Peer Review Report

The Royal Brompton Hospital – London
Adult Centre

12 March 2013

Cystic Fibrosis our focus

BIPRS

British Thoracic Society

Contents

1. Executive summary

1.1 Overview of the service (Maximum 150 words)

The Royal Brompton Adult Cystic Fibrosis Centre is a highly respected national and international centre of excellence. It has a strong academic pedigree that delivers care to the largest number of CF patients in the UK. The centre has a highly skilled, experienced and dedicated multi-disciplinary team (MDT) providing a very high standard of care. Over the past two years 654 patients have been registered and the present population stands at around 592, with a median age of 31 years and median age of death at 28 years. Prevalence of chronic Pseudomonas Aeruginosa ranges between 39% and 68% according to age population (lower than average). There remains a low prevalence of Burkholderia Cepacia Complex, MRSA and Non-Tuberculosis Mycobacteria. The centre complies with modern therapies, with a higher than average prescription of Pulmozyme, Macrolides and nebulised antibiotics.

1.2 Good practice examples (Maximum 50 words)

1. A high quality research programme. Guidelines and protocol production to guide treatment in all aspects of the disease.
2. Proactive dietetic team with innovative use of telephone and email follow up. Good food service/provision with few complaints
3. The introduction of a high quality, nurse lead annual assessment

1.3 Key recommendations (Maximum 200 words)

Review and invest in the Psychology service which is under resourced.
Data regarding audit of admission to hospital revealed 16% waited >2 weeks and up to 30.8% had, at some time in the past, waited >2 weeks to be admitted to hospital. This is unacceptable and reflects the lack of investment in inpatient beds. Thee are 25 available cubicles. The three private rooms should be provided immediately for the care of CF patients and future protected provision of these arranged .
Appoint 1 WTE CF Clinical Nurse Specialist (CNS) to allow for increased support for both inpatients and outpatient care.
Appoint as already agreed 1 WTE physiotherapy technician to support exercise provision and free up qualified physiotherapy time, in addition to 1 WTE physiotherapist post already submitted.
Appoint 1 WTE pharmacist to support inpatient review and home care.
Review staffing levels of all key staff as numbers are inadequate for patient numbers.
There is an urgent need to recruit an additional consultant to ensure standards of care are maintained This has already been approved by management.

1.4 Areas for further consideration (Maximum 200 words)

The peer review panel were surprised that there was no social worker attached to the department. The team explained that due to the way social work services are commissioned in London this model cannot be adopted and therefore deliver the service utilising social support provided by existing staff. The unit has invested in an advisor skilled in welfare rights. The peer review panel feel that the unit may be unaware of the usefulness and true role of a social worker. It was suggested that they should hold a meeting and explore the potential role with social workers from other CF centres.

Appoint 1 WTE dietitian to a full time training post to help with succession planning.

2. Performance against CF Standards of Care

2.1 Models of care

Summary

Like many units annual assessments remain a problem with a high prevalence of DNA (did not attend) and cancellations, although uptake has increased significantly from 31% to 62%. This has been achieved through the MDT's hard work, nurse led annual assessment and because individuals with CF are appreciating the benefit of the dedicated time with the team. Work is being undertaken to improve this further. High quality annual assessments are offered, although percentage figures within the Risk matrix are below CF Standards of Care (2011). Possibly offering a shorter assessment for those who do not presently attend may help hit targets for example in relation to ultrasound, DEXA and diabetic screening.

2.2 Multidisciplinary care

Summary

The peer review panel were very impressed by the highly skilled, experienced and dedicated MDT. There was a real passion to deliver the best service, despite low staffing levels.

The percentage of patients with CFRD (Cystic fibrosis related diabetes) reviewed at a joint CF / Diabetes clinic needs to increase.

2.3 Principles of care

Summary

The percentage of patients admitted within 7 days of the decision to admit and treat is unacceptable. This in in no way a reflection of the excellent service provided by the team and needs urgent review / investment. Despite this the feedback from patients was excellent, demonstrating the high standards of service. The peer review panel unanimously suggest a revisit in 6 months with the Commissioners, to assess how recommendations have been actioned and what improvements have been made with respect to bed availability and timeliness of admission.

2.4 Delivery of care

Summary

Care delivered by the team is of a high standard and is only undermined by lack of staff resource in psychology, physiotherapy and CNS input. Business cases have already been put in place for additional staff in physiotherapy, psychology and CNS resource.

2.5 Commissioning

Summary

**Note: Full commissioner's summary, see Appendix 8. The Trust enjoys a national and international reputation as a world leader in research and development benefiting enormously from an experienced and dedicated MDT. The Trust has a high volume of patients and numbers are increasing placing significant demands on both inpatient and outpatient accommodation and staffing. Complaints and incidents were all of a good low acceptable level, according to the Risk Matrix. On review day 25 beds were full, and a further 22 patients awaited admission. The patient survey reports delayed admission being the single biggest issue. It was also of concern that 3 beds were allocated to private patients, when the Trust has a separate private patient wing. The clinical team, Trust managers and local commissioners are working together, to develop a regional strategy and detailed plans to address both the short term and long term capacity and projected demand. The Trust is considering a range of options around reconfiguration of its services and future location. Whilst it is acknowledged that such developments are complex, delays in decision making will clearly have an impact on the Trust's ability to effectively manage this very large patient group. Level of investment in CF services made by commissioners, should be sufficient for all service providers to meet the requirements of the newly published and agreed service specifications,

