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Peer review report
Frimley Park Hospital
23 April 2015

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1. Executive summary

Overview of the service

Frimley Park provides care for 110 adults with cystic fibrosis (CF). Many new team members have joined the Frimley Park CF service. The peer review panel was particularly impressed by the team's enthusiasm and dedication to delivering a high quality clinical service, and the very positive feedback from the patient survey and interviews.

The service has a dedicated facility for both inpatients and outpatients, and excellent clinical care guidelines. The centre has benefited from the support provided by the very active and successful 'CF care at Frimley Health' charity and is likely to expand at an increased rate in comparison to the historical growth rate as the reputation of the centre continues to grow and links to paediatric centres are enhanced. As such, there is a need to create a five-year plan to map predicted patient numbers and increase staffing within the team to meet future demands.

Good practice examples:

- The centre has a purpose-built inpatient and outpatient facility.
- An enthusiastic multidisciplinary team (MDT) committed to providing excellent care.
- The service has excellent clinical care guidelines.

Key recommendations:

- Current staffing shortfalls in the team compared to the recommended levels from the Cystic Fibrosis Trust's Standards of Care (2011) need to be addressed, in particular within physiotherapy (1.5 whole time equivalent (WTE)), pharmacy (0.75 WTE), psychology (0.5WTE) and social work (0.5 WTE).
- The CF team and Trust management should work with the commissioners to develop a five-year plan forecasting annual increases in patient numbers and ensure the unit is adequately resourced to provide a high standard of care for additional patients. This should consider expansion is likely to occur at an increased rate compared to the historical rate as the centre's reputation for delivering high-quality care continues to grow and links to paediatric centres are enhanced.
- Develop a transition pathway with centres whose patients will transfer their care to Frimley Park.
- Expansion of support for homecare service.

Areas for further consideration:

- Develop a program of clinical research and explore potential academic links with University of Surrey.
- Improve MDT attendance at international CF meetings.

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

Models of care

Summary

110 adults currently attend the Frimley Park adult CF centre.

The centre has a dedicated facility for CF care, which includes an outpatient department and inpatient beds, adjoining the main respiratory ward.

There is a lack of a transition pathway. Historically, many paediatric patients in the potential regional catchment area transferred to other adult centres. The proportion of patients who transfer from paediatric care to the Frimley Park adult CF centre has increased and is likely to increase further. The centre must now develop a structured transition pathway for patients who will transfer their care to Frimley Park.

Over 90% of patients are registered on the UK CF Registry and have had an annual assessment in the last 12 months.

The centre runs a homecare program, but support is only available for selected patients due to capacity limitations within the MDT.

Multidisciplinary care

Summary

The appointment of recent posts has demonstrated the commitment of Frimley Park Hospital to enhancing its multidisciplinary care, although shortfalls in some disciplines should be addressed.

The MDT is enthusiastic and has a clear commitment to high quality clinical care.

There are a number of areas of excellent practice.

Principles of care

Summary

The infection control practice at the centre is of a high standard.

There are monthly joint clinics held with the CF and diabetes service.

Delivery of care

Summary

The patient survey and individual interviews provided very positive feedback on the service.

The centre has excellent clinical care guidelines.

Although the proportion of patients receiving a nebulised antibiotic appeared low from UK CF Registry data, the CF team was able to provide updated figures that demonstrate a much higher proportion of those patients with chronic *Pseudomonas aeruginosa* infection who are receiving a nebulised antibiotic.

There is no dedicated CF social worker and pharmacy support is provided by rotational pharmacists. The centre should develop CF expertise by appointing permanent social worker and pharmacy posts with fixed CF care sessions.

Administrative support is under-resourced and this is leading to delays in communication to other care providers.

Commissioning

Summary

NHS England contribution to Cystic Fibrosis Trust peer review at Frimley Park 24/4/15

Specialised Commissioning reviewed the peer review documents. The quality of the documentation is excellent and comprehensive.

Particular attention was given to the risk matrix, patient satisfaction survey and reported incidents. The handbook is thorough and describes a service compliant with NHS England's national service specifications.

Patients report good experiences of the service and this was echoed on the day of the peer review.

It is noted there are some issues with the current staffing levels for the service, in particular admin support, physiotherapy, social work and clinical psychology.

The Trust is anticipating growth in the CF service at Frimley. Some patients are already choosing to move to Frimley from other centres.

Recommendations:

- The Trust needs to plan staffing levels to ensure individual clinicians can utilise their skills.
- The Trust should plan for growth in the current CF service.
- The Trust should begin to engage with commissioners to plan for growth over the next five years.
- The number of patients transitioning to this CF service will increase. The team should develop pathways to enable smooth transition.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	108
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		Male	Female	
FEV₁	Median FEV ₁ % pred at age 16 years split by sex	0	0	
	Number and % of patients with FEV ₁ <85% by age range and sex	16–19 years	4; 63.7% (27.37–92.1)	4; 58.99% (41.26–95.51)
		20–23 years	4; 70.06% (23.37–75.36)	13; 46.27% (26.69–99.44)
		24–27 years	7; 76.27% (21.83–113.01)	6; 46.72% (36.31–62.69)
		28–31 years	12; 67.52% (31.87–106.13)	8; 88.94% (40.31–97.44)
		32–35 years	16; 58.13% (33.12–100.1)	5; 69.4% (61.6–87.36)
		36–39 years	2; 94.96% (72.18–117.73)	3; 62.01% (75.88–87.64)
		40–44 years	4; 56.19% (36.31–66.07)	5; 69.77% (53.14–93.82)
		45–49 years	1; 70.72% (70.72)	7; 53.95% (19.71–95.43)
50+ years	5; 46.05% (33.86–52.75)	2; 33.84% (33.84)		

