In partnership with

Cystic Fibrosis why we're here

British Thoracic Society

BIPRS

Peer review report

Aberdeen Royal Infirmary
Adult Cystic Fibrosis Centre
9 May 2014

1. Executive summary

1.1 Overview of the service

The Aberdeen cystic fibrosis (CF) team is well established, enthusiastic and patient-centred, with excellent feedback from service users. The multidisciplinary team (MDT) is experienced and, on the whole, well-staffed. The service covers a large geographical area, managed through outreach clinics in addition to home visits from the MDT. At the time of the peer review, 67 adults attended the Aberdeen CF centre. There is a need for succession planning within the MDT as several senior members are due to retire. There is also growth predicted within the patient population, requiring careful consideration as to how the team will adapt to meet this expansion.

1.2 Good practice examples

1. The CF team offers excellent MDT care, as indicated by highly positive patient feedback.
2. This is a consultant-delivered service, with same-day response for urgent visits and ability to admit to the ward the same day.
3. The team is able to deliver multidisciplinary homecare.

1.3 Key recommendations

1. Succession planning of the cystic fibrosis posts is crucial to the continuation of the service. The dietitian due to retire has a strong interest in CF-related diabetes. This role will need to be supported by the diabetes service and others within the CF team until a replacement with an interest in diabetes can be found. The new dietitian will need to spend time training in a large centre to develop skills in CF-related diabetes. Similarly, the current microbiologist who is due to retire carries out CF synergy testing for all CF centres within Scotland. While it would be difficult to recruit a specialist CF social worker, a member of the current social work team could be paid to deliver a weekly session.
2. There should be cross-cover for the CF specialist physiotherapist.
3. The CF team is encouraged to continue the ward staff training programme.
4. The CF team requires access to negative pressure rooms to facilitate care of patients with *B. cepacia*/*M. abscessus*.

1.4 Areas for further consideration

1. As the CF centre grows, consideration needs to be given to increasing CF specialist pharmacist time, to support inpatient care and to develop policies for self-medication.
2. Ideally, patients should have access to homecare delivery.
3. Greater use of physiotherapy assistants would release CF specialist physiotherapy time for complex care. In order to develop social work support and CF expertise, a named social worker should have fixed sessions in cystic fibrosis care.

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

2.1 Models of care

Summary

The Aberdeen MDT meets the Cystic Fibrosis Trust's Standards of Care requirements for models of care. In addition to on-site facilities, members of the CF team attend outreach clinics, reflecting the large geographical region served by the centre.

2.2 Multidisciplinary care

Summary

All members of the team attend clinic and patients are therefore able to access full multidisciplinary care. Currently there is no social worker (SW), but the team could approach the SW department to commission sessions from a designated SW, who would require training from the team and wider cystic fibrosis community. Several key members of the team are approaching retirement, eg specialist dietitian and CF microbiologist, requiring the Hospital Trust to support succession planning.

2.3 Principles of care

Summary

Good overall performance.

2.4 Delivery of care

Summary

The team is able to complete annual reviews, clinics and inpatient work according to the Cystic Fibrosis Trust's Standards of Care.

2.5 Commissioning

Summary

Areas of good practice

- Excellent relationships between commissioners and the Hospital Trust focused on the long-term sustainability of the service.
- Coordinated, generally well-staffed and functioning team with good 'light touch' relationship with Hospital Trust management.
- Effective communication across the organisation.

Areas for improvement

- Ensure that the physical environment is fully utilised to provide resources to support patient care, eg the availability of negative pressure rooms for some inpatients.

Recommendations

- The Hospital Trust needs to look at succession planning for staff approaching retirement to ensure that the excellent skill base within the team is maintained.
- It may be helpful for the Hospital Trust to look at utilising video conferencing and similar technology for patients who are unable or unwilling to travel to the centre.
- There is an expectation that the service will need to grow significantly over the next few years to reflect the general growth in the CF population of Aberdeen, and the service needs to be prepared for this.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set. Note: This data is 2012 data.	59

			Male	Female
	Median FEV_1% pred at age 16 years split by sex		53.8 yrs	59.3 yrs
FEV_1	Number and median (range) FEV_1% predicted by age range and sex	16–19 years	(2) 39.83% (37.36–42.29)	(6) 79.47% (30.13–100.61)
		20–23 years	(6) 62.55% (18.59–102.59)	(2) 52.93% (not done–52.93)
		24–27 years	(6) 42.34% (32.92–70.63)	(3) 70.05% (30.2–79.9)
		28–31 years	(3) 66.83% (52.08–66.83)	(6) 66.63% (22.61–93.92)
		32–35 years	(4) 78.83% (48.08–92.35)	(5) 57.79% (33.32–72.66)
		36–39 years	(3) 72.15% (39.03–105.26)	(2) 57.95% (55.67–60.23)
		40–44 years	(4) 79.88% (13.57–109.56)	(1) 81.61%
		45–49 years	(3) 80.19% 61.02–99.36)	0
		50+ years	0	(3) 47.85% (25.27–70.43)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	10 (17%)	12 (20%)
	Number of patients and % with BMI <19 split by sex	4 (7%)	4 (7%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	29 (49%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	23 (79%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	19 (32%)
	Number and % of patients on chronic macrolide without chronic PA infection	10 (17%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- The Aberdeen CF team is well staffed with consultants (1.0 whole time equivalent (WTE) for 67 patients) and comprises three colleagues, led by Graham Devereux. Colleagues rotate CF inpatient cover weekly. Out-of-hours cover is provided by the respiratory on-call physician, who liaises with the CF consultants as required. Patients phone the ward directly to come in out of hours. Ad hoc patients are seen and, if needed, can be admitted to the ward on the same day within two to four hours. Graham Devereux previously trained in cystic fibrosis at Nottingham and Newcastle. Owen Dempsey and Prasima Srivastava have both trained in Aberdeen, working within the CF service prior to appointment.

