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Cystic Fibrosis why we're here

British Thoracic Society

BIPRS

Peer review report

The Royal Belfast Hospital for Sick Children

13 February 2014

1. Executive summary

1.1 Overview of the service

Belfast Children's Hospital cares for about 196 children with cystic fibrosis and covers the whole of Northern Ireland; there is no network care. They transition to a single adult centre in Belfast. There is a high prevalence of the R117H genotype within the clinic compared to the UK population as a whole. The clinic has low rates of chronic *Pseudomonas aeruginosa* at 10% and good use of mucolytics. The median FEV_1 sits above the UK average in all age ranges, at 96% for 6 to 12 year olds and 90% for 13 to 18 year olds. The clinic's dedicated, multidisciplinary team has had only very minor development since the last peer review. Most areas of the team remain overstretched, with a common feeling that they are providing a reactive service because of inadequate facilities, support services and staffing levels, rather than the proactive one they strive for. Despite this, the team provides a comprehensive and excellent standard of care for the children within their service that is appreciated by the families.

1.2 Good practice examples

1. Good relationships and communication across the multidisciplinary team (MDT), including the extended MDT, with close links to microbiology and the newborn screening service.
2. Annual data report produced and presented to whole team, allowing constant service improvement. Whole MDT buy into this as they have a desire to improve quality.
3. Good availability of the whole MDT in the outpatient setting, despite inadequate facilities.

1.3 Key recommendations

1. The outpatient facilities need to be fully utilised to allow all patients to be seen in their own outpatient room, to enable full, confidential access to the MDT and to tighten infection control measures.
2. The shortfalls in staffing levels against the Cystic Fibrosis Trust's Standards of Care need to be addressed, particularly in consultant time available to the service. There are significant shortfalls in nursing, pharmacy, physiotherapy and psychology.
3. There are several areas of the service that are essentially run single-handedly. This leaves the service vulnerable and will also need to be addressed. Key areas include the newborn screening pathway, social work, psychology and microbiology.
4. Succession planning for retirement in some areas that are run single-handedly, and elsewhere, needs urgent attention.
5. Many staff are also covering non-CF areas within the children's hospital, which seems to conflict with their time available for the CF service. This needs addressing.

1.4 Areas for further consideration

1. The car parking facilities for patients appear to be a barrier to allowing patients to access the clinics in a timely manner. This came across multiple times in the parent and patient survey and, based on staff interviews, it also seems to be a barrier to ensuring better running of the service.
2. Better availability of bone mineral density (DEXA) scans must be ensured for the service to reach the Cystic Fibrosis Trust's Standards of Care for annual reviews.
3. Better staffing would allow all members of the MDT to regularly attend continued professional development (CPD) activity and participate in audits and, potentially, research.
4. To explore, with support from the Trust, developing some cystic fibrosis-specific key performance indicators and quality review mechanisms that could be used to strengthen the commissioning model for the service.

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

2.1 Models of care

Summary

Clinics are run in a segregated manner by both age charting and past sputum pathogens. The outpatient facilities are not adequate to allow children and families to be seen in private, with consultations with individual members of the MDT happening in the waiting area. A lack of rooms also increases the risk of cross infection in the current model of care. There may be adequate facilities to provide better care within the current outpatient area if all available rooms are used, rather than some being used for administration by other non-CF staff. In the future, with better staffing within the MDT, other models of care involving outreach care at external centres and increased provision of home services could be explored.

All patients are invited for annual reviews, although they are not all comprehensive, with particular problems around DEXA scanning and time management of the reviews. Some of this is outside the team's control, with very long delays waiting for car park places meaning that patients arrive late for appointments after travelling long distances to come to clinics.

Inpatient single rooms are adequate to allow timely admissions within seven days. Some rooms are in need of refurbishment. There is limited availability of parent accommodation.

Data is recorded in both Port CF and an internal database, including a comprehensive microbiological one.

2.2 Multidisciplinary care

Summary

The extremely dedicated team is quite stretched by the constant demands on their time, both from the sheer volume of their workload with cystic fibrosis patients but also from non-CF duties that many members of the team have. This is particularly noted for medical staff, pharmacists, dietitians and physiotherapists. Urgent review and improvement of staffing levels is needed.

Parent questionnaire feedback on the team was excellent.

2.3 Principles of care

Summary

Good MDT meetings, including the team meeting, take place on an annual basis to review all their clinical outcome data, allowing them to review against their previous figures and target further areas of improvement. Over the years this has allowed them to drive up their quality of care. The team also has specific quality improvement projects running.

The whole team provides good care that is evidence-based, with no restraints on the use of high-cost therapies. Its data from Port CF have always shown good outcomes.

2.4 Delivery of care

Summary

The care delivered by the team is of a high standard across the board, with some unique elements and personnel. This is despite significant shortfalls in staffing numbers compared to the Cystic Fibrosis Trust's Standards of Care guidance.