3. Registry data

		Male	Female
BMI	Number of patients and % attaining target BMI of 22 for Females and 23 for Males	Males = 137(41%) (n=335)	Females = 85(33%) (n=257)
	Number of patients and % with BMI <19 split by sex	Males = 33(10%)	Females = 52(20%

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		1 (98.64%)	3 (86.80%)
	Number and median(range) FEV_1 % pred by age range and sex	16-19 years	29 (70.74%)	41 (73.73%)
		20-23 years	43 (71.42%)	38 (93.37%)
		24-27 years	48 (62.19%)	44 (57.82%)
		28-31 years	48 (61.23%)	35 (63.49%)
		32-35 years	47 (56.38%)	24 (58.98%)
		36-39 years	28 (47.13%)	28 (66.47%)
		40-44 years	39 (51.2%)	19 (73.24%)
		45-49 years	31 (61.99%)	14 (47.02%)
		50+ years	22 (63.48%)	14 (61.90%)

Data Input	Number of complete annual data sets taken from verified data set (used for production of National Report)	592

Pseudomonas Chronic PA is 3+ isolates between 2 annual data sets	Number and % of patients with chronic PA infection	327(55%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	297(91%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	262(80%)
	Number and % of patients on chronic macrolide without chronic PA infection	112(42%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

There are presently 3 consultants 0.9 WTE, 0.9 WTE, 0.7 WTE. Sickness has had a significant impact on the team who, despite this, have delivered an excellent service through dedication.

The peer review team acknowledged that recruitment of a new consultant was imminent and will support maintenance of the standards.

The consultants are of high calibre, and are very supportive of one another. The team have a strong academic pedigree and this needs to be supported, with appropriate protected time for academic research.

The team is also supported by a Trust Grade doctor, and SpR and a Senior Clinical Fellow working at consultant level.

The peer review panel were all very impressed by the team dynamics and how the MDT team pulled together, despite low staffing levels. However, this is not sustainable in the long term and investment is needed urgently.

The centre lead/ director is Dr D Bilton.

Excellent hand overs and regular case discussions. Clinical support between seniors is very apparent.

4.2 Specialist nursing

• The CNS team are extremely hard working, caring and dedicated to looking after CF patients. There are 3.6 WTE CNS and 1 WTE consultant nurse for 594 patients. The presence of the consultant nurse is crucial in maintaining clinical care delivery and plays a significant and important role in leadership of the nursing team in this large centre. The CF Trust Standards of Care (2011) recommend 5.0 WTE CF CNS for 250 patients. The current staffing levels are significantly below this. All CF CNS are band 7 and cross cover each other for annual leave and sickness.
• All CF CNS and consultant nurse are members of the CFNA and attend meetings annually. Two have been previous chairs.
• At least one of the CF CNS team two consultant ward rounds and one MDT ward round every week
• At least one member of the CF CNS team attends the European and North American CF conferences on an annual basis.
• The CF CNS and consultant nurse have been involved in many research trials and carried out several audits over the past 5 years.
• The CF CNS and consultant nurse are involved in all aspects of care including outpatients, annual reviews, home care and limited inpatient care as required. They are also heavily involved in palliative care and attend weekly palliative care meetings

Good Practice:
The annual review service is well structured. The CF CNS run a nurse led annual review clinic 3 x a week where all the relevant tests and discussions take place. There are appointments for 4 patients in each clinic.
The sweat test clinic has been set up 3 x a month. This is also a nurse led service.
Two of the nurses are non medical prescribers with plans for one other in the next 12 months.

Recommendations:
• The CNS team are currently in a very cramped office with 1 telephone line. A larger office with at least 3 x telephone lines is required.
• Increase staffing. Need 1 WTE CF CNS to allow for more support with all aspects of care for both inpatients and outpatients.
• Develop more effective discharge planning to allow patients to go home earlier.

4.3 Physiotherapy

Staffing: An excellent specialist physiotherapy service, adheres to all standards of care. Under resourced with 5.5 WTE (4 CF specialists), well below recommendation of 6 WTE for 250 patients (RBH = 594).

Clinical service delivery: A specialist physiotherapist attends all MDT ward rounds, clinics and annual reviews. A home care service is provided by the Band 8a for complex patients, where specific need is identified. 1 day per week allocated to this service, although recently home care activity has reduced. The outpatient service demands on physiotherapy are high, with cover provided for 3 clinics and approximately 12 annual reviews a week, MDT meetings, ward rounds and day patient reviews. All patients have appropriate access to nebuliser and airway clearance adjuncts. On average the team provides physiotherapy to 20 CF inpatients. The risk matrix shows 85% inpatients are reviewed twice daily, including weekends, however audit reports a large variation, 1-66 contacts per admission. Excellent outpatient provision is prioritised over inpatient care resulting in a reduced level of specialist support to the inpatient cohort, relying on junior and non-specialist physiotherapists to provide assistance with airway clearance/exercise. The planned business case for 1 WTE Band 6 specialist training post should be prioritised. Exercise provision for inpatients is very good with 90% of inpatients receiving exercise assessment/sessions. The proposed business case for a Band 4 technician will 'protect' exercise provision and free up physiotherapy time to increase specialist intervention for airway clearance or other identified patient needs.