- There is ample cross-cover for leave.

- The service is consultant-delivered, with junior doctors attending clinics for training purposes.

- Consultants see CF patients daily on the ward and provide informal cover at weekends. Patients can see the on-call respiratory consultant at weekends if necessary.

- The new ward has telemedicine facilities to facilitate Scottish consultant meetings. Members of the team also attend the Scottish CF Day (an MDT day focusing on clinical topics within cystic fibrosis). Members of the consultant team last attended the European Cystic Fibrosis Conference (ECFS) in 2012. All consultants have extensive commitments in addition to cystic fibrosis.

- The consultants attend peripheral clinics to see both general respiratory and CF patients.

- Patient numbers have risen between 2011 and 2015 (from 45 to 72) and as the CF population of Aberdeen continues to expand, the service is predicted to grow further. The paediatric unit is small (20 to 30 patients) and Inverness paediatric patients do share care with Aberdeen paediatrics, before being transitioned to Edinburgh. If any of these patients went to Aberdeen, this would enhance the growth of the centre.

As the centre grows, one consultant may need to provide further time for CF care, which would prove challenging in light of their existing commitments.

Areas of good practice

- Consultant-delivered, flexible service, with same-day response for adhoc visits and ability to admit to the ward the same day.
- *M. abscessus* treatment and patient isolation are in line with new guidelines.
- There is an active research programme within the CF centre, led by Professor Devereux.

Areas for improvement/recommendations

- Attendance at international CF conferences for all consultants.
- Home-delivered IV therapy (an issue across Scotland).
- Consideration of how to handle the workload as the unit expands.
- Need to replace retiring microbiologist with another colleague interested in CF microbiology.

4.2 Specialist nursing

Areas of good practice

There are two clinical nurse specialists (CNS) providing 1.5 WTE hours and a ward-based Band 6 nurse (1.0 WTE). The nursing team provides personalised care to support 67 patients and is meeting standards well. The nurses have a wealth of experience in cystic fibrosis – one CNS has 21 years' experience and has been in post since the instigation of the Aberdeen service in 1993. She has a Masters in Palliative Care and is a non-medical prescriber. The other CNS has eight years' experience and is currently completing further education, including clinical history note taking and examination.

Being situated on the same site as the paediatric service enables good liaison between teams. Patients are spread across Grampian and to the Shetland Isles. Home visits using a hospital car can be offered to those up to 1.5 hours away. For patients on the Shetland Isles they have forged links with local provision there for lung function and are considering tools such as video conferencing to enhance future communication. Meanwhile, charitable funds support patients travelling long distances.

The CNS are members of the Cystic Fibrosis Nurses Association, and one is secretary to the group. They regularly attend Scottish network meetings and national and international conferences. They audit regularly, including six-monthly reports to their commissioners, and participate in local research projects.

The CNS team communicates well and is a passionate, supportive and dedicated team, with an open environment for discussion. A dedicated ward nurse liaises between team and ward, and manages any issues that occur through regular reviews with the ward sister. Admissions to a new ward with excellent facilities are arranged with little waiting time. The CNS provide informal support to the ward out of hours.

Areas for improvement

The inpatient ward is still relatively new; it moved from the old department in 2012. Patients have noted some gaps in the ward nurses' knowledge in wider cystic fibrosis issues. The CNS team organises educational sessions for ward staff, utilising the whole MDT.

The current provision of home IV antibiotic therapy is supplied by the hospital pharmacy. It may be beneficial for some patients to use a homecare IV provider. However, there are issues applying to all the Scottish centres, eg geographical constraints that limit this provision county-wide.

The hospital diabetes CNS team appears to be quite busy. Currently the CF dietitian has the expertise to provide support and advice to patients with CF-related diabetes. However, the imminent retirement of this dietitian will impact on this care.

Currently patients with *B. cepacia* or *M. abscessus* are treated on the same ward as other CF patients. The nurses are therefore split into separate teams to prevent cross-infection, which is aided by the ward layout. The review felt this provision was adequate for preventing cross-infection. The CNS team also works with the ward team to educate on infection control issues.

Recommendations

- Continue the formal half-day training sessions for the ward nurses.
- Look into the feasibility and availability of home IV delivery in the region for certain groups of patients, eg palliative care.
- Continue to forge links with the diabetologists. One nurse may explore diabetes as their specialist area. The existing diabetes CNS team will need to plan to provide their expertise for CF patients, with the dietitian's retirement imminent.
- Recommend that the CF team is also given the option of utilising the negative pressure isolation rooms for patient safety with particular organisms, eg *B. cepacia* or *M. abscessus*.

4.3 Physiotherapy

The existing 1.0 WTE Band 7 manages the CF and home oxygen service (HOS) (0.75 CF and 0.25 HOS) as well as providing a service for other chronic lung disease patients. The Band 7 is supported at present by a Band 6 WTE (HOS), and there is a vacancy of 0.5 WTE within CF funding (Band 6/7). This post should be filled and an additional 0.75 WTE funded to achieve the recommended staffing levels of 2.0 WTE for 75 patients. In addition, the HOS funds 20 hours Band 3 Health Care support worker, and 20 hours Band 2 administration managed by the existing Band 7.