The environmental constraints of poor patient parking facilities, lack of outpatient rooms and low availability of some radiology-delivered services, such as DEXA scans, impact on the team's ability to deliver the comprehensive annual reviews it would like to.

2.5 Commissioning

Summary

Areas of good practice: The commissioning system works through a single Health & Social Care Board across Northern Ireland. It was evident that commissioners had developed a clear strategy for tertiary paediatrics in conjunction with the Trust through its 'vulnerable groups' workstream, transition and network model, and through this investment had been put into specialised services.

There was evidence of an active dialogue between Trust managers and commissioners responsible for cystic fibrosis, and additional investment has been secured in previous years. Trust managers recognised that some further investment was necessary and were committed to prioritising this in the planning cycle in future years.

Areas for improvement: The Hospital Trust was developing some service budgeting, but it was difficult to determine the costs versus the income for cystic fibrosis. This is important as there remain some shortfalls in the actual staffing levels required to support a cystic fibrosis service of this size. The Hospital Trust representatives saw any major development of costing methodologies as dependent on commissioner support and investment.

The contract and quality review processes appeared to focus on generic measures and were not developed at a service level.

Improvement in outcomes in cystic fibrosis relies on preventative treatment and timely review of patients' disease status. Achieving this requires embedded review and audit processes, and the lack of sufficient outpatient space hampers this process.

Recommendations

- The service, with support from the Hospital Trust, should aim to develop some cystic fibrosis-specific key performance indicators within contracts and develop quality review mechanisms for the cystic fibrosis service within the contract review process.
- Commissioners and the Hospital Trust may find it helpful to review the NHS England tariff, developed specifically for cystic fibrosis, to better understand the cost drivers within the service.
- Prior to the opening of the new Children's Hospital, capacity for outpatient review on site, or through outreach, should be explored and resolved.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	183

			Male	Female	Total patient number
FEV_1	Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0	41
		4–7 years	0	1 (5%)	44
		8–11 years	6 (29%)	5 (25%)	31
		12–15 years	9 (42%)	8 (40%)	37
		16+ years	6 (29%)	6 (30%)	30

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	5 (3%)

***Pseudomonas aeruginosa* (PA) Chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	18 (10%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	17 (94%)

Macrolides	Number and % of total patients on chronic macrolide with chronic PA infection	10 (6%)
	Number and % of total patients on chronic macrolide without chronic PA infection	9 (5%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- There are two consultants delivering the service, with only 0.85 whole time equivalent (WTE) of time between them to deliver care to a large CF clinic. This falls well short of the Cystic Fibrosis Trust's Standards of Care.
- The second consultant is stretched across a very onerous, general consultant paediatric commitment as well as other respiratory duties, and has probably less than the one day a week documented to give to the cystic fibrosis service. Some of the out-of-hours cover is delivered by other paediatric respiratory consultants who maintain some elements of cystic fibrosis specialisation in their CPD. There is also a CF Associate Specialist who is integral to the service. There are no training grade doctors involved in the outpatient side of the service and the rotational general paediatric trainees cover the inpatient service. There is a unique and highly dedicated newborn screening (NBS) service in Northern Ireland, which is essentially run by a single doctor with the support of a solitary NBS nurse.
- Despite the shortage in consultant numbers, the team is extremely dedicated, providing an individualised service to their patient population hampered mainly by lack of investment in the service.
- Additional consultant time is urgently needed.
- Succession and sustainability planning for the single-handed newborn screening service needs to take place.

4.2 Specialist nursing

There are two experienced WTE Band 7 nurse specialists in post, who each work four days. Nursing cover is provided Monday to Friday from 8am to 6.15pm. When compared to the Cystic Fibrosis Trust's Standards of Care, there is a shortfall of at least 1.5 WTE. Both are members of the Cystic Fibrosis Nursing Association (CFNA). One is currently Regional Representative on the CFNA committee for Ireland and Northern Ireland. The North American Cystic Fibrosis meeting (NACFC) is regularly attended and the European Cystic Fibrosis meeting (ECFSC) is attended every two to three years.

Their roles are split between hospital and community. The nurse, who is community based, covers the hospital-based nurse's mid-week day off as well as annual leave. There is no fixed cover in the community for days off and annual leave, although this does happen on an as required basis. The nurses have a good working relationship and are flexible to the needs and demands of the service. One of them is always present for multidisciplinary clinic and ward rounds.

Areas of good practice:

- Both nurses are accessible to the patients and their families and provide excellent level of nursing cover and continuity of care.
- Participation in audit and service improvement.

Areas for improvement:

- Continue to work towards all eligible patients having an oral glucose tolerance test as part of annual assessment.
- Improve the inpatient facilities for parents resident with their children.

Recommendations:

- Address the deficit in the current nursing establishment and look towards succession planning.
- Change the organisation and structure of the clinic, so that all team members can review patients in a clinic room.

