predicted <85% (ie below normal) on DNase	(n=30); 10 (33%) (smaller %age than children's clinic)
If not on DNase, % on hypertonic saline	1 (3%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2014)	
Number and % of patients with chronic PA infection	23 (61%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	16 (70%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	20 (87%) with chronic PA 10 (67%) without

Appendix 4

Patient survey

Castle Hill Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	0	1	1	0	1	3	1
Female	0	0	4	1	2	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	9	2	2	0
Communication	10	2	1	0
Out-of-hours access	5	3	2	0
Homecare/community support	3	1	1	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	8	3	1	1
Waiting times	5	1	4	1
Cross-infection/segregation	6	4	2	0
Cleanliness	8	5	0	0
Annual review process	7	3	3	0
Transition	1	3	1	2

How would you rate your inpatient care (ward)?

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

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	6	3	0	0
Availability of equipment	6	6	0	0
Car parking	1	4	3	4

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	10	1	1	1
Of the ward staff	5	4	1	0
Of the hospital	6	4	2	0

Comments about CF team/hospital

"Castle Hill Hospital. They are the best and the reason I'm still here at 44."

"Fantastic care all round. Excellent."

"As I am on a low-potassium diet, I often have to live on sandwiches as there are no suitable hot meals on the menu."

"The only thing I have to say is the parking is really bad at both hospitals; takes longer to get parked as not many spaces available and the prices are not really good either."

"CF team are very helpful. I have not been admitted for about six years. I have been able to use IVs at home."

"Every time I want to see my CF nurse, she is always having time off, so I don't even bother ringing her anymore because you just get fobbed off all the time. She is meant to come and do home visits for my blood and she won't even do that; always excuses all the time. My brother also has CF and they haven't sent him an appointment in about four years. It is all wrong. I have CF and don't even get appointments sent to me. It's a complete joke. Same with my brother - no appointment comes for him either."

"Really friendly and down to earth team. They make me feel welcome and relaxed when in their care."

Appendix 5

Patient/parent interviews

Patient A

Outpatient clinic

Patient A felt that segregation measures at outpatient clinic were fine. He is directed to a side room where he stays during the clinic appointment. The CF multi-disciplinary team (MDT) rotate and so come to his room at clinic. He felt that there is good use of hand gels at clinic and presumed that equipment was wiped down between patients.

Patient A felt fully involved in decisions made by the CF MDT on any changes to his treatments. He felt that the communication from the CF team was very good, adding that he has the telephone contact details of five members of the team, including the lead consultant.

Inpatient care

His one admission in the last year to hospital he described as an easy admission, without delay and he described the food as fine. He didn't require physiotherapy during this admission for what was not a cystic fibrosis-specific admission.

As a newly diagnosed CF patient, he and his wife have been taught airway clearance techniques, the teaching of which he was happy with.

Home care

Patient A has no home visits, but has just started receiving home deliveries of a nebulised antibiotic from the Boots service. He was happy with this service from early experience. Boots rang him on the Friday; his delivery took place next day.

Annual review

Patient A has had annual review in the last 12 months. All his assessments took place at Castle Hill Hospital, same day. The outcomes of annual review are reported back to patient A at end of annual review clinic, with most results available then. He receives a letter confirming the outcome of annual review around two weeks after the annual review.

Patient B

Outpatient clinic

Patient B has all his CF care at Castle Hill Hospital. At outpatient clinic he was satisfied that segregation was working well, adding that he is directed to a side room more or less straight away upon arrival at clinic. He explained that weight and spirometry take place in a separate room, before the CF team see him in the consultancy side room.

Patient B was happy with the decision making on changes to his medications, decisions made jointly with his CF team. He explained that his consultant always asks him how he feels about his various treatments and makes decisions accordingly.

At outpatient clinic patient B sees the consultant, clinical nurse specialist (CNS) and specialist clinical psychologist. He said he normally sees three or four members of his CF team including sometimes the physiotherapist, although he added that he's 'well on top with physio'.

Inpatient care

Not applicable to this patient.

Home care

Patient B does not have any home visits from his CF team. He does not require home IVs, but does have daily, nebulised antibiotics. He currently has a 50-mile journey to collect his Promixin every 2–3 months. He also has daily Pulmozyme DNase. He explained that his CF team is currently in the process of setting up home delivery of the Promixin and DNase through Boots home delivery service. In the meantime, patient B texts his CNS about a week before this medication is due to run out, upon which a new prescription is written up.

Annual review

Patient B has not had his first annual review as yet, due to late diagnosis.

Good practice

"They're (CF team) a nice, polite team; helpful and knowledgeable."

Areas for improvement

No suggestions mentioned.