Although the Band 6 post is on a year's rotation, the staff who come to the CF team are always experienced Band 6s and have completed previous general respiratory rotations. The team feels this is advantageous in that it exposes more staff to working with patients with cystic fibrosis, which means, outside of normal working hours, patients are more likely to be seen by a physiotherapist with knowledge of cystic fibrosis.

There are a high number of vacancies in the respiratory physiotherapy service Trust-wide, which is due to a number of factors. Active recruitment is taking place, although not for the CF 0.5 post as the current post holder is on a month-to-month secondment, awaiting a decision regarding recruitment to her seconded post.

Staff at Band 8a and above within the physiotherapy team have left and not been replaced, which has increased the management responsibility for Band 7 staff.

Areas of good practice

- The staff are active members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF).
- They have adapted the standardised ACPCF annual review and offer all patients exercise testing as part of this.
- At present they are able to see patients as inpatients, outpatients or during home visits.

Areas for improvement

- The existing staff have identified the need to include more structured postural screening into the annual review process.
- There is no cover available for the CF team from other teams at times of annual, sick or study leave.
- Succession planning needs to be given attention, which is difficult within the present structure in light of the difficulties in local recruitment.

Recommendations

- Staffing levels should be brought in line with the recommended levels of 2.0 WTE.
- Consideration should be given to the skill mix within the team, eg move the current Band 7 up to a Band 8a and recruit a physiotherapy assistant to free up the time of qualified staff for more specialised interventions.
- The physiotherapy exercise provision would benefit from access to a selection of portable exercise equipment so that patients can exercise in their rooms and out of hours when the hospital gym is not available.

4.4 Dietetics

The current staffing level of 0.6 WTE Band 7 meets the Cystic Fibrosis Trust's Standards of Care. The dietitian currently in post has 19 years' experience of cystic fibrosis, in both adult and paediatric care (paediatric until May 2013). They are a member of the UK Dietitians Cystic Fibrosis Interest Group and a founder member of the Scottish Dietitians CF Group, regularly leading on regional research and audit projects. The current post holder is due to retire in October 2014.

All inpatients receive regular dietetic review, as do outpatients at the weekly outpatient clinic. All patients who attend for annual review are seen by the dietitian and discussed with the team at a monthly annual review meeting. The dietitian attends the transition clinics along with the rest of the team. Home visits are carried out for patients who require them.

The dietitian leads the service on vitamin supplementation, diabetes and continuous glucose monitoring, alongside the diabetes and cystic fibrosis nursing service. However, support from the diabetes nursing service is currently limited due to this service being short staffed. The dietitian is able to advise patients on adjustments to insulin doses thanks to a local protocol in place and the current post holder's previous experience in diabetes. The service is well supported by a diabetologist who is available to see patients as required and conducts a joint diabetic clinic six times per year.

Cover during periods of annual leave is provided for inpatients only by the respiratory dietitian, and this is a reciprocal arrangement.

The service has a supportive catering department and patients can use the staff canteen. Snacks such as sandwiches and cheese and crackers are available between meals, and patients can order a cooked breakfast. Cereal and toast is available at any time of day from the ward kitchen. Fridges are available for patient rooms. The service has additional funds available to buy extra snack items for patients or meals at a local cafe.

Areas of good practice

- Highly experienced dietitian with previous experience in diabetes and paediatrics.
- Home visit service as required.
- Up-to-date, continued professional development and involvement in regional research and audit projects.

Areas for improvement

- Recruitment of a replacement to the post to allow overlap and sufficient time for training and handover before the current post holder retires in October 2014.
- Improving the availability of hot snacks from the catering department, particularly during the evening.

Recommendations

It is essential for the service that a replacement is recruited several months before the current post holder retires, to allow sufficient handover and training to take place. As the role is highly specialised, the post should remain at Band 7 grade. The team may need to increase the input they provide to CF-related diabetes until the new post holder is fully trained and has some experience in the role.

4.5 Pharmacy

- Pharmacist attends all MDT meetings and annual reviews, and provides a daily review of inpatients.
- Member of CF Pharmacists Group and attends annual regional and national meetings when able. Also planning to attend ECFS conference this year.
- Pharmacist conducted an audit on Tobramycin dosing and serum concentrations to ensure best practice was being followed.
- Planning to investigate the feasibility of ready-made home IV antibiotics and once-daily Tobramycin in collaboration with paediatric pharmacist.
- Pharmacy technician (two days per week) supports the pharmacist by carrying out routine tasks on ward.
- Self-administration policy in development for health board.
- Report on staffing WTE – actual and expected:
    - Current resource = 0.2 WTE
    - Current number of patients = 67
    - Projected growth for next year = 72–75
    - Recommended resource in Cystic Fibrosis Trust's Standards of Care = 0.5 WTE pharmacists for 75 patients
- Shortfalls:
    - WTE resource should be increased to 0.5 to meet the current and projected demands of the service.

Areas of excellence/good practice

- Non-medical prescribing utilised both in clinic and ward.
- Antibiotic guidelines approved.
- Inpatients reviewed daily, including during leave.

Areas of improvement

- Currently unable to attend ward rounds.
- Lack of time for development such as research, audit and guidelines.

Recommendations

- Funding for increased resource is required.
- This would allow the development and updating of guidelines, further research and audit, which in turn would improve quality of care and also allow the pharmacist to attend ward rounds.

4.6 Psychology

Until March 2014, the Aberdeen adult CF psychology service was in a state of flux. Historically they have had 0.2 WTE clinical psychology sessions provided to the team, but since 2010 when the post holder left, they had been unable to recruit into the post. As a short-term measure, the team had a locum psychologist work 0.1 WTE in the team.