Weekend physiotherapy provision: CF patients are not guaranteed physiotherapy at weekends, they are prioritised alongside all respiratory patients, based on acuity and dependence on assistance for airway clearance. The weekend service is provided by 2.0 WTE physiotherapists and most priorities are seen at least x1/day. This is inadequate. In line with NHS strategy to reduce the inequitable/skeleton service patients receive at weekends this should be immediately addressed and resourced adequately.
Personal and professional development: The team are hugely experienced and specialised in CF with national and international reputations - one has been chair of the national group and another is currently vice-chair of the international group. All regularly attend ACPCF meetings and play active committee roles There is always a representative at international conferences and national meetings. The team demonstrate an impressive commitment to research and audit. All receive an annual appraisal and achieve their PDP. There are clear CF therapy and research objective plans.

Areas of good practice:
• Proactive team in terms of research and service improvement, with large number of abstracts and conference presentations.
• Excellent CF Physiotherapy Standards, provide clear timeline of expectations for an inpatient admission.
• Excellent senior/specialist support to physiotherapy team, with structured teaching and in-service training.

Areas for improvement:
• Increase in specialist physiotherapy staffing in line with standard recommendation, to further improve delivery of care.
• Consideration of protected CF physiotherapy weekend service in line with CF Standards of Care (2011).
• Exercise provision : ensure planned business case for Band 6 physiotherapist and Band 4 physiotherapy technician is successful.

4.4 Dietetics

1. All dietitians working in CF are members of the UK Dietitians' CF Interest Group. One of the Band 7 dietitians is currently chair and all the dietitians are active members of the Dietitians' CF Interest Group.

2. The Band 7 dietitians rotate ward round participation and both attend every MDT Meeting.

3. The Band 7 dietitians cover for each other, overseeing all aspects of work.

4. Both Band 7 dietitians have attended and participated at the North American CF Conference in 2012 and have attended a European Cystic Fibrosis Conference within the last five years. However, funding is becoming more difficult each year.

5. The dietitians actively participate in audit and research and apply this in practice to enhance patient care.

6. The Band 7 dietitians participate in the transition process.

Good practice:
• Proactive team with one dietitian being nationally and internationally recognised.
• Innovative use of telephone and email follow up (in part due to understaffing)
• Good food service/provision with few complaints

Recommendations:
• The service is understaffed by 2.25 WTE dietitians. Increasing staffing too quickly could be problematic due to training needs. To enable patients to be seen twice weekly on the ward and at annual review, the peer review panel recommends:

• The Band 6 post be increased to a 1WTE training post, to help with succession planning.
• A service of this size with increasingly complex workload is well led by a band 8 physiotherapist (physiotherapy and dietetics team). Consideration should be given to a clinical specialist or a consultant dietitian (as seen in other smaller services in the UK) – this would allow for clear dietetic leadership and succession planning.

• Further development of the CFRD service with appointment of a diabetes educator.

4.5 Pharmacy

The CF service for 594 patients is covered by 3 respiratory exceedingly dedicated pharmacists, equivalent to 1 WTE. CF Standards of Care (2011) recommend 1 WTE for >250 patients. In addition there is 1 WTE medicines management technician (MMT) who serves the respiratory ward. The pharmacy team endeavour to cross cover for each other for annual leave and study leave. No cover is provided for the MMT in their absence, so the workload falls back on the pharmacists. The pharmacists currently look after 410 patients who obtain medication through home care companies, of which 250 are CF patients. With the advent of specialist commissioning this workload is only likely to increase. They have no technician or administrative support. There are plans for a Band 3 administrator to support the hospitals home care service which would include CF services.
Pharmacists are not involved in annual review yet plans are underway to become so. A room to perform this service has to be identified. Due to current workload there is a concerns they will be unable to provide a sustainable commitment to undertake 12 Annual reviews/week, despite the MDT's enthusiasm for them to be involved. The pharmacists endeavour to attend weekly MDT, though in practice this happens ~80-85% of the time, due to staffing constraints. They prioritise patients as they are unable to see all daily. CF Trust Standards of Care (2011) are not met for all patients to see each member of the MDT at least twice per year. All are active members of the UK CF pharmacist group. One recently attended both NACFC and ECFS and presented. Two have attended the UK Pharmacists study day and the third team member has attended local events in order to undertake relevant CPD. They are well received and integrated into the MDT. They are unable to do personal research due to workload and staffing constraints.
Patient feedback indicates long waits for prescriptions. The physical constraints of space in pharmacy undoubtedly affects this. There is also a concern that the length of time waiting could lead to compromise of cross infection control segregation policies. Waiting times have been identified as a concern by pharmacy management and are now a key performance indicator and are being tracked and audited, with plans for a new system of tracking and recording being investigated. Additionally it is hoped the process improvement programme put in place for home care will impact on this. Clinical pharmacists, including the respiratory pharmacy team, are now included on the rota to tackle this, although there are concerns as to how this will impact the time they have available on the wards and for their other duties.
Good practice:
• Dedicated, hard working team managing a very challenging workload.
• Have assisted in the writing of comprehensive clinical guidelines for and with the team on a variety of treatment modalities.
• The addition of a 3rd member of the team 8 months ago has improved the home care service for patients and helped tackle the difficulties of patients struggling to obtain some medicines in primary care.
Recommendations:
• Whilst no formal staffing levels are available for services > 250 patients, the current service appears severely understaffed and under resourced for pharmacists and support staff. In order to undertake annual reviews, see patients twice yearly as per the current CF Standards of Care (2011), manage the growing requirements for home care provision and ensure adequate cover.
Short term:
• Review of staffing to include consideration of an additional 1 WTE pharmacist and 1 WTE pharmacy technician for home care & cover for the MMT.
In the medium to longer term:
• Review of staffing to include a further 1 WTE pharmacist to add strength and depth, enable research and a sustainable service.. Additional 1 WTE administrative support.
In the long term:
• The medium-long term plan of developing the Consultant Pharmacist role, which the CF Centre Director has planned with the Director of Pharmacy should help address the need to tackle pharmacy waiting times.. Development of a consultant pharmacist post to support a service of this size and complexity should be a main goal.
• The provision of outpatient pharmacy to ensure no compromise made to infection control policy, by utilising relatives or volunteers to collect medicines whilst the projects to improve waiting times are underway, is already a goal.