Patient Interviews on peer review day – Hull Adults Cystic Fibrosis Service

Patient A

Patient A is a twenty-one-year-old male who lives very close to the cystic fibrosis service at Castle Hill hospital.

Patient A was diagnosed with having cystic fibrosis at eleven months old.

Following diagnosis, patient A received shared care from the paediatric service in Hull and from the Royal Brompton Hospital in London until he transitioned to the adult service in Hull at the age of 16 years.

Patient A has not been an inpatient for over two years but as he has B. cepacia, when he is admitted for treatment he stays on a separate ward to other patients with cystic fibrosis to prevent cross-infection.

Patient A feels that the current television service is expensive and would appreciate the provision of free Wi-Fi as the stays for patients with cystic fibrosis are often long.

Patient A has a blue badge so never finds parking at the hospitals problematic.

Patient A described the food offered on the ward as bland and boring and not very warm. When in hospital he prefers to have food brought in for him. High-fat snacks are available if required.

Patient A has been on the lung transplant list since November 2014. He has had regular appointments with the service's psychologist and found these sessions particularly helpful when he'd recently been added to the transplant list.

Patient A and her mum have a good relationship with the multi-disciplinary team (MDT) and feel that they are always accessible.

Patient A now sees a physiotherapist at his outpatient appointments and he finds his time with her very useful.

Patient A and his mother feel that they would benefit from having social worker input. As patient A is now unable to work, they are sometimes unsure of what benefits he is entitled to.

Patient B

Patient B is a twenty-nine-year-old female who lives in south Hull; a 15-minute drive from the service at Hull Royal Infirmary and a ten-minute drive from the outpatients' department at Castle Hill Hospital.

Patient B was diagnosed with cystic fibrosis at birth. The family lost her sibling at the age of eleven years who also had cystic fibrosis.

Patient B transitioned to the adults' service from the Hull paediatric cystic fibrosis service. It is over three years since she was admitted as an inpatient; she is very rarely admitted for treatment and keeps generally very well. She remembers the food provided on the ward as being "not too bad" and that high fat snacks were available if required.

She remembers the TV service being expensive and the lack of free Wi-Fi. When the need has arisen for admission this has happened very quickly.

Patient B has a good relationship with the MDT and calls or texts the Clinical Nurse Specialist (CNS) whenever she needs help or advice. She sees the same CNS every four weeks at an outpatient appointment but doesn't necessarily see anyone else from the MDT at these times. She has recently been seeing the physiotherapist; she feels this has been beneficial and has been working with her on a new fitness plan.

Patient B is a blue badge holder so does not find parking at the hospitals problematic.

Patient B reported that she sometimes has to wait in waiting areas at outpatient appointments with other patients who have cystic fibrosis. She is concerned about the risk of cross-infection.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic – Hull Adult Cystic Fibrosis Centre

	Hospital Name	Castle Hill Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	There needs to be a significant improvement in the equipment to allow for all five rooms to be adequately equipped as clinic rooms ie IT equipment, clinical equipment (height/ weight equipment for each room, spirometry equipment), tables, chairs etc. Currently there is only enough equipment to allow for one clinic room to be running.
Do patients spend any time in waiting room?	No	All patients who attend are able to be segregated into individual rooms.
Is there easy access to toilets?	Yes	There are two toilets available for patients, one being a disabled access toilet. The toilets are coded for infection control.
Where do height and weight measurements take place? Is this appropriate?	No	This currently takes place in a specific weighing room and is cleaned in between patients with Tristell and Clinell wipes. Ideally there needs to be separate equipment in each of the five clinic rooms.
Where are the lung function tests done for each visit?	No	As above. There is not enough spirometry equipment in order to separate for the rooms. The two spirometers available have different turbines for different microbiology and filter mouthpieces are used. Again the equipment is cleaned between patients.
Are clinic rooms appropriately sized?	Yes	There is adequate space in the consultation rooms and the clinic rooms.
For annual review patients, are any distractions provided?	No	Apart from magazines (infection control concern?) which are replenished regularly there are no other activities currently available although a quiet room is planned with TV, comfortable seating etc (only one patient at a time).
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	They are seen in a separate clinic where they are able to be segregated into rooms as required in the diabetic clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	During the transition process all patients are invited for a look round (separately) in order to make themselves familiar with the adult set-up.
Transition/new patients – do they get information pack?	No	There is no formal pack given at the present time, although this is being planned for the future.

Additional comments

There does need to be some investment into the new centre in order that the outpatients clinics from the other two outpatient areas can be moved into the new centre, which will allow for improved cross-infection control and patient access.