4.3 Physiotherapy

Enthusiastic, experienced and committed physiotherapy team with good evidence-based practice and most of the Cystic Fibrosis Trust's Standards of Care met. The integrated part of the whole, hard-working MDT. Being a single centre, it has the advantage of equity of standard of care throughout the country. Good availability of inpatient and outpatient physiotherapy, including at weekends. Exercise prescription or promotion is done for inpatients with very limited outpatient exercise, as patients have to travel to the hospital and the physiotherapist is unable to do community visits. Progress has been made on better use of the respiratory physiologist for pulmonary function testing at annual review. Handing over the exercise testing and provision of pulmonary function testing at review clinic could free up some physiotherapy time. A variety of strengths of nebulised hypertonic saline are used and first doses of Colomycin are given in the community with no spirometry. At 1.75 WTE Band 7, staffing is below the recommended 3.5 WTE for a centre of this size.

All three physiotherapists are members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF). Full-time physiotherapist is current Ireland ACPCF representative. There are opportunities to attend international meetings but limited study leave or expenses for attending Irish or UK meetings.

Areas of good practice:

- Experienced, committed staff with excellent availability for inpatients and outpatients.
- Evidence-based practice.
- Excellent inpatient gym facilities.

Areas for improvement:

- Use of 7% nebulised saline where clinically indicated as per evidence base.
- The establishment of a community cystic fibrosis physiotherapy post to extend exercise testing and programming in local facilities, provide input to newly diagnosed families and provide home review of airway clearance, including nebulisation, to lower admission rates as per evidence base.

Recommendations:

- Upgrade of one Band 5 to Band 6 physiotherapist to cover medical patients in wards to allow a more experienced physiotherapist to take responsibility for these patients, enabling the CF physiotherapist to give more time to cystic fibrosis care.
- Experienced Band 7 physiotherapist post for cystic fibrosis community services to improve service integration in the community (post to be similar to CF nurse specialist in the community).

4.4 Dietetics

There are three paediatric dietitians: Band 8a (0.5 WTE) – over 15 years' experience; Band 7 (0.3 WTE); Band 6 rotation (training) post (0.2 WTE), leaving a 0.25 WTE deficit. Cover is mainly provided from within the team. All provide cover to other areas of dietetics and can get pulled out of the cystic fibrosis service to cover periods of leave. This gives rise to a greater than 0.25 WTE deficit.

- The Band 8a and Band 7 dietitians are members of the UK Dietitians CF Interest Group, however, they have not been able to attend any recent group meetings. There has been limited attendance at Irish, European and North American cystic fibrosis conferences and only the Band 8a dietitian has ever attended to date.
- A dietitian is present at the MDT meeting following most of the clinics.
- There is a lack of space in clinics at times, resulting in dietitians conducting short interviews in waiting, play and administration areas.
- Inpatient cover has improved recently, although there is limited attendance on ward rounds and standards for seeing inpatients are not always met.
- The dietitians have not been involved in any research projects or audit. They do, however, attend research meetings.
- The dietetic team sees all newly diagnosed infants regularly in clinic.
- The transition clinic is staffed by both adult and paediatric teams, with twice yearly handover meetings to discuss the transfer of patients.

Areas of good practice:

- Good communication with and support from the multidisciplinary team.
- Good patient support literature and information gathering tools.
- Traffic light dashboard to highlight the urgency/level of dietetic support required, enabling some form of prioritisation. This is required due to inadequate staffing levels.

Areas for improvement

- The development of a proactive rather than reactive approach to nutritional management.
- Increased involvement with inpatients and better facilities for seeing patients in clinic.
- Improve access to CDP and education through attendance at national and European conferences, which will allow greater opportunity for research and audit.

Recommendations:

- Increase staffing levels and dedication of existing staff to the cystic fibrosis service. This will enable improvement in the areas identified above.

4.5 Pharmacy

All children are looked after by the team at Belfast Children's Hospital. There is no shared care provision across Northern Ireland.

The cystic fibrosis care team identified 0.6 WTE pharmacist time, however, this is shared with general duties and ward pharmacy service and is not cystic fibrosis-specific; actual cystic fibrosis-specific time is 0.3 WTE, but this is currently at Band 7. There is no support from a medicines management technician. The pharmacist has been able to attend MDT meetings in the past.

The post holder is currently on secondment to a role within the specialist medicine team, but is still able to provide a very limited service to the cystic fibrosis team at one session a week. Northern Ireland has a specialist medicines list which contains all cystic fibrosis-specific inhaled therapies and Ivacaftor. Medicines on this list must be provided by the specialist team. These medicines are provided by the hospital and couriered to the patient's home. The specialist medicine team provide this service.

Number of patients: 196

Staffing standards for CF pharmacist: 1.0 WTE

Staffing shortfall for service: 1.0 WTE highly specialist pharmacist (Band 8a)

Inpatient services

- Patients are not seen routinely by the pharmacist at annual review in outpatients. When the patients are admitted, they are seen and formal medicines reconciliation is performed. However, this is a very small cohort of patients, less than 10%.
- During in-hours there is good availability of pharmacists to answer queries and provide medicines management support.
- Patients have their IVs provided via in-house Centralised Intravenous Additive Service when on the ward.