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=55) 28(51%) BMI ≥23;	(n=53) 18(34%) BMI ≥22
	Number of patients and % with BMI <19 split by sex	9 (16%)	12 (23%)

<i>Pseudomonas aeruginosa</i> (PA) chronic PA is 3+ isolates between two annual data sets	Number and % of patients with chronic PA infection	69 (64%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	42 (61%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	63 (91%)
	Number and % of patients on chronic macrolide without chronic PA infection	30 (77%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

There are three consultants providing 0.7WTE, 0.55WTE and 0.1WTE, giving the service a total 1.35 WTE, in keeping with national recommendations for the Cystic Fibrosis Trust's 'Standards of Care (2011)' for the current number of patients at the centre. The consultants work well as a team. They are enthusiastic and dedicated to the provision of high quality multidisciplinary care for the patients at the centre. The centre has excellent comprehensive clinical care guidelines and protocols.

Areas of good practice:

- Consultant delivered service.
- Excellent clinical care guidelines.

Areas of improvement:

- Administrative support should be enhanced to ensure clinical correspondence is provided in a timely manner.
- Potential links to the University of Surrey to support the development of academia should be encouraged.

Recommendations:

- Development of a transition pathway.
- Develop consultant support either through job planning of existing staff and/or an additional appointment within a five year plan for the centre.

Specialist nursing

There are two WTE Band 7 Senior Sister/Specialist Nurses in post. One position is relatively new having been in post for six months. This provides adequate cover presently with recommended levels being 1:50 patients. They provide an excellent service with cross cover for each other when annual leave/study leave necessitates.

Both inpatients and outpatients are reviewed by the clinical nurse specialist (CNS), but homecare and transition are limited due to the role being somewhat diluted with ward responsibilities. Non-specialist nurse roles such as sweat testing are also undertaken. There is a CNS presence for weekly MDT meetings and ward rounds.

Both CNS are members of the Cystic Fibrosis Nursing Association and attend annual national meetings. They are also members of the Wessex CF Club and attend local meetings as they occur. They have not been able to attend European CF meetings to date, but with their increased staffing, from 1.0 to 2.0 WTE CNS, feel they would now be able to consider this.

The service has benefited from an increase in CNS time and the service is regularly audited. The CNS ensures all patients have the opportunity to be seen by dividing their responsibilities into outpatient and inpatient care. The patients are easily able to contact them by telephone and have started offering a limited homecare service which they are keen to expand.

Annual reviews are offered to all patients and there is an excellent uptake on these. The CNS discuss transplant, fertility, contraception, infertility and options available at annual review.

Areas of good practice:

- Regular audit by the CNS service is carried out.
- Annual review is undertaken well, with review by the consultants at a follow-up clinic.
- The CNS is available for all outpatients and inpatients.

Areas of improvement:

- The development of a transition service would be beneficial for future patients.
- The CNS to continue to develop homecare service.

Recommendations:

- To look at the sweat test clinic being undertaken by a laboratory technician.
- To look at further withdrawal from ward managerial and ward cover responsibilities by the CNS to free up more specialist nurse time and allow service expansion.
- Plan to recruit more CNS with expansion of the clinic over the next five years.

Physiotherapy

Considering the staffing shortfall, the physiotherapy service provides a very good standard of care. The specialist Band 7 physiotherapist should be commended for proactively developing her role, particularly in the outpatient setting, and educating non-CF colleagues about the needs of the CF service, especially at weekends. Now the physiotherapy service is established, consideration needs to be given to the personal development of the Band 7 to ensure attendance at CF conference, as well as the usual attendance to the national interest group study events, and peer support sought for advice regarding developments and efficiencies as the service grows. According to the Cystic Fibrosis Trust's Standards of Care, two WTE physiotherapists are recommended for 75 patients. Despite having 117 patients recorded at review, there are currently only 1.3 WTE physiotherapists for the CF service, leaving a shortfall of at least one WTE with no specialist CF physiotherapy cover if the Band 7 is absent.

Areas of good practice:

- A fully comprehensive physiotherapy assessment is provided to clinic patients by the CF specialist Band 7 physiotherapist with the opportunity to do inhalation medication test dosing and support of exacerbating outpatients.
- An excellent protected annual review service with full evaluation of needs including an exercise test even if CF specialist Band 7 is absent – covered by the Band 6.

Areas for improvement:

- Continuity of senior physiotherapist input for the inpatients when the CF specialist Band 7 is on leave especially those with more complex presentations e.g. end stage disease, pregnancy and transition.
- Provision of supervised exercise/musculoskeletal sessions for all inpatients in addition to airway clearance needs and irrespective of the outpatient commitments of the service.

Recommendations:

- Consider an additional one WTE CF specialist Band 7 physiotherapist to ensure adequate cover for absence, skill level to manage patients with complex needs and to help develop a needs-led homecare service.

- Consider a 0.5-1 WTE Band 4 exercise practitioner role to support patients with supervised exercise and develop musculoskeletal programmes. This will prevent the programmes being down prioritised when airway clearance needs are high.
- Explore the possibility of increasing the Band 6 physiotherapist time from 0.3 to 1 WTE to support the unit as it grows in patient numbers and potentially size – this post could rotate as a CF training post or be static on the unit.

Dietetics

The service currently has one WTE Band 6 dietitian. All inpatients are seen at least twice weekly, and all outpatients are assessed at clinic appointments and annual review. The dietitian attends all multidisciplinary meetings, wards rounds and a weekly meeting with the pharmacist to discuss vitamin levels and changes to supplementation regimes.