Environmental walkthrough: outpatients department

Outpatients/CF clinic – (Soon to be closed)

	Hospital Name	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)	Yes	
Do patients spend any time in waiting room?	Yes	Different waiting areas to access.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In the processing room, no room or electrical supply in the treatment room.
Where are the lung function tests done for each visit?		In the clinic room or the Lung Function unit/room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	No	
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Brocklehurst Diabetic Clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No	This is being planned for the next group of transition patients.

Additional comments

This facility should no longer be used for CF patients when Castle Hill is open as it will not be serviced by the MDT. All patients should be required to attend the specialist clinic.

Environmental walkthrough: ward

Ward name: Ward 500 HRI

Microbiology status: Non *B. cepacia* patients only

		Hospital name	Hull Royal Infirmary
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	Respiratory ward but is suitable for CF care
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Four en suite utilities for CF preference. Usually <2 in use at a time
Number of side rooms?		Four	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		No	Not as yet but there are some locked units on order for the cubicles and for the main ward.
Can you use mobiles?		Yes	
If there is a television, is the service free?		No	No televisions currently; availability is being planned for (W500).
If no, are there any concessions for CF patients?		No	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	They try to accommodate family on the ward. There is no specific designated area and a requirement for two new put-up beds.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open visiting.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes/No	The cubicles have fridges but no access to a microwave or kitchen facilities.
What facilities are provided for teenagers?		None	They are trying to facilitate TV and internet access.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No/Yes	No gym access – but access to exercise equipment via physiotherapy.
What facilities are there to help with school and further studies?		Studies can be undertaken on the ward, or patient could, if well enough, leave the ward to facilitate study. Single rooms would allow for tuition.
Is there a relatives' room?	Yes	Not really appropriate for giving bad news.
What internet access is there?	No	They are looking into the provision of this.
What facilities are there to enable students to continue to work and study?		They have single rooms. Work/tutors could come into the ward.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Single rooms/en suite.
What facilities are provided for those with MRSA?	Yes	Cubicles
What facilities are provided for those with *B. cepacia*?	None	Ward 500 not for *B. cepacia* patients. Ward 5 for these patients.
What facilities are provided for those with other complex microbiology?	N/A	Do not have any other complex microbiology patients. However, Infectious Diseases ward could be accessed.
Are patient information leaflets readily available on ward?	No	There will be leaflets. They are waiting for leaflet racks to be in place and currently get leaflets from chest clinic if required.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: ward

Ward name: Ward 5

Microbiology status: *B. cepacia* CF patient ward. NB only 1/40 patients have *B.multivorans* and he has not been in for ages so the ward nurses cannot be skilled in CF

		Hospital name	Hull Royal Infirmary
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	Previously a designated CF ward. Ward 5 is a respiratory ward with a Respiratory High Observation area.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Four	
Do the en suites have:	**Toilets?**	No	
	Wash basins?	Yes	
	Bath or shower?	No	
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	Medication lockers can be made available.
Can you use mobiles?		Yes	
If there is a television, is the service free?		No	
If no, are there any concessions for CF patients?		No	
Are there facilities to allow parents/ carers/partners to stay overnight?		No	
Visiting hours – are there allowances for CF patients' families out of normal hours?		No	This can be assessed on an individual basis.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		No	
What facilities are provided for teenagers?		None	

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	
What facilities are there to help with school and further studies?	None	
Is there a relatives' room?	No	There is a quiet room on the ward that can be accessed but this is for all relatives.
What internet access is there?	None	
What facilities are there to enable students to continue to work and study?	N/A	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	No	
What facilities are provided for those with MRSA?	Cubicle	Barrier nursing precautions would be taken. These patients would be nursed on ward 500.
What facilities are provided for those with *B. cepacia*?	Cubicle	These patients are nursed on ward 5 and kept separate from the inpatients on ward 500.
What facilities are provided for those with other complex microbiology?	N/A	These patients would be nursed on ward 500.
Are patient information leaflets readily available on ward?	No	Not now that patients are very rarely admitted to ward 5; these could be accessed from the CF nurse.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	Hull Royal Infirmary
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	The patients will go for investigations at different times.
Do patients have to wait at pharmacy for prescriptions?	Yes	Infection control concern.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?		Yes to poster/leaflets again can't be displayed as awaiting racks for display.
Are there patient comment/ feedback boxes?	No	No but they do give out friends and family feedback forms/will discuss a comments box with matron - in place in other areas in the Trust.