Outpatient services

- Patients are not routinely seen by a pharmacist at annual review clinics.
- Patients are able to access home IVs but there is no ready-made IV service. Parents are therefore taught to make the antibiotics up themselves and add them to Intermate devices for drugs that need infusing and drawn into standard syringes for boluses.

Other

- Financial reporting is limited by lack of available time.
- There is no patient's own drug (POD) scheme available which, if introduced, could provide cost savings within the Hospital Trust.
- Paediatric CF pharmacist is lone worker and relies on access to UK and US email forums for support.
- Liaison with adult CF pharmacist at Belfast City is limited but available if needed. Not involved in transition currently.
- No cystic fibrosis-specific audit/research at the moment.

Areas of good practice

- Pharmacist has a good working relationship with the rest of the cystic fibrosis MDT.
- Pharmacist attends MDT meeting when possible, with one session per week.
- Pharmacist is still able to screen and organise IV and high-cost medicines prescription. This identifies errors and reduces excess spend.

Areas for improvement

- Insufficient staffing is having a significant impact on the service that the pharmacist can provide. There is a large shortfall against the Cystic Fibrosis Trust's Standards of Care and, as a consequence, the pharmacist is not able to provide the level of service, at annual review in particular, that is expected.
- Pharmacy technician support would allow a better skill mix and improved delivery of service in relation to specialist medicines list and inpatient POD schemes.
- Pharmacist involvement in guideline writing and development is limited by time.

Recommendations

- Improve staffing levels to the Cystic Fibrosis Trust's Standards of Care, i.e. 1 WTE Band 8a highly specialist pharmacist. The cost for this could be counterbalanced with savings made in drug expenditure by better medicines management.
- Support the development of a medicine management technician, 0.5 WTE for inpatient and outpatient work.
- Improve liaison between adult and paediatric pharmacist to provide disease-specific support and CPD.

4.6 Psychology

UK Psychosocial Professionals in Cystic Fibrosis (UKPPCF) meetings attended: Plan to attend UKPPCF in 2014. List serve used.

Cystic fibrosis MDT meetings attended for discussion of inpatients: 100%; outpatients: 68%

No cover when absent. Urgent inpatients can go to 'on-call' paediatric psychology.

Conferences attended: NACFC in 2012.

Research/audit: Preparing qualitative project to look at impact of Ivacaftor on families and staff.

Involvement in life stages: Transition: The team has a transition clinic every fifth Thursday. The adult clinical psychologist (CP) and paediatric CP review cases together. Cystic fibrosis baby clinics: CP available in all of these clinics.

Areas of good practice:

- CP worked hard on ensuring a visible presence with the team. Cystic fibrosis team very welcoming of CP and have used psychology well. CP available for all cystic fibrosis team members to approach for case consultation at other times.

Areas for improvement:

- Room space in cystic fibrosis clinic. If this was available, more patients could be seen. The current policy of the paediatric psychology department for seeing outpatients adds an unnecessary layer of administration, which results in a high 'did not attend' rate. Service needs more than 0.5 WTE.

Other issues:

- Inclusion of CP at annual review – need room space. Clinic room space: Psychologist attending the cystic fibrosis clinics as much as possible but no clinic room to see patients. This is not a good use of psychologist time in the long term. The need for psychologist room space is essential to meet the Cystic Fibrosis Trust's Standards of Care. Impact on patients if CP not available parallel to cystic fibrosis clinic: If an outpatient appointment for CP is sent, it must follow the policy set by the paediatric psychology service, which is to first send opt-in questionnaire. This results in it not being possible for the patient to be seen within two weeks.

4.7 Social work

Areas of good practice

- The social worker post is long established and well integrated into and valued by the team. There is a particularly good working relationship with the psychologist.
- The service is provided from diagnosis through to a strong transition programme and there is emphasis on home visits as part of assessment.
- There is good provision of access to training and conferences.

Areas for improvement

- Recommended staffing is 1 WTE post. It is currently staffed at 0.9 WTE. In addition to this shortfall, the social worker provides some extra cover to the social work department and suffers from being a lone worker – i.e. no one covers this post during holidays, sickness or training.
- Outpatient clinic accommodation. The fact that the social worker cannot see patients at clinic in a confidential and routine way is a major loss to the social work service. It is crucial to building relationships and delivering brief interventions. This area is a significant barrier to the normalisation of social work input, preventative working and collaboration with colleagues, such as the psychologist and dietitian.
- Currently the social worker has no formal input to annual assessment.