A new home visit service is due to commence with the aim of visiting two patients per week. The dietitian liaises with the paediatric dietitian regarding transition of patients from Frimley Park Hospital and visits paediatric patients before transfer to the adult service.

A CF-related diabetes clinic is held once a month alongside the CF clinic with a consultant diabetologist and diabetes specialist nurse. The diabetes specialist nurse service is flexible and reviews inpatients as required. Continuous glucose monitoring is available and the results and treatment plan are discussed by the CF dietitian and diabetes specialist nurse.

The service has access to a nutrition nurse for gastrostomy care. The CF dietitian also covers a caseload of medical patients on the haematology ward. This can, at times, consume more CF time than the allocated three hours per week. During periods of leave cover is provided by Band 5 dietitians in the respiratory rotation. Patient feedback regarding the hospital food is generally good. Patients can choose as many dishes as they require from the menu and catering offer a very flexible service that allows patients to request additional foods from an extras list. All patient rooms have fridges and the ward kitchen is stocked with ready meals, tinned foods and snacks. Ward staff prepare food for patients in between meals or as an alternative to main meals. Friends and family members have access to the kitchen where they can prepare food. The ward also has a snack trolley which visits patients 2-3 times per day. The food in the ward kitchen and snacks are funded from the CF centre charity.

The dietitian is a member of the UK CF Dietitians' Interest Group, has visited other CF units to gain experience and attends local CF network meetings regularly. The CF dietitian regularly audits the service and is currently collecting data for a small research project.

Areas of Good practice:

- Audit and research being undertaken.
- Weekly meeting with the pharmacist to discuss vitamin levels and changes to supplementation regimes.

Areas for Improvement:

- Dietetic CF time exclusively used cover CF.
- Continue to develop links and liaise regularly with larger adult CF centres within the region for peer support and expertise.

Recommendations:

- Progression of the post to Band 7. This would bring the dietetic post in line with the banding of other therapists in the multidisciplinary team and reflect the highly specialised and extended nature of the role.
- Discontinuing the use of CF dietetic time to cover haematology patients.

Pharmacy

- The clinical pharmacy service to the CF centre at Frimley Park is provided by a rotational Band 7 pharmacist, who also covers the 45-bed respiratory ward. This post is just under 0.2 WTE for CF. The minimum recommendation for a clinic of 75 patients is 0.5 WTE; Frimley Park has 117 patients which warrants 0.75 WTE. The pharmacist should be a permanent 8a specialist pharmacist rather than a rotating Band 7 pharmacist.
- The clinical pharmacy service is provided to both inpatients and outpatients. One hour per day is allocated to seeing CF patients, one extra hour is allocated for the weekly annual review clinic. The pharmacist carries out a full medication review. The pharmacist and the dietitian then jointly decide what recommendations to make regarding vitamin supplementation. The CF pharmacist attends the weekly CF MDT meetings. After the weekly CF clinic there is another MDT meeting to discuss the clinic patients, which the CF pharmacist also attends. Cover is normally provided by one of four pharmacists who have been trained. One pharmacist is currently on maternity leave.
- The current post holder is a member of the UK CF pharmacist group. It is difficult to attend CF study days due to pharmacy staffing levels. There has been no involvement in any CF research or audits.
- There is no Medicines Management Technician (MMT) for the CF unit or the respiratory ward, which impacts greatly on the pharmacist's workload. There is a nurse-led self-administration scheme in place which follows the Trust's Medicines Management Policy.
- Calea Homecare Company provide a home IV service to patients.
- There is an on-call pharmacy service, a CF handbook is available and the CF pharmacist is happy to be contacted, as are the CF consultants.
- High-cost drugs are provided by a number of different homecare companies. The CF CNS deal with queries regarding these patients.

Areas of Good Practice:

- Patients have an annual medication review, with a report sent to consultant.
- Attendance at CF MDT meetings and post clinic MDT.
- Excellent communication with CF team, including consultants.

Areas for Improvement:

- CF pharmacist post is rotational. The quality of the service may vary according to the experience of the post holder. The CF pharmacist post should be permanent and held by an experienced pharmacist with training and experience in CF care.
- The current homecare service provision is chaotic and patients may be getting drugs from several providers. Queries are dealt with by CF CNS.

Recommendations:

- The pharmacy service is excellent due to the dedication of the current post holder, but a CF specialist pharmacist should be in place. For this clinic size, a 0.75 WTE Band 8a pharmacist is recommended, increasing to one WTE as the clinic grows in size.
- An MMT for CF (and respiratory) would help with inpatient workload and support the self administration scheme.
- The pharmacist would benefit from attending CF pharmacists study days and other CF meetings regularly.

Psychology

The service currently has a 0.2 WTE clinical psychologist which means the clinical psychology service is understaffed according to the recommended clinical psychology staffing for a service of 110 patients. The clinical psychologist is able to provide evidence based psychological therapy, to 'gate keep' for onward referrals and liaise with other agencies, to coordinate urgent psychiatric assessments, and provide consultation and training for the team. The clinical psychologist is well integrated into the team and is keen to develop the service.

Areas of good practice:

- The clinical psychologist has made links with the national psychosocial professional group and plans to attend relevant CF specific study days.
- Psychological screening is offered at annual assessment, allowing for the identification of issues which may require input by the psychologist.
- The clinical psychologist has provided advice and training for staff members regarding identifying potential risk issues and safety planning.

Areas for improvement:

- Due to shortfall in recommended staffing there is currently no clinical psychology service for inpatients.
- Due to shortfall in recommended staffing, referrals are not responded to within the timeframes outlined in the Cystic Fibrosis Trust's Standards of Care. If the shortfall in staffing is addressed, the clinical psychologist could provide input at key life stages including diagnosis, transition, end-of-life care, transplantation and family planning.