Due to the scarcity of psychology services and the gaps within provision, there is no psychology service framework, procedures or audits to evaluate. From the team's report, it sounds as if, in spite of minimal psychology input, the previous psychologist still managed to meet the peer review criteria in terms of offering individual therapy and support to patients, and was able to attend inpatient and outpatient discussions. Due to time constraints, there was no psychology input at annual reviews and minimal training and service development work.

Going forward, the team has funding for 0.3 WTE psychology sessions. At the time of review, the post holder had only just started working in the service. The volume of psychology time is 0.2 WTE below that advised by the Cystic Fibrosis Trust's Standards of Care for a service of this type, but it is too early to evaluate the impact that this will have on the service provided. The psychologist has arranged his working hours to enable him to attend inpatient and outpatient discussions, and the team is aware that developing psychology input as part of annual reviews is a priority.

The current post holder is a Health and Care Professions Council (HCPC)-registered counselling psychologist and offers a range of evidence-based therapies. At present, the Cystic Fibrosis Trust's Standards of Care specify that psychology should be provided by a clinical psychologist due to the specific training requirements.

Recommendations

- The post holder has been advised to develop the psychology service in line with the guidance in the Cystic Fibrosis Trust's Standards of Care.
- He has now joined the UK Psychosocial Professionals in CF (UKPP-CF), which sets the standards for psychologists. This will enable him to gain peer support in developing the service.
- To meet requirements, another 0.2 WTE psychologist should be recruited and, if this is to meet current standards, this should be a clinical psychologist.

4.7 Social work

Areas of good practice

- While the service does not have a specialist social worker as part of the MDT, it recognises the importance of addressing the social care needs of patients and is able to refer them to local services.
- Patients can access social work support through the main hospital social work service.
- In relation to housing, benefits advice and accessing financial support/grants, patients are referred to local services such as the Butterfly Trust – a local cystic fibrosis charity in Edinburgh – as well as the Citizens Advice Bureau and the Cystic Fibrosis Trust.
- The annual review forms for the service ensure patients' social circumstances are considered.

Areas of improvement

- The needs of CF patients are complex and, while patients may have access to social services and other organisations for general care support, having a dedicated qualified social worker would ensure that services are consistent and that all aspects of patients' needs are addressed, including housing, employment, education and welfare advice.
- In the current economic climate, where local authorities are increasing the eligibility threshold for accessing services, many CF patients are unlikely to meet the eligibility criteria for social work support. This has been recognised by the CF CNS in the Aberdeen service.

Recommendation

- The service should consider employing a social worker as per the Cystic Fibrosis Trust's Standards of Care.
- The social worker would work on a part-time basis given the number of patients/WTE as per the Cystic Fibrosis Trust's Standards of Care recommendation.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	0	2	5	4	4	0	0
Female	4	2	2	4	0	0	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	18	8	2	0
From the ward staff	7	10	1	0
From the hospital	12	16	0	0

Areas of excellence

1. CF team – communication
2. Outpatient availability – see all staff (social worker on referral)
3. Outpatient – cleanliness

Areas for improvement

1. Food – need menu just for those with cystic fibrosis
2. Staff – overstretched
3. Parking

6. Appendices

Appendix 1

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

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

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

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

Aberdeen Royal Infirmary Adult Cystic Fibrosis Centre

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include annual review.)	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 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	Service all situated on one large site, facilitating referrals.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	100% seen by a consultant.
	% patients with cystic fibrosis-related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	

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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* in the previous 12 months	100%	Green	Green	
	% patients admitted within seven days of the decision to admit and treat	100%	Green	Green	Patients are admitted to the ward on the same day.
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis related diabetes (CFRD)	% patients > 12 years of age screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% patients > 5 years of age with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age 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	% patients seen by a CF consultant a minimum of twice a week while 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 clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	There is no cross-cover for annual leave.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Green	
	% availability of clinical psychology at clinic	100%	Green	Green	
	% availability of clinical psychology for inpatients	100%	Green	Green	New colleague appointed.
	% availability of social worker at clinic	100%	Red	Red	No designated social worker.
	% availability of social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of pharmacist for inpatients	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	% 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 in the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
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	N/A	

Appendix 2

Staffing levels (adult)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Aberdeen Royal Infirmary 67 patients
Consultant 1	0.5	1	1	0.33 WTE
Consultant 2	0.3	0.5	1	0.33 WTE
Consultant 3			0.5	0.33 WTE
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.4	0.8	1	
Specialist nurse	2	3	5	1.5 WTE
Physiotherapist	2	4	6	1.25 WTE
Dietitian	0.5	1	2	0.6 WTE
Clinical psychologist	0.5	1	2	0.3 WTE
Social worker	0.5	1	2	
Pharmacist	0.5	1	1	0.2 WTE
Secretary	0.5	1	2	0.81 WTE
Database coordinator	0.4	0.8	1	
Ward-based CF nurse				1.0 WTE

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

CF Registry data – 2012	
Demographics of centre	
Number of active patients (active being patients within the last two years) registered	62
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	59
Median age in years of active patients	29
Number of deaths in reporting year	2
Median age at death in reporting year	43.5

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number in age categories	16–19 years	8
	20–23 years	8
	24–27 years	9
	28–31 years	9
	32–35 years	9
	36–39 years	5
	40–44 years	5
	45–49 years	3
	50+ years	3

Genetics	
Number of patients and % of unknown genetics	6 (10%) females; 6 (10%) males