Recommendations

- Clinic: Use of accommodation so that patients can have clinic rooms and all staff can see patients confidentially.
- Consider increasing staffing to cover shortfall and mitigate the effects of single-handed working.
- Psychosocial team to review input to annual assessment, particularly for families where significant work has been undertaken.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	12	8	12	2
Female	12	10	9	3

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	55	2	0	0
From the ward staff	32	11	3	0
From the hospital	30	20	3	0

Areas of excellence

1. Accessibility
2. Communication
3. Dedication of multidisciplinary team

Areas for improvement

1. Car parking
2. Inpatient food
3. Provision of increased community services

6. Appendices

Appendix 1

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

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

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

Amber = Failing to meet all the Standards of Care with improvements required

Red = Failing to meet the Standards of Care with urgent action required

Hospital name

The Royal Belfast Hospital for Sick Children

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%	N/A	N/A	

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	Y	Y	Stretched staffing. No clinical incidents reported.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile 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	Quite a few members of the team have only attended local meetings in the last few years.

2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green	Green	Some involve links to English centres, eg Birmingham for CF liver disease.
	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	No trainee doctors in clinic.
	% patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Amber	Low levels of CFRD. Access to diabetes management clinic available.

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	Some rooms in need of refurbishment. Decoration and windows require attention.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	

3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* in the previous 12 months	100%	Green	Green	
	% patients admitted within seven days of the decision to admit and treat	100%	Green	Green	Although lack of bed availability seen as a reason not to be more involved with some research studies.
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 CFRD	% patients >12 years of age screened annually for CFRD	100%	Green	Amber	Internal audit suggests 39%, which is an improvement from 21% in 2012.
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%	Red	Red	No routine DEXA scanning only on clinical grounds, due to poor availability of slots.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Amber	Amber	Direct discussion suggested informal review occurs rather than ward round review.
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/ shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Amber	84% sent within 10 days.
	% dictated discharge summaries completed within 10 days of discharge	100%	Red	Amber	Of those that didn't, 70.8% had handwritten letter produced within the 10 days, usually at the time of discharge.
	% 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%	Amber	Green	97% seen by physio in clinic, 68% seen by Band 7 specialist. Lack of clinic rooms for review.
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	Other non-cystic fibrosis patient caseload can be prioritised: 41% seen twice a week, 39% seen within first three days, 20% had no inpatient review.
	% availability of clinical psychology at clinic	100%	Amber	Amber	Only 0.5 WTE post, no outpatient dept. room availability. Single-handed service.
	% availability of clinical psychology for inpatients	100%	Red	Red	
	% availability of social worker at clinic	100%	Red	Amber	0.9 WTE social worker quoted to be available to the service, working on a referral basis.
	% availability of social worker for inpatients	100%	Red	Amber	As above.
	% availability of pharmacist at clinic	100%	Red	Red	No dedicated CF pharmacist.
	% availability of pharmacist for inpatients	100%	Red	Red	As above.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
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	No recent deaths.

5 Commissioning

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

Appendix 2

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	The Royal Belfast Hospital for Sick Children 196 patients
Consultant 1	0.5	1	1	0.65 WTE
Consultant 2	0.3	0.5	1	0.2 WTE
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	1 WTE
Physiotherapist	2	3	4	1.75 WTE
Dietitian	0.5	1	1.5	1 WTE
Clinical psychologist	0.5	1	1.5	0.5 WTE
Social worker	0.5	1	1	0.9 WTE
Pharmacist	0.5	1	1	0.1 WTE
Secretary	0.5	1	2	0.8 + 0.5 WTE
Database coordinator	0.4	0.8	1	
CF bacteriologist				1 WTE
Associate specialist				1 WTE
Clinical medical officer				0.3 WTE
Community nurse specialist				1 WTE
Physiotherapist job share				0.75 WTE
CF administration				0.5 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 The Royal Belfast Hospital for Sick Children	
Number of active patients (active being patients within the last two years) registered	196
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	183
Median age in years of active patients	8
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number in age categories	0–3 years	41
	4–7 years	44
	8–11 years	31
	12–15 years	37
	16+ years	30

Genetics	
Number of patients and % of unknown genetics	22

Body Mass Index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	5 (3%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
		Male	Female
Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
	4–7 years	0	1 (5%)
	8–11 years	6 (29%)	5 (25%)
	12–15 years	9 (42%)	8 (40%)
	16+ years	6 (29%)	6 (30%)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	41
	4–7 years	44
	8–11 years	31
	12–15 years	37
	16+ years	30
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	2
	12–15 years	8
	16+ years	8
***Burkholderia cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	3 (2%)	
Number and % of *cenocepacia*	0	
Meticillin-resistant staphylococcus aureus (MRSA)		
Number and % of total cohort with chronic infection with MRSA	12 (7%)	
Non-tuberculous mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	0	

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % total cohort identified in reporting year with ABPA	14 (8%)
Cystic fibrosis related diabetes (CFRD)	
Number and % total cohort requiring chronic insulin therapy	2 (1%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	1 (0.5%)

CF liver disease	
Number and % total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (0.5%) with PH and 6 (3%) without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantation assessment in reporting year	0
Number of patients referred for transplantation assessment in previous three years	5
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	40
	4–7 years	70
	8–11 years	100
	12–15 years	221
	16+ years	112
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	16
	16+ years	12
Total number of IV days split by age group	0–3 years	40
	4–7 years	70
	8–11 years	100
	12–15 years	237
	16+ years	124