Recommendations:

- The recommended staffing level would be between 0.5–1.0 WTE for the current patient numbers. This shortfall does not, understandably, allow for all of the relevant Standards of Care to be met so additional staffing would be recommended.

Social work

- Frimley Park adult CF centre currently has 110 patients. The recommended social work staffing from the Cystic Fibrosis Trust's Standards of Care should be 0.5 WTE. Frimley Park does not employ any social workers as part of its MDT.
- In 2013, the patient satisfaction survey identified a lack of social work support with 21% of patients requesting social work input in the survey. There do not appear to be any plans to fill this role.
- Although the report submission suggests there would be a referral to social services locally if needed, social services do not routinely provide social work advice regarding housing, benefits, education, work to patients as mandated by the service specifications for CF social work. In reality, this support falls to the CNS who feel ill-equipped to provide this kind of support. There is also support provided by the psychologist who is newly in post and under the recommended staffing level. Inevitably she will also address the social needs unless there is a specialist social worker.
- There is excellent informal support for the families of people affected by CF provided through Frimley Parks' own CF charity. While this is not their key role, being able to talk to someone who understands cannot be underestimated.
- This informal provision of social support takes professionals away from the key tasks in their role and will become more challenging to sustain as the centre grows.

- A social worker would provide specialist support for patients and be part of an MDT providing an alternative to a medical model of care and keeping up to date with current social issues. This would allow the CNS to devote their time and skill to specialist nursing tasks.
- While the staff have undertaken training in regards to their responsibilities in safeguarding, there does not appear to be any particular expertise within the team regarding the needs of vulnerable adults or child protection for patients under 18.

Recommendations:

- The recommended staffing level would be between 0.5-1.0 WTE for the current patient numbers. It is recommended recruitment to this post should be made to allow the Cystic Fibrosis Trust's Standards of Care to be met and reduce the impact on other disciplines.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	3	0	4	7	4	2	0
Female	2	0	6	5	5	0	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	30	7	1	0
From the ward staff	22	7	0	0
From the hospital	21	14	2	0

Areas of excellence:

- 1 The CF MDT, and its accessibility/friendliness.
- 2 Availability of team at outpatient clinic.
- 3 Cross-infection/segregation measures – patients led straight to outpatient rooms and MDT rotate between rooms.
- 4 Cleanliness of the inpatient and outpatient facilities.

Areas for improvement:

- 1 Car parking – only five bays for CF patient free parking, by the CF unit. Difficult finding a space otherwise.
- 2 Pharmacy waiting times and outpatient clinic waiting times – fair, but could be improved.
- 3 Transition experience is variable.

6. Appendices

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

Frimley Park Hospital

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	92%
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	108 of 117 (92%) patients.
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 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	The centre has an excellent comprehensive clinical guidelines document.
	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	Green	Consultant delivered clinical service.
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Amber	91% offered appointments, 84% attended.

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 <i>Pseudomonas aeruginosa</i> (PA) in the previous 12 months	100%	Green	Green	
	% 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	59% in 24 hours, 87% in 48 hours.
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	All patients under the service for last three years offered appointment.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A	N/A	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

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%	Red (mean time =17 days)	Red	11% compliance. – Enhanced secretarial support is required to meet this target.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Amber Feedback to trainees for improvement	Amber	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	No cover at times when Band 7 physiotherapist is away.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	94% on weekdays, 61% at weekends.
	% 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	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red New appoint Jan 15	Amber	Recent appointment of 0.2 WTE clinical psychologist, but still falls below recommended staffing.
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red Local referral.	Red	No dedicated CF social worker at the centre. See social worker section for further comments.
	% availability of a social worker for inpatients	100%	Green	Red	No dedicated CF social worker at the centre. See social worker section for further comments.
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

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	Green	Not directly concerning CF service.
5.2	Number of clinical incidents reported within the past 12 months	<1%	25	25	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	N/A		

Appendix 2

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Frimley Park Hospital 112 patients
Consultant 1	0.5	1	1	0.55
Consultant 2	0.3	0.5	1	0.7
Consultant 3			0.5	0.1
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.4	0.8	1	0.2
Specialist nurse	2	3	5	2
Physiotherapist	2	4	6	1.3
Dietitian	0.5	1	2	1
Clinical psychologist	0.5	1	2	0.2
Social worker	0.5	1	2	
Pharmacist	0.5	1	1	0.2
Secretary	0.5	1	2	0.4
Database coordinator	0.4	0.8	1	1

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2013, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2013	
Demographics of centre – Frimley Park Hospital	
Number of active patients registered (active being patients within the last two years)	117
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	108
Median age in years of active patients	31
Number of deaths in reporting year	3
Median age at death in reporting year	49

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	8 (7%)
	20–23 years	17 (16%)
	24–27 years	13 (12%)
	28–31 years	20 (19%)
	32–35 years	21 (19%)
	36–39 years	5 (5%)
	40–44 years	9 (8%)
	45–49 years	8 (7%)
	50+ years	7 (7%)

Genetics	
Number of patients and % of unknown genetics	Two patients with no genotype on one allele.