4.6 Psychology

1. Low rate of attendance at UKPPCF meetings attended due to significant under resourcing of staff.

2. CF MDT meetings attended for discussion of inpatients: 100% outpatients: 100%, however Clinical Psychologists (CP) only usually attend part of MDT meeting, for discussion of patients who have been referred.

3. Team of 4 can provide some limited cover for each other when absent , but no additional staff available, eg for sickness or maternity leave cover.

4. No CF Conferences or courses recently attended due to under resourcing.

5. No CF related research/audit carried out by CP service to date. No new service developments.

6. Good level of involvement for referred patients at (adult) diagnosis, transition, transplantation and end of life. No current opportunity (due to staffing level) for more routine involvement with these priority groups in terms of: screening/preventative work/service development/provision of expert opinion on psychological care. No input into issues re: planning families unless referred.

7. Effective and valued CP service been developed. Good relationships with MDT reported and well integrated service for patients referred. Close working relationships with Liaison Psychiatry, Palliative Care and Transplant CP services allow for good joint working..

8. CP service significantly understaffed. CF Standards of Care (2011) not met in that annual assessments not currently performed, CPs have limited opportunity for sufficient CF specific CPD.

CF research/audit not currently carried out. Opportunities for team to consult re psychological care of patients (especially care of patients not referred to CP service) seem somewhat limited due to staffing. Training/supervision for CF team not been possible and presence of CP in other team activities - e.g. whole service development - could possibly be greater, with more CP staffing.

4.7 Social work

Whilst dedicated psychology support for the CF service has been developed, there appears to be no history of dedicated social work support for adults attending the CF service. Expectation is for an already under resourced MDT - particularly the psychologist and CNS team - to draw upon their commitment and skills to perform the tasks usually carried out by a dedicated social worker.
Currently social and welfare needs of patients are met by the psychologists, CNS, with skilled welfare rights support from a specialist adviser who covers all adult and paediatric patients across the RBH and Harefield Hospital Trust and the hospital's palliative care team. Commendable though the efforts of the aforementioned are, it is questionable whether this coverage can be in any way comprehensive enough to support a large group of adult CF patients, amongst whom will be patients with complex needs and considerable support.
The local commissioner advised on peer review day that appointing a social worker would not be recommended given the provision of social work in each London Borough and the model of delivery given elsewhere would not best support the London population. The CF MDT have reviewed provision to ensure all aspects of care listed in the Standards of Care (2011) are being provided by other members of the MDT. There does not appear to be a plan to change the current mode of social and welfare support for patients attending this CF service, which is a concern. This CF service would benefit from a dedicated social worker, as recommended in CF Standards of Care (2011) as an integral part of the CF team, bringing with it time and expertise which are considerably more difficult to provide from other under resourced areas particularly psychology.

5. User feedback

	Completed surveys (by age range)						
	16-18	19-20	21-30	31-40	41-50	51-60	61+
Male	4	2	21	15	20	4	5
Female	4	6	32	16	14	2	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	87	42	8	1
From the ward staff	60	46	10	6
From the hospital	54	62	16	7

Areas of excellence

1. Communication - treating patient as individuals
2. Knowledge - multidisciplinary approach
3. In patient facilities - food/comfort/wifi

Areas for improvement

1. Waiting times - long admission times
2. Out of hours - contact via e-mail good, but phone not
3. Car parking

6. Appendices

Appendix 1

Performance against standards of care

RAG rating defined as the following:

Green = Meeting all Standards of care (2011)
Amber = Failing to meet all Standards of care (2011) with improvements required
Red = Failing to meet Standards of care (2011) with urgent action required

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%	Amber	Amber	This is due to DNA rates, but numbers attending AA has significantly increased over the past year.
1.2 Specialist centre care	% of patients with completed data on the 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%	**N/A**	**N/A**	