Body Mass Index (BMI) (ref: 1.13 Annual Data Report 2012)		
	Male	**Female**
Number of patients and % attaining target BMI of 22 for females and 23 for males	10 (17%)	12 (20%)
Number of patients and % with BMI <19 split by sex	4 (7%)	4 (7%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	3 (38%)	1 (13%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
		Male	**Female**
Medium FEV_1% predicted at age 16 years split by sex		53.8 yrs	59.3 yrs
Number and medium (range) FEV_1 % predicted by age range and sex	16–19 years	(2) 39.83% (37.36–42.29)	(6) 79.47% (30.13–100.61)
	20–23 years	(6) 62.55% (18.59–102.59)	(2) 52.93% (not done–52.93)
	24–27 years	(6) 42.34% (32.92–70.63)	(3) 70.05% (30.2–79.9)
	28–31 years	(3) 66.83% (52.08–66.83)	(6) 66.63% (22.61–93.92)
	32–35 years	(4) 78.83% (48.08–92.35)	(5) 57.79% (33.32–72.66)
	36–39 years	(3) 72.15% (39.03–105.26)	(2) 57.95% (55.67–60.23)
	40–44 years	(4) 79.88% (13.57–109.56)	(1) 81.61%
	45–49 years	(3) 80.19% 61.02–99.36)	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	8
	20–23 years	8
	24–27 years	9
	28–31 years	9
	32–35 years	9
	36–39 years	5
	40–44 years	5
	45–49 years	3
	50+ years	3
Number of patients with chronic PA by age group	16–19 years	2
	20–23 years	3
	24–27 years	7
	28–31 years	4
	32–35 years	6
	36–39 years	2
	40–44 years	1
	45–49 years	1
	50+ years	3
***Burkholderia cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	3 (5%)	
Number and % of *cenocepacia*	0	
Meticillin-resistant staphylococcus aureus (MRSA)		
Number and % of total cohort with chronic infection with MRSA	5 (9%)	
Non-tuberculous mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	1 (2%)	

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % total cohort requiring chronic insulin therapy	11 (19%)

Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (2%) without PH and 0 with PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantation assessment in reporting year	2 (4%)
Number of patients referred for transplantation assessment in previous three years	5
Number of patients receiving lung, liver, kidney transplants in previous three years	1 (2010)

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	5
	20–23 years	84
	24–27 years	115
	28–31 years	9
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	113
Number of days of home IV therapy in reporting year split by age group	16–19 years	79
	20–23 years	28
	24–27 years	157
	28–31 years	208
	32–35 years	98
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	14
Total number of IV days split by age group	16–19 years	84
	20–23 years	112
	24–27 years	272
	28–31 years	217
	32–35 years	98
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	133

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged >16 years with FEV_1% predicted <85% (i.e. below normal) on DNase	(n=45) 15 (33%)
If not on DNase, % on hypertonic saline	8 (18%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	29 (49%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	23 (79%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	19 (32%) with chronic PA; 10 (17%) without chronic PA

Appendix 4

Patient survey

Aberdeen Royal Infirmary Adult Cystic Fibrosis Centre

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	0	2	5	4	4	0	0
Female	4	2	2	4	0	0	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	14	13	0	0
Communication	19	7	2	0
Out-of-hours access	9	9	1	0
Homecare/community	6	4	1	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	15	11	2	0
Waiting times	9	12	6	0
Cross-infection/segregation	12	11	0	1
Cleanliness	14	14	0	0
Annual review process	12	16	0	0
Transition	5	9	0	1

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	8	8	0	0
Cleanliness	6	9	1	0
Cross-infection/segregation	8	7	1	0
Food	2	7	6	1
Physiotherapy availability to assist/assess airway clearance and exercise during weekdays	6	9	1	0
Physiotherapy availability to assist/assess airway clearance and exercise during weekends	2	4	3	1

How would you rate?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	8	5	1	0
Availability of equipment	10	8	1	1
Car parking	2	4	6	12

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	18	8	2	0
Of the ward staff	7	10	1	0
Of the hospital	12	16	0	0

Comments about CF team/hospital

Hardly any homecare has been offered. I complained recently and it has got a bit better. No IV electrical equipment loaned out; has caused problems. CF team expect me to stay two to three weeks just for IVs, which I refuse to do. No information on funding or equipment (wheel chair/vest/pump/stair lift) given.

Very few nurses trained to insert port needle so sometimes have to wait a few days before getting IVs started. I feel individuals in the team work harder and are more dedicated to patients than others, but whole team takes credit. Three consultants often with different views on treatment.

My transition was many moons ago from Great Ormond Street. The team are great but pushed to the limit!

Everything's on hand if I need, but I feel that they leave your care to yourself, instead of pushing you to do better! They don't take it seriously enough.

I have not been an inpatient for three years and so my comments are based on last period spent in the ward. Since then the ward has been relocated to a new part of Aberdeen Royal Infirmary.

All the staff have been very attentive.

Excellent team, CF nurses are always available to speak to via phone or email and will bend over backwards to accommodate any situation you may have.

Parking is awful almost any time except night time. Food on the ward is not nice and very basic. Massages for outpatients would be great!!

Cracking bunch!

Having to sit and wait sometimes for long periods between consultants. They took a long time to investigate a health condition I have; another hospital instigated it first.

Appendix 5

Patient/parent interviews

Patient A

Outpatient clinic:

- Patient arrives at outpatient clinic, waits initially in open, shared area (5-10 mins sometimes) and is then put in consultancy room where spirometry takes place. Patient is concerned about who he's sitting next to in open area. Weight measured in corridor near consultancy rooms. Patient mentioned "good cross-infection precautions in consultancy room when using equipment".
- Patient stays in consultancy room; MDT rotates. Patient feels decisions on treatments are made with him, as shared decisions – "the team are very flexible with me".
- Patient has no concerns about pharmacy waiting or associated possible cross-infection – "it's fine".
- If admitted following clinic, patient cannot get pancreatic enzymes so cannot eat for a number of hours while waiting for admission.