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=55) 28(51%) BMI \geq 23	(n=53) 18(34%) BMI \geq 22
Number of patients and % with BMI <19 split by sex	9 (16%)	12 (23%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	8 (89%)	8 (67%)

FEV₁ (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Medium FEV1 % predicted at age 16 year split by sex		0	0
Number and medium (range) FEV1 %n predicted by age range and sex	16–19 years	4; 63.7% (27.37-92.1)	4; 58.99% (41.26-95.51)
	20–23 years	4; 70.06% (23.37-75.36)	13; 46.27% (26.69-99.44)
	24–27 years	7; 76.27% (21.83-113.01)	6; 46.72% (36.31-62.69)
	28–31 years	12; 67.52% (31.87-106.13)	8; 88.94% (40.31-97.44)
	32–35 years	16; 58.13% (33.12- 100.1)	5; 69.4% (61.6-87.36)
	36–39 years	2; 94.96% (72.18-117.73)	3; 62.01% (75.88-87.64)
	40–44 years	4; 56.19% (36.31-66.07)	5; 69.77% (53.14-93.82)
	45–49 years	1; 70.72% (70.72)	7; 53.95% (19.71-95.43)
	50+ years	7; 74.6 (33.87- 89.02)	6; 51.8 (30.38-68.49)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic <i>Pseudomonas aeruginosa</i> (PA)		
Number of patients in each age group	16–19 years	8
	20–23 years	17
	24–27 years	13
	28–31 years	20
	32–35 years	21
	36–39 years	5
	40–44 years	9
	45–49 years	8
	50+ years	7
Number of patients with chronic PA by age group	16–19 years	2
	20–23 years	11
	24–27 years	11
	28–31 years	10
	32–35 years	12
	36–39 years	3
	40–44 years	7
	45–49 years	6
	50+ years	7

<i>Burkholderia cepacia</i> (BC)	
Number and % of total cohort with chronic infection with BC complex	4 (4%)
Number and % of <i>cenocepacia</i>	2 (50%)
Meticillin-resistant <i>staphylococcus aureus</i> (MRSA)	
Number and % of total cohort with chronic infection with MRSA	4 (4%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	5 (5%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	36 (33%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	48 (44%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	11 (10%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (1%) with PH 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantation assessment in reporting year	2
Number of patients referred for transplantation assessment in previous three years	2
Number of patients receiving lung, liver, kidney transplants in previous three years	1

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	55
	20–23 years	306
	24–27 years	91
	28–31 years	116
	32–35 years	34
	36–39 years	6
	40–44 years	46
	45–49 years	200
	50+ years	134
Number of days of home IV therapy in reporting year split by age group	16–19 years	137
	20–23 years	691
	24–27 years	98
	28–31 years	116
	32–35 years	266
	36–39 years	42
	40–44 years	281
	45–49 years	149
	50+ years	381
Total number of IV days split by age group	16–19 years	192
	20–23 years	997
	24–27 years	448
	28–31 years	556
	32–35 years	300
	36–39 years	48
	40–44 years	327
	45–49 years	349
	50+ years	515

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV ₁ , % predicted <85% (ie below normal) on DNase	(n=82) >16 years with FEV ₁ <85% 61(74%)
If not on DNase, % on hypertonic saline	5 (6%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	69 (64%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	42 (61%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	63 (91%) with chronic PA 30 (77%) without chronic PA

Appendix 4

Patient survey

Frimley Park Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	3	0	4	7	4	2	0
Female	2	0	6	5	5	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	28	7	3	0
Communication	22	12	3	0
Out-of-hours access	13	12	3	0
Homecare/community support	4	4	2	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	23	14	1	0
Waiting times	14	12	8	0
Cross-infection/segregation	29	9	0	0
Cleanliness	29	9	0	0
Annual review process	22	12	0	1
Transition	5	4	1	2

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	14	5	0	0
Cleanliness	21	1	0	0
Cross-infection/segregation	19	3	0	0
Food	7	11	4	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	12	9	0	1
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	6	11	1	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	16	5	1	1
Availability of equipment	18	9	0	0
Car parking	11	9	8	8

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	30	7	1	0
Of the ward staff	22	7	0	0
Of the hospital	21	14	2	0

Comments about CF team/hospital

Lengthy attached response in written letter

“The CF team at Frimley is excellent. Nothing is too much trouble. If you need any help or advice, they are only a phone call away and if they don’t know the answer, they always find someone who does and they always ring back.”

“More segregation required for difficult bugs.”

“Physiotherapy – not enough time allowance. Weekday and weekend car parking. No access to the CF unit through main hospital – awful when the weather is bad. Car park too far away. There are designated disabled car spaces outside the CF unit for 3 CF patients, but if they are taken up (always!), you need to drive out of the hospital, join the long car parking queue and walk right around the unit. Why can’t there be access through the hospital building to the unit?”

“I really appreciate all the support from the CF team. All members of staff are caring and genuinely interested in caring for people with CF.”

“I feel so happy with the care provided by Frimley CF Unit. Everyone is so friendly; it feels like a second family and this does make a difference to how I feel about my CF/health and wellbeing. I would like to know what is done at the unit regarding infection control/segregation – for example, how do I know someone has cleaned the room after the last patient? Do they hold separate clinics for patients with certain bacteria? Making this clearer/more obvious would be very reassuring.”

“I have recently transferred from another hospital and really prefer the Frimley Park CF unit. The staff are so friendly and always have time to talk to you.”

“No comments.”

“I have other medical conditions in addition to CF. The team provide a holistic service which also covers these conditions.”

“My only observation of the annual review would be it would be better if everything was on one day. I don't like having to take two trips when the second is just to see a consultant. Other than that, the CF unit is excellent!”

“What would we do without Judith?!”

“Been under Frimley for nearly a year. Overall experience has been good; very accommodating and staff are helpful and friendly.”

“Fantastic hospital and CF unit. Staff very supportive and excellent cleanliness. Only negative – annual reviews need improving!”

“Are two toilets for all the outpatient CF attendees enough, bearing in mind cross-infection?”

“Recently transitioned and felt very welcome at Frimley. The team all knew my name and who I was. Look forward to experiencing annual review in February.”