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 AR).	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal.	100%	Green	Green	
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the CF Trust standards.	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Green	
	% patients with CFRD reviewed at a joint CF / Diabetes clinic.	100%	Amber	Amber	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission.	100%	Green	Green	
	% 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 7 days of the decision to admit and treat.	100%	Red	Red	As above - bed numbers inadequate
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%	Amber	Amber	
3.5 Liver disease	% patients > 5 years of age with a recorded abdominal ultrasound in the last 3 years.	100%	Amber	Amber	DNA rate for AA has been high in past
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Green	Green	
3.7 Reduced BMD	% patients >10years of age with a recorded DEXA scan in the last 3 years.	100%	Amber	Amber	DNA rate for AA has been high in past

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% patients seen by a CF consultant a minimum of twice a week whilst inpatient.	100%	Green	Green	
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	
	% dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	

	% patients reviewed by a CF CNS at each clinic visit.	100%	Amber	Amber	
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Green	Green	
	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Green	Green	Physio performs all spirometry. Recommend Respiratory Technicians take over allowing Physio to review techniques
	% patients reviewed by a physiotherapist twice daily, including weekends.	100%	Amber	Amber	Need for investment
	% availability of a CF specialist dietitian at clinic.	100%	Green	Green	
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	60%	Green	Green	
	% availability of clinical psychology for inpatients and at clinic.	100%	Amber	Amber	Need for investment
	% availability of social worker for inpatients and at clinic.	100%	Welfare adviser?		see comments
	% availability of pharmacist for inpatients and at clinic.	100%	Green	Green	
4.3 Home care	% 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%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months.	<1%	Green	Green	
5.2	Number of clinical incidents reported within the past 12 months.	<1%	Green	Green	
5.3	User survey undertaken a minimum of every 3 years.	100%	Green	Green	

Appendix 2
Staffing levels

	75 Patients	150 Patients	250 Patients	Royal Brompton Hospital 594 patients
Consultant 1			2.5	0.9
Consultant 2				0.9
Consultant 3				0.7
Staff grade / Fellow			1	1
Specialist registrar			1	1
Specialist nurse			5	3.6 (1 consultant nurse)
Physiotherapist			6	5.5
Physiotherapy assistant				
Dietitian			2	2.5
Clinical psychologist			2	0.8
Social worker			2	
Pharmacist			1	1.6
Clinicians assistant				
Secretary			2	2.8
Admin assistant				
Database coordinator			1	1
CF unit manager				

Appendix 3
Registry data

CF Registry data	Royal Brompton Hospital
Demographics of centre	
Number of active patients (active being patients with data within the last 2 years) registered	654
Number of complete annual data sets taken from verified data set (used for production of National Report)	592
Median age in years of active patients	31
Number of deaths in reporting year	7
Median age at death in reporting year	28

Age distribution *(Ref: 1.6 National Report)*		
Number in age categories	16-19 years	70
	20-23 years	81
	24-27 years	92
	28-31 years	83
	32-35 years	71
	36-39 years	56
	40-44 years	57
	45-49 years	46
	50+ years	36

Genetics	
Number of patients and % of unknown genetics	see Appendix 8

BMI *(Ref: 1.13 National Report)*		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	137(41%) (n=335)	85(33%) (n=257)
Number of patients and % with BMI <19 split by sex	33(10%)	52(20%)

FEV_1 *(Ref: Figure 1.14 National Report)*		
	Male	Female
Median FEV_1% pred at age 16 years split by sex	1 (98.64%)	3 86.80%)
Number and median (range) FEV_1 % pred by age range and sex		
16-19 years	29 (70.74%)	41 (73.73%)
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36-39 years	28 (47.13%)	28 (66.47%)
40-44 years	39 (51.2%)	19 (73.24%)
45-49 years	31 (61.99%)	14 (47.02%)
50+ years	22 (63.48%)	14 (61.90)

Lung infections *(Ref: 1.15 National Report)*		
Chronic Pseudomonas Aeruginosa (PA)		
Number of patients in each age band	16-19 years	70
	20-23 years	81
	24-27 years	92
	28-31 years	83
	32-35 years	71
	36-39 years	56
	40-44 years	57
	45-49 years	46
	50+ years	36
Number of patients with chronic PA by age band	16-19 years	27
	20-23 years	40
	24-27 years	54
	28-31 years	56
	32-35 years	43
	36-39 years	29
	40-44 years	32
	45-49 years	27
	50+ years	19
Burkholderia Cepacia (BC)		
Number and % of total cohort with chronic infection with BC complex	10(2%)	
Number and % of cenocepacia	12(2%)	
MRSA		
Number and % of total cohort with chronic infection with MRSA	20(3%)	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	27(5%)	

Complications *(Ref:1.16 National Report)*	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	59(10%)
CFRD	
Number and % of total cohort requiring chronic insulin therapy	179(30%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	58(10%)
CF Liver Disease	
Number and % of total cohort identified with Cirrhosis with Portal Hypertension (PH) and Cirrhosis with no Portal Hypertension	15(2%) with PH; 6(1%) no PH

Transplantation *(Ref:1.18 National Report)*	
Number of patients referred for transplant assessment in reporting year	17
Number of patients referred for transplant assessment in previous 3 years	44
Number of patients receiving lung, liver, kidney transplants in last 3 years	2008 - 2010 = 18 2011 = 7