Annual review:

- Patient last had annual review (AR) in December 2013. He's offered an AR each year. At the AR, the patient sees all of the MDT, including psychologist. He doesn't see the social worker and has never needed to. Liver scan takes place on AR day, but DEXA scan conducted weeks before at another hospital. AR report is fed back verbally to patient at next clinic appointment. Dietitian informs GP of any changes to treatments.

Inpatient care:

- Patient can be admitted in two hours. He feels it's a lot quicker than it used to be. He's always accommodated in an en suite side room. He feels ward nurses' skills/knowledge are variable; "some clued up, one had no clue". He feels IVs/treatments are given on time ("perfect") and that there's sufficient equipment on ward.
- Patient considers food "awful" – eg rice very dry, potatoes soggy or undercooked. He feels portions are tiny, but is refused a second helping of what he does like (fish, custard). Cystic fibrosis menu "is same as hospital menu, but bigger portions; food not very good, not enough of it. Ward microwave has been taken away, yet dietitian can bring her fridge around from room to room."

Homecare:

- Patient has to mix home IVs himself, administered via a portacath. He returns to hospital for port flushes and Tobramycin level checks (tries to coincide with outpatient appointments).

Give three areas of good practice in your CF service, if you can:

- "Doctors and nurses very friendly, very good and listen to you."
- "CF team give good advice (when to take medications, what to eat, notifying what's happening in cystic fibrosis and advances in CF drugs)."
- "Good with outpatient clinic timings."

Give three areas for improvement in your CF service, if you can:

- "Parking – it's a nightmare."
- "Better organisation and communication of how the 'massage' programme works" – ie patient would like one when an inpatient. He was told it's only for outpatients and for inpatients who are in for longer.

Patient B

Outpatient clinic:

- On arrival at clinic, the patient is put into a side room almost straight way – within five minutes he's seen by someone in the clinic team. Weight is measured in the hospital corridor, oxygen SATs and spirometry take place in a consultancy room where he's seen by each of the MDT.
- Patient feels decisions on his treatment are "very much two-way". He feels the pharmacy medication collection is okay – it does not involve a long wait, as his prescription from clinic is faxed to the pharmacy.

Annual review:

- Last had an AR in October 2013. Patient is offered an AR each year, near birthday. At the AR, the patient sees 'all' of the MDT, with referrals to the psychologist and social worker where needed. His individual assessments all take place at the AR, though the bleep test is sometimes on a different day. His AR outcome is fed back to him verbally at the next outpatient clinic. Patient says the team will phone him if there's an issue beforehand (eg blood sugars).

Inpatient care:

- Patient says he can usually be admitted quite quickly – within three to four hours, usually same day. If asked if he can wait, the wait is usually only up to two days. He usually gets an en suite side room. He feels some ward staff (the more experienced) are very good/knowledgeable, and says the newer nurses get a bit baffled. Patient generally felt it's "pretty good" on the ward, that medications and IVs are "pretty on time, but sometimes it gets busy causing delay" and "the CF nurse gets a lot done".
- Patient talked about the ward catering hospital food in a resigned manner. He spoke more enthusiastically of the cystic fibrosis menu, including the extra portions, sandwiches, yoghurts and special menu.

Homecare:

- Patient mixes his own home IVs, which are administered through a cannula. He used to have a port, but says it contracted MRSA. His port flushes and Tobramycin levels take place at the hospital.

Give three areas of good practice in your CF service, if you can:

- "Team can see you quickly."
- "Team communicates well with me and returns calls quickly."
- "Generally a nice team, they don't seem like doctors so it makes life easier."

Give three areas for improvement in your CF service, if you can:

- "More training for newer ward nurses."

Patient C

Outpatient clinic:

- On arrival at clinic, the patient sometimes has to wait (sometimes with other CF patients and other respiratory patients) before being ushered to a consultancy room. Weight is measured in the hospital corridor, oxygen SATs and spirometry take place in a consultancy room, where she sees the MDT – including the consultant, CNS, physiotherapist and dietitian, when needed. Patient explained the service used to have a psychologist but now relies on a part-time psychologist.
- Patient feels decisions about her treatment are shared with her, the team is "very good at discussing treatment options and let me decide as they say I know best". She says picking up medication at the pharmacy can take a while, as it's a small pharmacy. She used to send her parents to the pharmacy, to avoid risk of cross-infection with other CF patients.

Annual review:

- Last had an AR in November 2013. Patient is offered an AR each year. At the AR, the patient sees 'all' of the MDT. sees the psychologist when a part-time psychologist is available. But there's no social worker that she's aware of – the CNS deals with these queries.
- Patient is now post-transplant. Her AR outcome is fed back to her verbally at the next outpatient clinic.

Inpatient care:

- Patient says she can usually be admitted on the same day as requesting it. She has always been put into an en suite side room. She feels that some ward staff are more knowledgeable than others about cystic fibrosis and its treatments and that some doctors on the ward "have no clue", but that the CF ward nurse (works three days a week) on this general chest ward is good. Patient felt hygiene varies – some nurses don't swab, others do.
- Patient explained there is no gym on the ward, but didn't think there is insufficient equipment.
- When asked about what she thought of the ward food, patient responded "not a lot, but I'm a fussy eater perhaps". She said, "It depends on what you order, there's a special snacks menu and Fortisips", but that the menu would benefit from "less choice and dishes without sauce".