“Not spent time on the ward so cannot comment.”

“Excellent team. Only issue is the consultant's lateness for routine appointments, especially when you work full-time and try to schedule during lunch hour.”

“Since moving to Frimley Park Hospital, I have really felt comfortable with the staff and they have helped me get over a lot of obstacles related to my CF. They have changed my outlook on CF so I'd like to thank them.”

Appendix 5

Patient/parent interviews

Patient A felt segregation measures at Frimley Park outpatient clinic are very good, doors closed and patients led straight into consultancy rooms where they stay for the rest of clinic. Patient A felt there is good use of hand gels and wiping down equipment between patients. She explained decisions on changes to her treatments are made with her views taken into full consideration – ‘negotiated decisions’, adding, “I know the consultants and they ask me ‘what do you think?’” Patient A sees all of the MDT she needs to at the clinic. She hasn’t needed to see the clinical psychologist but knows there is one available, if needed. Patient A felt it can be a long wait at pharmacy for take-home prescribed medications, although half an hour on average.

Inpatient care (ward): Patient A described the staff nurses as ‘excellent’ and the food on the ward as ‘very, very good – the look and taste of the food’. She felt catering had improved when the military started being treated at the hospital.

Patient A described twice daily physiotherapy Monday to Friday, and twice at the weekend if needed.

Annual review: Patient A is offered annual review each year and has had this year’s annual review. She explained all assessments take place at Frimley Park except the bone mineral density (DEXA) scan, carried out at Aldershot Medical Centre.

She sees all of the MDT at annual review and the outcome is reported back by letter ‘with all information’, as well as being called back to an appointment to have all points verified by the doctor at CF clinic.

Patient A was happy with the communication from her CF team. She contacts the CF centre manager/answerphone or telephones the nurses’ station on the ward, if urgent. She explained they help or refer queries to a doctor who then calls her back.

Homecare: CNS would telephone Patient A to see if all is ok after (home, pre-mixed) IVs, but patient has since undergone lung transplant, no longer requiring homecare.

Areas of good practice:

- “Always someone to answer your questions.”
- “Seen to at short notice.”
- “Very friendly staff who know you as an individual.”

Areas for improvement:

- “Hospital took ward’s washing machine and tumble drier away” – Patient A appreciates it is not the CF team’s fault, but would like the machines reinstated for patient use again.

Patient B explained “recently individual consultancy rooms have been put in place which works well.” She described good use of hand gels and wiping down equipment between patients, adding there had been a reminder in the centre newsletter. Patient B sees all the MDT at clinic and can access psychosocial support if needed. She felt the CF team make joint decisions on treatments, taking into account her views and needs, adding: “they try hard to put me on suitable drugs and accommodate me really well.”

Inpatient care (ward): Patient B felt it was easy to get admitted to the ward same day. She described the ward staff nurses as ‘brilliant’, including their timing of medications. She explained she has not needed physiotherapy whilst being on the ward. She described the ward food as ‘not very good’, adding that snacks are provided, but explained that meals came from the central kitchen and described them as ‘soggy (vegetables) and bland taste.” In terms of exercise on the ward, Patient B referred to the exercise bike being available.

Annual review: Patient B has had annual review this year and is offered one each year. She explained outcomes are communicated by letter/written report and verbally at next clinic. She sees all of the MDT necessary at annual review, adding all assessments apart from DEXA scan take place at Frimley Park – her DEXA scan at Aldershot.

Homecare: No homecare is required by Patient B. In the past she had pre-mixed IVs, encountering a one-off error in quantity provided by the homecare company earlier in the year.

Areas of good practice:

- “Very friendly, professional team.”
- “They listen to me and my complicated life and are accommodating.”
- “They’re always there and bend over backwards to fit me in.”

Area for improvement:

- No suggestions made.

Patient C feels that segregation measures at outpatient clinic at Frimley Park are very good. He sees all of the MDT, including access to psychosocial support. He felt decisions made regarding his treatments are made with his full view/consideration taken into account – ie not dictated to. He added that, “there is good use of hand gels and wiping down of equipment at clinic, between patients.” Patient C explained waiting times at hospital pharmacy can be “quite bad”, so he tends to take his prescription to his GP.

Inpatient care (ward): Not applicable.

Annual review: Patient C is offered annual review each year and has his annual review for this year. He explained all assessments take place at Frimley Park, apart from his Liver CT scan and DEXA scan. The outcome of his annual review is provided at his next (follow-up) appointment three weeks later, and a note in writing is provided if there are any other concerns.

Homecare: According to this patient, no homecare is required. However, he added communication is very good from the CF team, usually by phone, and his point of contact, the CNS is very good.

Good practice:

- “Difficult to specify three good points as everything is good, I’d say.”
- “A very dedicated, caring CF team – can’t fault them.”
- “CNS is absolutely amazing.”

Areas for improvement:

- “Pharmacy waiting time.”
- “Illogical routes to other parts of the hospital, which are not easy to find.”
- “Only three CF parking bays, right opposite the CF Centre; everyone uses them though. CF patients have to park elsewhere or in disabled bays as a result, so it can take 40 minutes to find a parking space.”

Patient D feels outpatient segregation at Frimley Park is good, adding that he is directed straight into an outpatient clinic consultancy room, where he stays for the duration of clinic; the CF team rotate between rooms. Patient D firmly believes the CF team consult him before making any changes to his treatments. He is also happy that the clinic team use hand gels and wipe down equipment between seeing patients every time. He sees all of the CF MDT apart from the psychologist or social worker, though he knows they are available, if needed. Patient D has no problems with hospital pharmacy arrangements, although he added that the CNS often collects his Promixin and Tobramycin prescription, as a sort of ‘fast-track’ method of collection.