IV therapy *(Ref:1.21 National Report)*		
Number of days of hospital IV therapy in reporting year split by age groups	16-19 years	783
	20-23 years	1458
	24-27 years	1253
	28-31 years	866
	32-35 years	611
	36-39 years	412
	40-44 years	373
	45-49 years	359
	50+ years	219
Number of days of home IV therapy in reporting year split by age groups	16-19 years	56
	20-23 years	377
	24-27 years	558
	28-31 years	620
	32-35 years	338
	36-39 years	108
	40-44 years	175
	45-49 years	115
	50+ years	43
Total number of IV days split by age groups	16-19 years	839
	20-23 years	1835
	24-27 years	1811
	28-31 years	1486
	32-35 years	949
	36-39 years	520
	40-44 years	548
	45-49 years	474
	50+ years	262

Chronic DNase therapy *(Ref: 1.22 National Report)*	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1 % pred <85% (ie: below normal) on DNase	72% (338) (n=467 with FEV1 <85%)
If not on DNase % on hypertonic saline	20 (16%)

Chronic antibiotic therapy *(Ref: 1.22 National Report)*	
Number and % of patients with chronic PA infection	327(55%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	297(91%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	262 (80%) with chronic PA; 112 (42%) without chronic PA

Appendix 4 – User survey results

Other hospitals attended

	Completed surveys (by age range)						
	16-18	19-20	21-30	31-40	41-50	51-60	61+
Male	4	2	21	15	20	4	5
Female	4	6	32	16	14	2	1

How would you rate your CF team

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	83	46	12	4	1
Communication (verbal/written)	69	56	13	8	0
Out of hours access (via phone or ward)	22	41	24	14	35
Home care/community support (appointments/advice)	28	19	13	8	78

How would you rate your outpatient experience

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	54	63	16	8	2
Waiting times	16	43	45	30	0
Cross infection/segregation	48	54	21	13	10
Cleanliness (room)	59	68	11	4	1
Annual review process	46	61	21	9	6
Transition (paediatric to adult)	22	20	12	4	88

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	22	32	32	19	36
Cleanliness (cubicle/bathroom)	46	46	7	7	37
Cross infection segregation	47	46	6	4	37
Food (quality/quantity)	33	43	19	9	38
Exercise (gym equipment/facilities)	26	48	14	3	48

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	37	25	3	4	73
Availability of equipment (physiotherapy aids/nebuliser parts)	55	45	11	1	29
Car parking (availability/ease of reach)	2	6	17	43	72

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	87	42	8	5	1
Of the ward staff	60	46	10	6	20
Of the hospital	54	62	16	7	4

Comments about CF team/hospital

Areas of Excellence

Communication - treating patient as individuals

"E-mail access to the team is really useful as before it would take days to get hold of someone. Now you have the CF e-mail I get replies the same morning which is brilliant."
"Always find the team/hospital staff willing to go that extra mile to support my experiences in hospital/outpatient experience."
"...always go the extra mile to help."
"...my first port of call and incredibly helpful..."
"...know that the care the hospital and CF team/nurses provide is available at any time."
"Staff very good, helpful, understanding and supportive."
"...they take time to listen to you and help..."

Knowledge - multidisciplinary approach

"A professional caring and knowledgeable team and hospital..."
"All staff approachable and knowledgeable."
"...I owe a lot of my good health and education of CF to them."

In patient facilities - food/comfort/wifi

"...I was very impressed with the overall improvement of care by all staff and efficiency and kindness shown compared to by gone admissions that I have had."
"...food –very good but still would not want to pay for it."
"...can't fault – patient's kitchen, kettles tea/coffee, microwave and toaster."
"Food has improved; complained about food being served on plastic plates with plastic cutlery, now all food is on china plates."

Areas of Improvement

Waiting times - long admission times

"Waiting times -Except pharmacy typically a 1 hour wait having finished all other part of visit."
"Too long waiting time for beds."
"The main areas needed for improvement are waiting times which are dreadful when juggling a job too. I waited 7 weeks once!"
"Waiting times are poor/average."
"Bed availability in the summer when I needed a bed was horrendous - even after 2 week wait none available so had to do home Ivs as no alternative."
"...considerable change in waiting time for admission. It's gone from days to weeks..."

Out of hours - contact via e-mail good, but phone not

"Not good at ringing you back."
"Can you - Ring when sputum results are available..."
"CF needs answering phone facility."

Car parking

"Use public transport."
"Not enough car parking spaces."
"No suitable parking at hospital."
"...limited parking/meters."

The above themes have been formed from the rating scores and comments submitted via the patient survey and the patient interviews.

Appendix 5

Patient/parent interviews

Patient 1
Sees team every 3months, if need to get hold of team outside of this goes through switchboard.
Hasn't got any other contact details.
Attends cystic fibrosis related diabetes clinic and a gene therapy study.
Outpatient experience is sitting in corridor (can see other CF patients but apart) then taken into waiting room where each discipline comes to see you.
Annual review (A/R) process is a whole day of tests – improvement would be electronically having notes for annual review the same as in normal clinic.
Excellence was food –very good but still would not want to pay for it.