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	74 (78%)
If not on DNase % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	18 (10%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	17 (94%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	10 (6%) with chronic PA and 9 (5%) without chronic PA

Appendix 4

Patient survey

The Royal Belfast Hospital for Sick Children

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	12	8	12	2
Female	12	10	9	3

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	55	10	0	0
Communication	50	14	1	0
Out-of-hours access	30	17	7	2
Homecare/community	38	15	6	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	49	15	1	0
Waiting times	29	23	7	0
Cross-infection/segregation	30	21	5	5
Cleanliness	37	24	4	0
Annual review process	34	20	6	0
Transition	4	4	2	1

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor
Admission waiting times	16	17	5	0
Cleanliness	22	11	4	1
Cross-infection/segregation	22	11	1	1
Food	4	15	9	9
Exercise	10	16	5	2

How would you rate:

	Excellent	Good	Fair	Poor
Home IV antibiotic service	10	3	0	0
Availability of equipment	32	13	3	0
Car parking	2	5	25	24

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	55	2	0	0
Of the ward staff	32	11	3	0
Of the hospital	30	20	3	0

Comments about CF team/hospital

Excellent team doing a great job with limited resources.

Very accessible and helpful CF team. Only disappointment is dietitian's advice; feel that they should be more involved promoting omega 3 healthy eating and calorie diet, as opposed to solely calories and Creon management.

CF team is fantastic, always easy to communicate with. Would like full disclosure of detailed results from annual assessment, e.g. blood tests results, rather than paragraph stating that they were satisfactory. Ward – inpatient food is appalling. Very little fruit, veg or fresh food.

CF team is an excellent service with dedicated staff who take a personal interest not only in the patient, but in the patient's family also.

The parking facilities are terrible. After completing a 100 minute journey to RUH it takes between 15–50mins to park, on average at least 20 minutes' wait to get into the car park – very stressful.

Our CF team has always been excellent, but the inpatient stays are very difficult. Our daughter was recently an inpatient for 14 days and we found the timing of her IV/nebuliser doses very haphazard and unpredictable. One day she had been given no nebuliser Colomycin until after 1pm when I went to ask; should have been given in the morning. We had to supplement all meals as the food was inadequate. One day she was given no lunch until we went to ask; it had not been ordered for her. After a bronchoscopy in the afternoon, she was offered nothing to eat or drink until 9am the next day – we provided our own food having come prepared. I had to either ask for jugs of water or ignore the 'no parents' sign on the kitchen door as we rarely saw a nurse except for IV doses. We were not offered any clean bed sheets until day 11 of the stay. The cleaning was superficial, although cleaners did come in every day and bins were emptied. Plates were rarely taken away after meals; we did this ourselves. The staff appeared constantly pressurised/disinterested.

The specialised care of the CF team is tremendous. With my son's hospital care the nurses are on the whole very good, but there is very little time to cover all the needs of a CF patient.

Our son is only nine months old and has been very well up to now. The care and support provided by the CF team is excellent. We were particularly well supported when we received the diagnosis, which obviously was a very difficult time. We are confident that the team is very knowledgeable and that our son is receiving the best possible care.

The team is wonderful, they do a super patient-driven job in difficult times as funding is cut and patient numbers are increasing. For us it's been like having our own private medical insurance and we can't praise the staff enough.

I have noticed over the past two years the CF team is under constant pressure. They always seem to need to be in two places at the same time! It is their professionalism and dedication to their patients that enables them to deliver their excellent service, however, I do believe cutbacks and management in the hospital hinder their work.

The team at the Royal provide an excellent service for my daughter. The team are top class. The facilities are very good and my daughter receives fantastic care. The parking is a nightmare!

Appointments are an 80-mile journey away – more time missed from school and exhausting for child. Service is excellent and a great comfort. Weekend contact is difficult and that's often when he is ill. I would be reluctant to try and contact the team at weekends.

CF consultants, CF nurse and physio are outstanding. We have total confidence in their care of our daughter. We are aware though they work over and above their required hours.

The food is very poor; very bad choice. The same food is on the menu all the time. Definitely could be more on the menu which is suitable for children.

We just couldn't praise the team enough; they have been at our beck and call and supported, answered and guided us through every question, query and anxiety!

Our son has been treated at RBHSC since birth. The standard of care is excellent – a real team effort. They are cooperative, caring and always consider the individual child's needs to ensure excellent service. They should be highly commended. The only issue is parking at the hospital site, especially at the Children's Hospital – it's too small and often used by staff!