Annual review: Patient D is offered annual review each and he has already had his annual review for this year. He has all assessments at Frimley Park, apart from DEXA scan and liver ultrasound. He receives a detailed letter covering the outcome of his annual review, which are also discussed in clinic and six weeks later with the consultant, with a plan for going forward. Patient D feels communication from his CF team is very good – “you can ring them 24/7, for example two weeks ago I thought I had a chest infection, so they offered to get me in within 48 hours.”

Homecare: Patient D hasn’t needed homecare since home IVs in 2010 and he has had no problems since. He used to have BUPA for home deliveries, but uses Calea Homecare Company now.

Good practice:

- “Can’t fault the place. I wish I’d moved from the Brompton sooner.”

Areas for improvement:

- “Portions of ward inpatient food could be larger.”

Patient E feels segregation at the outpatient clinic is really good, adding they are directed straight into a consultancy room and all assessment takes place in the same room. She added that the CF team tell her what is best for her, but they take into account her comments/viewpoints in the decision-making process on changes to treatments. Patient E explained she sees the whole MDT most of the time, although the physiotherapist is occasionally on a day off. Patient E described her experience of hospital pharmacy as “very good on the whole.”

Inpatient care (ward): Not applicable.

Annual review: Patient E is offered annual review each year and has had annual review recently. She sees all of the MDT at annual review and all her assessments take place at Frimley Park, apart from DEXA scan and liver ultrasound, which are performed at Aldershot and Feet respectively.

Homecare: This patient does not require homecare – ie no home IVs and or supplementary feeds.

She added the CF team’s communication system is good, explaining, “It’s pretty easy to get through by phone.”

Good practice:

- “Staff are really good, always really friendly and they’ve got time to chat to you.”
- “A lot smaller than the Brompton Hospital, so I see the same staff all of the time.” – transitioned a year ago.

Area to improve:

- “I can’t think of anything.”

Patient F transitioned to Frimley Park one year ago. She describes segregation measures there as ‘a lot different to paediatrics, but a pretty good standard’, adding “I never see another person with CF; we go into our own rooms and the MDT come to us individually.” Patient F described staff as always using hand gels and wiping down equipment, or wrapping it in cling film if not easy to clean between patients’ use. She felt that the CF really take into account her point of view when making decisions about her treatments, always consulting her. Patient F gets her take-home medications delivered to her home or to her local pharmacy.

Inpatient care (ward): Not applicable to this patient.

Annual review: Patient F is offered annual review each year, although has not had annual review yet for this year as she’s recently transitioned. She explained the CF team have explained what she should expect at annual review and she felt it seemed very well organised.

Homecare: All set up with the drug company, pre-packed. Patient F does not have home visits. Her port flushes are conducted at Frimley Park outpatient clinic.

Good practice:

- “Facilities are brilliant.”
- “Prefer that it’s a small centre, with a lung function machine in every room.”
- “Staff are all personable and know me and my background. They put me at ease during transition.”

Areas to improve:

- “Organisation of home IVs needs to be up to speed – getting a prescription for a home-delivered IV was difficult and needed a few phone calls from me at the time – a breakdown in communication between home delivery company and CF team I think – Alcura Healthcare is brilliant, on the ball.”

Patient G felt segregation measures at Frimley Park outpatient clinic were much better since the recent change at clinic, so that now no patients are in contact with one another. She added that there is good evidence of use of hand gels and wiping down of equipment between patients, explaining “it happens all the time’. Patient G sees or has access to all of the CF MDT including psychosocial if need be, at clinic and she is happy that the team try to accommodate her wishes when making decisions about changes in treatments. She does not experience hospital pharmacy much, since it is quite a slow process and so she gets her repeat prescriptions prescribed locally.

Inpatient care (ward): Not applicable.

Annual Review: Annual review is offered to Patient G every year and she had her annual review in the autumn this year. She explained the CF MDT all come to see her at annual review appointment, which she says “runs quite smoothly, quite quickly and is much improved.” Her annual review assessments take place at Frimley Park, with the exception of DEXA scan and liver CT scan, conducted at Aldershot and Fleet respectively. Patient G explained she has an outpatient appointment with the consultant six weeks after annual review where the consultant goes over the annual review outcome in detail, which the patient likes. Patient G has contacted her CF team twice in the last 12 months. She explained any query is responded to within 24 hours by the relevant member of the CF team.

Homecare: Patient G has all pre-mixed, home IVs delivered to home by Calea Homecare Company. She described their service as “absolutely brilliant”.

Good practice:

- “The adult service is more tailored to me and my life style. They understand the need for me to get on with my normal life.”

- “Everything is on site – equipment, scanning machines for CF-related assessment.”
- “We’re always able to get what’s needed – ie nebulisers, compressors, pre-mixed IVs; no limitation by funding.”

Areas to improve:

- None recommended.

Patient interviews on peer review day

Patient A

Patient A is a 24-year-old female who lives half an hour away from the hospital, in Surrey. She transferred to this service in late 2014 from a CF service in central London as she felt that waiting times for admission were getting far too long. On this occasion she has been in hospital for five and a half weeks.

Patient A couldn’t praise the service enough. She is a strong advocate for the service at Frimley Park and feels that the unit needs to be expanded as word is getting round about what fantastic care is provided by the CF team.

Areas of excellence:

- Always seen by the same members of the MDT resulting in a much more personable service than she has experienced previously. The nursing staff in particular are very friendly and approachable.
- Car parking hasn’t been a problem so far.
- The food is good and snacks are always available from the snack trolley (funded by the CF services’ charity).
- The team is always very accessible.