Patient 2
Can contact team direct when 9-5 but outside use switchboard to get on call respiratory registrar.
Rang up for appointment got it straight away and bed next day if needed but this is down to haemoptysis.
In patient (IP) facilities – can't fault – patient's kitchen, kettles tea/coffee, microwave and toaster.
Catering staff - different menu more in control of food.
Knowledge of nurse's very good – long line inserted by nurse on ward – if no one can do it then venflon put in to avoid delay and then replace with long line.
Have to ring bell to finish intravenous antibiotics (IVs).
Physiotherapy - gym when I like. Want to do it myself and then they check on me daily. Give me a ball in room and different exercises.
Pharmacist – updates everyday and keeps supplies topped up.
If I wanted to see any team member while IP then I ask ward nurses or wait for team Drs to see me.
Excellence – knowledge fantastic/whole team and listen to you as a patient/individual.
Improvements – can't fault them.

Patient 3
See team every month. Segregated to bacteria and put in side room. Then each discipline comes to you.
If need attention outside of clinic come to day case unit or emergency. If unwell and needing IP waits around 1 week.
Port is accessed by nurses on Foulis ward. Not happy with the hygiene of this procedure as nurses are slap dash and not sterile enough. Some nurses are brilliant but others need a refresher course.
Home IVs mix of both – those that can be pre mix antibiotics done by Willow and those drugs that can not are mixed by self.
IP en-suite – fridge/TV/Wifi on ward, laptop to borrow.
Food – choose hospital menu and call order menu is available Mon-Friday. Snack packs also.
Visiting brilliant no structure just down to us and our discretion.
Did have washing machine would like that back especially when IP for such long periods.
Worried as beds have gone down in 20 years and not increased yet CF population is increasing so can't accommodate us – problem is only going to get work if no provision is made.
A/R – tests on one day – one month post results given verbally in clinic.
Excellence – Consultant's good relationship
CF nurse – home care team always helpful
Hospital recognises long stay provided free TV/Wifi.
Improvements – access to IPs

Patient 4
Access to team – Phone CFNS access them that day/next day.
IP – Had to wait 3 days for IP access. Have Cepacia so on end of ward – not allowed to go to gym but bike provided in room and physio x2 daily.
Long lines done by nurses.
Food is boring if in a long time, presentation needs improving. Not allowed in kitchen. But fridge in room.
Home IVs – mixture of both – premixed and do myself.
A/R on month of birthday.
Dietitian – easy access
Psychology - could if wanted but not routine.
Social worker advisor – able to access
Excellence – attentive to patient health care
Comfort of rooms
Staff medical knowledge
Improvement - waiting admissions

Patient A
Transitioned to adults aged 16
Brilliant staff and care; works brilliantly, good food.
Long waiting times at outpatient pharmacy
Heating in the corridor and rooms is too hot
Ambassador for school; brilliant service

Patient B
First came to RBH at 5 years old
Doctors and Nurses and Physios are very good; care about the person
Heating in the corridor and rooms is too hot, rooms are dry
New beds were installed in 2010; doesn't understand the need for a new bed when nothing was wrong with the previous one! Money could have been spent elsewhere.
Not enough beds, takes too long to get into hospital; needs addressing.

Patient C
All staff are fab!
Food has improved; complained about food being served on plastic plates with plastic cutlery, now all food is on china plates.
Rooms too hot
Clean rooms
More mental health support needed

Appendix 6

Environmental walkthrough – outpatients department

Outpatients/CF clinic

	Yes/no/ number/ n/a	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross infection control? *(reception, waiting room etc)*	Yes	Patients are all made aware of policy re: infection control
Do patients spend any time in waiting room?	Yes	When clinic rooms full
Is there easy access to toilets?	Yes	2 Male/2 Female. Not tidy on visit
Where does height and weight measurements take place? Is this appropriate?		Individual clinic rooms
Where are lung function tests done for each visit?		Individual clinic rooms
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		WIFI available, patients bring their own laptops/netbooks/phones
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?		CFRD Clinic – same area, different day
Transition patients – can they get tour of outpatient facilities?	Yes	Managed by Nurse Consultant
Transition/new patients – do they get information pack?	Yes	Comprehensive

Additional comments

Another room is also required for annual review and for pharmacy provision.

Respiratory Physiology Laboratory is well organised, well run and infection control policies are evident.

Environmental walkthrough – ward

Ward name Foulis Ward

Microbiology status All microbiology in all rooms

		Yes/no/ number/ n/a	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care? *(underline which one)*		Yes	Respiratory Ward (33 beds), 25 CF beds, Age range of all patients(16- 80+). All microbiology cared for in all rooms at different times. 2 negative pressure rooms are available and would be suitable for B.Cepacia patients
Are there side rooms available for CF care? *(if overflow facilities are required)*		Yes	25 Rooms plus 3 private patient rooms which can be utilised by any patient if no private patients are admitted
Number of side rooms?			as above
Do the en-suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? *(Include in notes policy of ward)*		Yes	Drug boxes in each room
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Patients also have access to TVs, DVD players and laptops
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents / carers / partners to stay overnight?		Yes	Team try to avoid overnight stays. Z beds available
Visiting hours – are there allowances for CF patients/families out of normal hours?			There are no visiting hours; however, recommend visiting is within reason
Is there access to fridge/microwave either in the side rooms or in a patient kitchen?		Yes	Microwave, freezer, toaster and kettle in patient kitchen. No more than one patient recommended to utilise kitchen at any time. Staff provide many snacks to patients minimising risk to patients utilising kitchen.
What facilities are provided for teenagers?		Yes	Reflexology, singing lessons, artist in residence
Is there access to a gym or exercise equipment in the rooms?		Yes	Equipment in rooms and a large gym