The medical staff and clinical nurse specialist and dietitians are excellent – always approachable, available and helpful. Our experience with the physios has been mixed – some individuals more helpful than others. I have had difficulty contacting the social worker recently and have found her unable or unwilling to help me in the past, e.g. with DLA renewal. I think this is due to time pressure. Maybe there should be a second social worker. Parking is a nightmare. We have a one-hour drive to Belfast and then often queue for 30–40 minutes to get into the car park. I am often on my own so can't take my daughter straight into the hospital while someone else parks the car. I also have a baby with me. It's all very difficult, especially if we have a 9am appointment, although the team doesn't seem to mind if we are late.

My only problem with the Royal is parking at peak times. Parking can take an hour or more at times, not great when you have a sick child to be seen at the hospital.

The CF team has very approachable, friendly staff. I particularly valued the support of the community nurse in my son's first year and feel they really do look at the patients as individuals – the care is second to none.

The team is brilliant; very dedicated people. Car parking is terrible though!

The CF team at the Royal Belfast is very good. They have been good to both myself and my daughter over the years. We will be sad to move on when she reaches adulthood.

Couldn't meet nicer people. Very helpful. Anything you ask for they try their best to get it. 10/10.

I have always found the staff fantastic. They are always available and easy to speak to.

Overall the CF team is excellent. They provide an accessible service and are always quick and prompt with any queries I have. My only negative aspect is on days of review appointments. There is always a delay in the X-ray department. The day is made so much longer because of this, and is frustrating for the child.

Children's CF team is fantastic to both us and our son. Couldn't ask for better; very dedicated CF team.

CF team is always very helpful. The only problem I have with the hospital is the car parking; it is terrible. When your child is in hospital the food is terrible; it needs to be improved.

I cannot praise my CF team enough. They are committed, patient, knowledgeable experts. We have followed their advice and recommendations regarding treatments and in doing so believe we have helped our daughter have a good quality of life.

The CF team is fantastic as far as I'm concerned. Go out of their way to help.

The Royal Belfast Hospital for Sick Children – CF unit provides an excellent service to our family with a team that is 100% dedicated and committed to our daughter.

I only use one word when talking about the CF team at the Royal – excellent. I hope they continue to keep up the great work.

Would be very beneficial to have physio visit home, as child is very stressed at hospital.

Could not fault the CF team in Belfast. Only fault of hospital is poor car parking.

Response time at outpatients is good, however, due to only one physiotherapist on duty, time waiting is too long – especially for children who have travelled far.

Letters that are sent out need to be more specific about ages to get certain vaccinations.

The CF team is outstanding. Their professionalism, care and support is second to none. They have made living with CF so manageable for us as a family because we know they are always there when we need a quick response to a concern/ problem. We feel very fortunate to have such an excellent service we can rely on.

I find the CF team great, but sometimes yearly assessments (MOTs) can take all day and are tiring for the child. I think clinic could run quicker; (more staff) especially physiotherapists.

Belfast Hospital provides excellent service, with some tired facilities. We pay for the services as we live overseas and therefore only attend for annual review on a yearly basis.

Always pleasant, caring, approachable and helpful; I couldn't fault them!

The staff on the CF team are very polite, approachable, knowledgeable and professional. We feel very lucky that this team deals with our son.

Lack of car parking and queues for car park. Each one of the CF team is excellent. They have given us a great understanding of all areas in CF and answer any queries in an honest way. They have been great support, especially during the first year of diagnosis, and have left us very confident in caring for our daughter. We have a genuine team looking after us. My dinky issue is lack of car parking spaces at RBH. I found it very stressful driving for one hour and then having to queue for a car park space with a young child.

Excellent service provided from past experience. Admissions at weekends: CF team not on duty. Procedure has also changed for admission now; I think you have to wait in A&E. In the past, straight to ward which was excellent. Suggestion: Two physios needed at clinics/annual assessment as always two/three doctors and have to wait for physio. All testing not done like bleep tests, as there's a physio shortage.

I don't like walking through people smoking at the front doors, it's terrible. The nappy changing stations could be cleaner. CF team fantastic.

Very difficult to get swabs done from CF community nurse especially in the winter. Another community CF nurse would be invaluable, so all the province could be covered as resources are very stretched. Nebulisers/compressors and components always seem to be in short supply. The team is excellent but work with very limited budget from Belfast Trust who very recently tried to close inpatient beds.

Brilliant, professional team.

Excellent service from all staff on Allen Ward and in CF team.

Very conscientious team; very dedicated. Many thanks.

Make the whole experience so much easier. Thank you

We will miss the team when we move onto the city.

The team in my opinion is excellent. Very easy to talk to; couldn't ask for better.

Excellent, committed team.

Very approachable, great advice.

Appendix 5

Patient/parent interviews

Patient 1

Parent of 16-year-old girl with cystic fibrosis. The girl was diagnosed as a baby; she has two non-CF siblings.