Areas for improvement:

- Whilst patient A understands the importance of segregation, she feels that the areas used in other wards for infection isolation is particularly lonely.

Patient B

Patient B is a 52-year-old male. He was diagnosed with CF at 37 and has since been a patient at Frimley Park. On this occasion he has been in hospital for one week. He lives 45 miles from the hospital.

Areas of excellence:

- Patient B considers the service and quality of care he receives to be superb.
- The staff are fantastic and nothing is ever too much trouble.
- Patient B appreciates the free snack trolley.
- Time for admission is within 24 hours.

Areas for improvement:

- The food is adequate although there is reasonable choice.
- Patient B feels that there should be more rooms. He was once admitted to the isolation area (he wasn’t growing any bugs at the time of admission) on ward G1 as there were no beds available on the CF unit. He didn’t enjoy this particular stay as he felt very lonely.

Patient C

Patient C is a 22-year-old female who lives in Frimley. She transitioned to this service aged 17 from the Frimley children's centre. She spoke very highly of the service and care she receives from all of the MDT. Patient C has in the past been offered psycho-social support but as yet not felt the need for it but appreciated the availability of it.

Areas of excellence:

- The CF team always provides a personal touch. She feels that she has an excellent relationship with those who provide her care and that she can be honest and open with them.
- Admission time is always very good – usually admitted within 24 hours.
- Patient C also appreciates the free snack trolley.

Areas for improvement:

- The food is poor – Patient C prefers to bring in her own food or order takeaways when she is in hospital.
- Car parking is poor – often struggles to get a parking space within the designated CF spaces.

Patient D

Patient D is a 51-year-old female living in West Sussex, and has been coming to Frimley Park since 1985. Patient D has never stayed in the hospital and only attends as an outpatient – she administers her own IV antibiotics at home. She unfortunately lost her twin sister to CF at the age of 49. Her sister had been a regular user of the inpatient unit at Frimley Park.

Areas of excellence

- Patient D said that she never feels rushed at her outpatient appointments.
- Her sister was always admitted on the same day.
- The MDT has handled her extremely sensitively since the passing of her twin and she has found the psychological input she has received recently very useful.

Areas of improvement

- Patient D feels that the unit could do with more than one 'zed bed' for relatives to be able to stay over.
- Sometimes finds it difficult to get through to nursing staff when phoning.
- Patient D found that expert CF care for her sister was reduced over a weekend and they weren't always receiving the best advice if general nursing staff were covering the CF ward which caused the family to feel anxious.
- Car parking is often problematic.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Frimley Park
	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	No waiting room
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	One male One female One disabled
Where do height and weight measurements take place? Is this appropriate?		In outpatient treatment rooms.
Where are the lung function tests done for each visit?		In outpatient treatment rooms.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Internet access, TV in room.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Seen in joint CF/Diabetic clinic 3rd Monday of month on CF unit.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	New transition leaflet being written. Have a welcome pack.

Environmental walkthrough: ward

Ward name:

Microbiology status:

		Hospital name	Frimley Park
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Overflow on side room on G1/G4.
Number of side rooms?		5	
Do the en suites have:	Toilets?	Yes	Baths and overhead showers.
	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	Lockable cupboards in rooms.
Can you use mobiles?		Yes	Land line in room too – paid for by CF service charity.
If there is a television, is the service free?		Yes	Free service.
If no, are there any concessions for CF patients?			The CF service charity pay for the TV service – patients on other wards pay for TV and then claim the money back from the charity.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	One Z bed.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Opening visiting hours but patients are encouraged to rest.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Fridge in all rooms. Spare fridge available to take to other areas. Microwave in kitchen.
What facilities are provided for teenagers?			Wii/TV with freeview, Internet access, DVD player and DVDs, Playstations.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Exercise bikes, gym balls, free weights and access to physiotherapy gym.
What facilities are there to help with school and further studies?		Internet access, laptops
Is there a relatives' room?	No	Use of treatment room if required.
What internet access is there?		Free broadband.
What facilities are there to enable students to continue to work and study?		Able to go out for periods of time to attend college. Internet access, laptops.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Bowls and washing up liquid provided. Patients asked to sterilise at home if possible.
What facilities are provided for those with MRSA?		Isolation rooms – in/out patients. Separate/end of clinics.
What facilities are provided for those with <i>B. cepacia</i> ?		Clinics on separate days. Inpatients on isolation ward in side room.
What facilities are provided for those with other complex microbiology?		Isolation rooms. End of clinic/epidemic clinics.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	Call and arrange with CFSN. Cepacia patients can visit but are not allowed to tour the unit.

	Hospital name	Frimley Park
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Five spaces for CF patients/families. Car park ticket stamped so no payment if parking is used in front main car park.
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?		Use private X-ray dept. and patients sent individually. Bone scans carried out at Aldershot – not given appointments at same time.
Do patients have to wait at pharmacy for prescriptions?		At clinic taken to pharmacy by care assistants, relatives or pharmacist. If patients take them they tend to leave them – go back and collect either from pharmacy or CFU.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/feedback boxes?	Yes	

Appendix 7

Panel members

Dr Andrew Jones*	Consultant	University Hospital, South Manchester
Elaine Bowman	Pharmacist	Royal Brompton Hospital
Nicola Reid	CF Specialist Psychologist	University Hospital, South Manchester
Fiona King	CF Clinical Nurse Specialist	Birmingham Heartlands Hospital
Jo Barrett	CF Specialist Dietitian	Birmingham Heartlands Hospital
Helen Parrott	CF Specialist Physiotherapist	Royal Brompton Hospital
Penny Martin	Social Worker	Papworth Hospital
Fiona Mackison	Commissioning	NHS England
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

*Clinical lead

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