What facilities are there to help with school and further studies?		School teachers/tutors visit ward and also invigilate examinations if required.
Is there a relative's room?	Yes	Sitting Room only, no overnight room accommodation.
What internet access is there?	Yes	WiFi
What facilities are there to enable students to continue work and study?	Students encouraged by staff to bring in work and laptops. Plans are being made to consider a quiet room with desk for examinations and study.	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	In own bathroom
What facilities are provided for those with MRSA?		Single rooms and cross infection policy
What facilities are provided for those with B.Cepacia?		Single rooms and cross infection policy
What facilities are provided for those with other complex microbiology?		Single rooms and cross infection policy
Are patient information leaflets readily available on ward?	Yes	
Transition patients - can they get tour of ward facilities?	Yes	Part of transition package

Additional comments

• Artwork by patients displayed on walls of ward and corridors.

• Singing for breathing lessons available.

• Achievements board on display.

• Equipment parking mats therefore equipment is returned to designated areas

• Good ventilation in IV treatment room, however little table top space to prepare IV therapy. This should be addressed.

Consider allocating the negative pressure rooms for the care of patients with Burkhoderia Cepacia Complex, to minimise potential cross infection risk.

Recommend increasing inpatient bed capacity from 25 to 28 by converting 3 private rooms in order to help reduce bed waiting times for CF patients.

Environmental walkthrough – other

	Yes/no/ number/ n/a	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	No parking on site. If a patient is in receipt of benefits parking in local car parks may be reclaimed.
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 e.g. radiology, pharmacy, DEXA scan?		Rarely have more than 1 or 2 patients at any one time in supporting services areas.
Do patients have to wait at pharmacy for prescriptions?	Yes	Space to sit apart from each other. Patients made aware of cross infection policy.
Patient information		
Is PALS well advertised – leaflets, posters?	Yes	On notice boards
Are there patient commentv / feedback boxes?	Yes	On notice boards, by the lifts

Additional comments

Most patients travel via public transport and when well enough enjoy trips out of the hospital to run and walk in local parks if able. The attractions of London museums, shopping and theatre are all close by and this location advantage should not be under estimated.

Appendix 7

Panel members

Dr Daniel Peckham*	Consultant and Clinical Lead for Royal Brompton Hospital, London Peer Review
Jackie Parr*	Commissioner
Clare Cox*	Pharmacist
Helen Oxley*	CF Specialist Psychologist
Josie Hussey*	CF Clinical Nurse Specialist
Alison Morton*	CF Specialist Dietitian
Hannah Jay	CF Specialist Physiotherapist
Anne Dealtry*	Social Worker
Sophie Lewis	Clinical Care Patient Adviser
Lynne O'Grady*	Peer Review Project Lead for CF Trust

* Peer Review Core Panel members attended Royal Brompton Hospital, London on Peer Review day

Appendix 8

Other information

* Registry Data:
Genetics
27 patients with genetics not done (5%). 1 patient with unidentified gene on 1st allele (0.17%) 125 patients with unidentified gene on 2nd allele (21%). 12 patients with unidentified genes on both alleles (2%).

** Commissioner's summary:

The Trust as a Specialist Centre and the Clinical Team: The Trust enjoys a national and international reputation as a specialist centre for CF and is a world leader in research and development benefitting enormously from an experienced and dedicated MDT.
Capacity for Cystic Fibrosis Care: The Trust has a high volume of patients and the number of new patients being referred is increasing. This is clearly placing significant demands on both inpatient and outpatient accommodation and staffing. On the day of the unit's current 25 beds were full, and a further 22 patients were awaiting admission. Staff found it very stressful, trying to manage patients on the waiting list, in particular deteriorating patients, as well as those already inpatients. In patient surveys, delayed admission is the single biggest issue for patients. It was also of particular concern that three beds on the unit had been allocated to private patients, when the Trust has a separate private patient wing. The clinical team, Trust managers and local commissioners are working together, to develop a regional strategy and detailed plans to address both the short term and long term capacity and projected demand. The Trust is considering a range of options around reconfiguration of its services and future location. Whilst it is acknowledged that such developments are complex, delays in decision making will clearly have an impact on the Trust's ability to effectively manage this patient group.
Impact of Trust Policy on the Care of CF Patients: CF is a specialised service, which now has unique commissioning currencies and tariffs. It is expected, therefore, that the level of investment in CF services made by commissioners, should be sufficient for all service providers to meet the requirements of the newly published and agreed service specifications, as well as to contribute appropriately and fairly, to organisational and corporate overheads. In this context, it was disappointing that the service at the Trust did not have a uniquely identifiable budget, including a funded staffing establishment, and that the level of contribution to overhead costs is not transparent. The CF MDT and Trust are in agreement and are working towards a clear and transparent budget however, they wish to highlight this has not been mandated in the current Standards of Care (2011) or peer review documentation. Although annual income to the Trust for 2012/13 has been confirmed as £10.331m, it is not clear how much of this investment is reaching the service.
Senior Management Representation: The participation of Trust and service senior managers in the review process was welcomed.
Summary Statement: The peer review overall poses an interesting question. Has the Trust got the balance right, between maintaining and raising its rightly earned international profile and getting the basics of high quality care absolutely right? The key to real success, of course, would be in achieving both!