Homecare:

- Patient mixed her own home IVs, which are administered through a portacath; but is now post-transplant.
- Her port flushes were carried out at the CF centre; Tobramycin levels checked by local health centre.

Give three areas of good practice in your CF service, if you can:

- "Experienced CF nurse specialist of 20 years."
- "New ward, so everyone gets a single side room – nicer, cleaner ward, with nice view from room."
- "Consultants are very good at listening."

Give three areas for improvement in your CF service, if you can:

- "Car parking."
- "Difficult to get through to the ward on phone. Difficult to access help for IVs at weekend."

Patient D

Outpatient clinic:

- Patient explained "on arrival we all start in the waiting room with other general public, then as soon as possible I'm called into a consultancy side room". Spirometry takes place in this consultancy room and MDT rotates. His weight is measured in the corridor. He would only see the psychologist and social worker if he requested to.
- Patient is happy about the treatment decision-making process – "everything goes through me, unless it's a new doctor".
- Patient felt the hospital pharmacy patient experience is "shocking". He acknowledged that it is a busy hospital, but said that it has a small dispensary and that he has to wait for two hours sometimes for his prescription to be processed.

Annual review:

- Patient had annual review just after Christmas 2013. He is invited to an AR each year.
- He sees all the MDT at the AR, including the psychologist. However, the social worker is available 'on request' through referral. All his assessments, apart from the DEXA scan, take place at the AR – the DEXA scan is conducted at another hospital on a separate occasion. His AR is reported back to him verbally at the next outpatient clinic – no written report.

Inpatient care:

- Patient stated he rarely has trouble getting admitted and that the admission process is fairly quick. He explained that the ward is in a new block now (opened December 2013), with new rooms. In the past he was sometimes admitted to an en suite side room; now all the rooms are en suite. He feels that 80% of ward staff are very knowledgeable about cystic fibrosis and its treatments, that 10% are a bit frightened of the patients' knowledge and that 10% will ask patients about their treatments and what is best for them. He felt IVs/medications are sometimes given late, but stressed that this was down to understaffing rather than being a reflection of staff competence – although he felt some staff were "less in-tune".
- Patient felt there wasn't enough equipment on the ward, that staff have to look in other rooms for certain equipment and that some of it seems to go missing. He said the exercise bike is shared between rooms, or he just goes for a walk for exercise.
- Patient felt food on ward was "okay" on about four out of seven days; it was nice enough. He has no problem bringing food into the ward. Sometimes there's a takeaway night, where ward staff take patients' takeaway orders.

Homecare:

- Patient has to mix his own home IVs, which are administered through a portacath. He flushes this himself, but has Tobramycin levels done at his local GP surgery.

Give three areas of good practice in your CF service, if you can:

- "So many changes over the years, nearly all for the better."

Give three areas for improvement in your CF service, if you can:

- "Understaffed clinic – staffing levels need increasing."
- "Encourage more patients to act as mentors/advisers to other patients."

Peer review day
Patient One

- Female patient, 36 years old. She was diagnosed at six months old. She is mother to a nine-year-old daughter and lives 10 minutes from the hospital. For clinic appointments, she brings in knitting to occupy herself. She is very rarely an inpatient; she tries to keep herself well as she has a family and dog to look after. She is trained to mix her own IVs, depending on the type being given.

Areas of good practice:

- "Staff are friendly, caring and take interest in the patients, which gives a family feeling and stability."
- "There is a wide range of food available;, food can also be taken in."
- "There is quick and easy access to get an appointment."

Areas for improvement:

- "Parking – horrendous" – Patient says she is prepared to pay a fee for a better service instead of fighting for a space. If she has a 2pm appointment, she says there is no chance of getting a space as it is also visiting time.
- "The chest ward is situated up a hill and also on the fourth floor, so have to use the lift."
- "Pharmacy – have waited up to three hours and may wait with other CF patients."

Patient Two

- Male, 22 years old. He was two years old when diagnosed. He does not drive so the parking issue does not affect him. He lives a 30-minute walk away. He attends university. He shares a flat with his friend and only sees his family once every two weeks. He enjoys cooking at home.
- He has attended Kilmarnock, Glasgow and, since last summer, he has attended Aberdeen. He has been an inpatient three times since October. His weight is now improving, the dietitian constantly checks his weight and he is given protein shakes as supplements.

Areas of good practice:

- "Staff are very easy to contact at any time. It is very easy to get an appointment."
- "The new rooms are amazing and very clean."

Areas for improvement:

- "Communication between staff: for them to know what treatment the patient has already had."
- "The food could be better, the choice is okay. There is an extra menu, but the standard could be better and more appetising."

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Hospital Name	Aberdeen Royal Infirmary (69 patients)
	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)	No	Best care taken. Patients should not meet if they keep to their appointment time.
Do patients spend any time in the waiting room?	No	
Is there easy access to toilets?	Yes	Two for males and one for females.
Where do the height and weight measurements take place? Is this appropriate?	Yes	Scales in corridor – patients have height and weight measured on arrival and are then taken directly to clinic room.
Where are the lung function tests done for each visit?		In clinic room. Five Vitalograph bellows machines, dependant on microbiology.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	No	Patients can bring their own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	These clinics are held every second month. Eight patients are seen by a diabetic specialist nurse and a diabetologist.
Transition patients – can they get tour of outpatient's facilities?	Yes	Majority of patients come from Aberdeen paediatrics and are aware of service. A tour can be arranged.
Transition/new patients – do they get an information pack?	Yes	Transition booklet available which contains all staff photos and contact details.