Appendix 7

Panel members

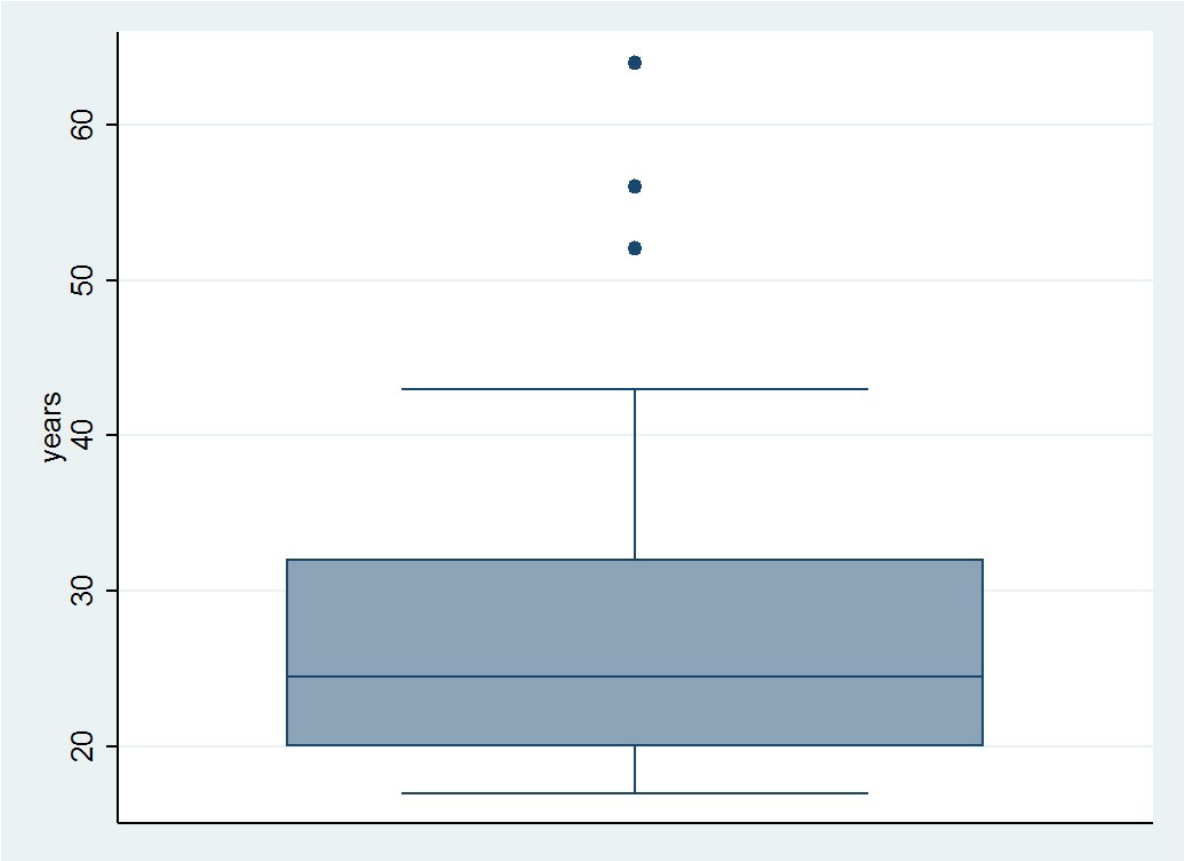
Frank Edenborough*	**Consultant**	**Northern General Hospital, Sheffield**
Ingrid Small	CF Specialist Dietitian	Wythenshawe Hospital, Manchester
Lily Lamb	CF Specialist Clinical Psychologist	Liverpool Heart and Chest Hospital
Robin Saadvandi	CF Specialist Pharmacist	Norfolk and Norwich University Hospital
Penny Agent	**Director of Rehabilitation and Therapies**	**Royal Brompton Hospital**
Rebecca Heise	**CF Specialist Nurse**	**King's College Hospital**
Jackie Parr	**Specialist Commissioner**	**Service Specialist, South Yorkshire and Bassetlaw**
Marie Donnelly	CF Social worker	Barnardo's Orchard Mosaic
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	**Quality Assurance and Control Manager**	**Cystic Fibrosis Trust**

*Peer review panel lead

Bold: panel members who attended on peer review day.

This report was edited by Professor Martin Walshaw, on behalf of the Peer Review Oversight Board who have endorsed its content.

Appendix 8 Other



Single Box plot for age Hull Adults:
Supplied by Elaine Gunn Registry manager, Cystic Fibrosis Trust.

A query from the Hull Adult Service regarding the maximum age of their patients supplied in the registry data (Page 21) was received. Investigations into this query were undertaken with the statisticians at Imperial College, London. Their response was “The reason the whiskers do not reflect exactly the maximum age as demonstrated in the registry data is because stata identifies these as outliers. This single box plot for Hull Adults demonstrates this”.

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