Additional comments

- The outpatient clinic is situated in the old part of the hospital. The waiting room is a large, carpeted area with 40-plus seats and many leaflet displays.
- There is one weekly clinic held on a Thursday afternoon with use of six clinic rooms, therefore the rooms are not reused and there is no need to clean in between.
- Two patients are seen at annual review on a Thursday morning.
- All patient notes are kept close to the clinic for ease of access.

Environmental walkthrough: ward
Ward name: 107
Microbiology status:

		Hospital name	Aberdeen Royal Infirmary (69 patients)
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Suitable	General respiratory ward.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	All single rooms are en suite.
Number of side rooms?		13	There have never been more than four CF patients admitted at any one time.
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	Locker.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service to patient line.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	There is only an easy chair in the room; there is also Red Cross accommodation or The Gatehouse. This facility is for the families of very ill patients; it is rarely used.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Regular visiting hours: 2.30–5pm and 6.30–8pm. Staff do try to stick to mealtime restrictions, however this is controlled case by case.
Is there access to a fridge/ microwave either in the side rooms or in the parent's kitchen?		Yes	A fridge will be wheeled into the room for use. There are no microwaves for use.
What facilities are provided for teenagers?			Patients can bring their own.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	The physiotherapy gym has a bike and treadmill. TV with Wii. There are weights, steps and bands – these can be taken to rooms for use.
What facilities are there to help with school and further studies?		None. Patients would have to bring in their own dongle for Wi-Fi access. Patients can attend school during their stay.
Is there a relatives' room?	Yes	A small room with seating. No tea/coffee facility apart from the ward tea round.
What internet access is there?	None	
What facilities are there to enable students to continue work and study?	None	Patients can bring their own.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Own sink in room.
What facilities are provided for those with MRSA?		Barrier nursed.
What facilities are provided for those with *B. cepacia*?		Barrier nursed.
What facilities are provided for those with other complex microbiology?		Barrier nursed.
Are patient information leaflets readily available on ward?	No	These are available at outpatients.
Transition patients – can they get a tour of ward facilities?	Yes	This is offered – paediatrics has good links with the adult service so patients are aware of the service at an early stage.

Additional comments

- The hospital is situated over a large site. There is a mix of old and newer buildings. The original buildings originate from the early 1900s, whereas the newest building, where the ward is situated, has only been open for 18 months. The ward is located on the fourth floor. At the entrance to the ward there is a large reception area with male and female toilet facilities. There are two lifts either side of the ward for use for clean and dirty waste, and security doors at the ward entrance. The en suite rooms are large, well equipped, modern and clean. The ward corridors are wide and bright. The interview room offers seating for 8–10 people, with a coffee table. There are two rooms with four beds each – separate male and female for other respiratory patients.

- Apron and glove dispensers are provided at various points along the corridor, but not outside every room.
- There are four surgical wards. There are no negative pressure rooms on the new ward.
- MRSA/*B. cepacia* complex microbiology – CF patients are nursed by separate nursing staff and would be placed in separate locations within the ward, away from each other. The new ward has doors to the corridor to enable this, and the shape of the ward also supports this.
- Three *M. abcessus* patients – these are barrier nursed by separate nursing staff.
- The utility room is used for mixing IVs. It does not have any windows, but it is a ventilated, large, bright and well-equipped room.

Environmental walkthrough: other

	Hospital name	Aberdeen Royal Infirmary (67 patients)
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	Free to all.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Good signage. New building has colour-coded zones and wards have been renamed.
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) scanning?		Pharmacy: This area is a tiny glass-walled room with seating for only five people; it is hot and poorly ventilated, however, a new pharmacy is currently being prepared for use in the near future. Through staggered appointments, patients do not leave clinic at the same time. The wait at the pharmacy can be as long as two hours, but patients do not generally wait. They will either collect their drugs from the ward or come back to collect them. The new pharmacy is positioned below the ward. It will be a spacious area with seats for 30-plus people. DEXA area is spacious, in a separate part of the hospital. Ultrasound for inpatients is situated in the new building, with a modern and spacious waiting area with seating for approximately 20 people. X-ray for outpatients has two entrance/exits to the waiting area with the reception in the centre, so patients could be segregated for infection control should the need arise.
Do patients have to wait at the pharmacy for prescriptions?	Yes	
Patient information		
Is the patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Have own version	Compliments/comments/complaints: The competed forms go to Grampian and feedback is filtered back to staff.
Are there patient comments/ feedback boxes?	No	

Additional comments

- Car parking – There are severe issues with parking for staff and patients. Although parking is free, there are not enough spaces. The attendants wear CCTV due to abuse from drivers and there are registration recognition cameras as it is believed that people park in the spaces and go into town.
- There is no official IV delivery service, however, the CNS is willing to deliver to patients. The IVs are not premixed; they are mixed by patients at home.

Appendix 7

Panel members

Joanna Whitehouse*	Consultant	Birmingham Heartlands Hospital
Douglas McCabe	Clinical Pharmacist	Western General Hospital
Alison Pearce	CF Specialist Psychologist	Southampton General Hospital
Heather Bateman	CF Clinical Nurse	Nottingham University Hospital
Joanne Barrett	CF Specialist Dietitian	Birmingham Heartlands Hospital
Elaine Lloyd	Clinical Specialist Physiotherapist	Liverpool Heart & Chest Hospital
Agnes Tansinda	Social Worker	Wythenshawe Hospital
Sarah Freeman	Specialised Commissioning	Birmingham
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2014. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 11 London Road, Bromley, Kent BR1 1BY.