- When she was born, the mother found that diet was the hardest thing to cope with. An instructional video was given for physiotherapy; she would have found it useful to have a physiotherapist home visit, even just for reassurance regarding the technique.
- The girl has been admitted for intense physiotherapy. Her mother thinks that home visits from the physiotherapists would be beneficial and would mean one less bed occupied, financially a good thing. The mother carries out home IVs. The physiotherapists and the nurses are very caring. The consultants speak directly to the patient, which is good.
- The weekend team is good, however not as good as the specialist CF team. The patient received awful service recently through lack of staff knowledge of what was required for CF treatment. The patient was not offered breakfast during all the time the CNS was away.
- Vouchers are issued for meals and are used in the canteen. The patient likes to have the fry-up breakfast. The parent is now known to the canteen staff and can get the meals on behalf of the patient. The patient often has takeaways delivered to the hospital; these are paid for by charity money, which the nurses issue.
- The parent can queue in the car parking queue while the patient attends the clinic appointment. However, the patient can be out before the parent has found a space. Improved parking would be helpful.

Patient 2

Female, 13 years old. Has one younger sibling. She lives near to the hospital. Her mother does drive to the hospital and finds the long wait at the car park a problem.

- She has been admitted to stabilise her diabetes. She does not like the food from the canteen and her family bring in her meals. On a typical day, she does not have any breakfast. She will have toast for lunch and her mother will bring in an evening meal.
- She thinks the nurses and staff are nice and enjoys the peace and quiet of her room. She receives physiotherapy twice daily and also goes to the gym to exercise. When she is well enough, she takes part in school PE (football and gym).
- She thinks the rooms could be more colourful, either by redecorating or pictures on the wall, as they are very drab. Room is also very cold and draughty from the aging double glazing, with large gaps visible around the windows.
- She likes to play board games, however the problem is finding someone to play with. She can sometimes feel lonely. Her main visitors are her mother and sister, sometimes her auntie, at weekends her daddy. She does have outside contact via her mobile phone and also Facebook.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Hospital Name	The Royal Belfast Hospital for Sick Children
	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	A large general waiting area for all, however, as up to 20 patients can attend one clinic it is inevitable that patients meet while waiting.
Do patients spend any time in the waiting room?	Yes	0–5 year olds in particular have to wait. There is a possibility that patients come into contact with each other. Although staff do try to separate patients, this can be stressful.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	In a curtained-off area	Two height and weight areas. Patients enter one after another, no cleaning in between.
Where are the lung function tests done for each visit?		In clinic rooms. MRSA/B. Cepacia tests carried out in physiotherapy room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	No	
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Patients attend the Monday diabetic clinic.
Transition patients – can they get a tour of outpatient's facilities?	N/A	
Transition/new patients – do they get an information pack?	No	Once diagnosed, the doctor brings the family to the hospital outpatient clinic and introduces them to the team.

Additional comments

- Clinic is shared, with a total of five clinic rooms. There are three clinic rooms for doctors, a dietitian room and a physiotherapy room available for CF use. Patients move around the rooms to see the MDT (patients with MRSA etc. would remain in one room and staff visit them).
- The rooms are bright, roomy and well equipped.
- After screening, the doctor visits newly diagnosed families at home, wherever this may be in Northern Ireland. The family is brought to the clinic, introduced to the team and given the doctor's own personal mobile number for contact at any time.
- There is a shop for general use in the hospital reception area. This is near to the outpatient clinic. Inpatients are advised not to use the shop during clinic times, with cross infection in mind.

Environmental walkthrough: ward
Ward name: Allen Ward
Microbiology status: All

		Hospital name	The Royal Belfast Hospital for Sick Children
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Suitable
Are there side rooms available for CF care (if overflow facilities required)?		Yes	All CF patients are allocated their own room.
Number of side rooms?		3 2	Allen Ward Cherry Tree Ward Belvoir Ward – infectious diseases ward used as required
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes – Shower	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		No	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Cot beds are available for use in the rooms. Cherry Tree Ward: One of the patient rooms can now be used by family if not in use by patients.
Visiting hours – are there allowances for CF patients families out of normal hours?		Yes	Open hours.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a fridge/ microwave either in the side rooms or in the parent's kitchen?	Allen Ward – No Belvoir Ward – Yes	Allen Ward: No access to microwave. Parents are not permitted to use the ward kitchen or drink hot drinks in any of the patient rooms. Belvoir Ward: Two of the rooms have fridges. Separate from the ward kitchen, there is use of a parent kitchen with microwave, toaster, kettle and fridge.
Are there appropriate play facilities?	Yes	Play specialist will take toys to rooms. However, play therapist locks away DVDs at weekends.
What facilities are provided for teenagers?		Xbox, laptops. Patients can bring in their own tablet, iPad, etc.
Is there access to a gym or exercise equipment in the rooms?	Yes	Cherry Tree Ward: Gym for use, a good space with trampette, exercise bike, weights, treadmill and large climbing frame. Also a gym area in physiotherapy dept.
What facilities are there to help with school and further studies?		Two ward-based teachers available.
Is there a relatives' room?		Allen Ward – No
What internet access is there?		Wi-Fi
What facilities are there to enable students to continue work and study?		Allen Ward: None Belvoir Ward: None Cherry Tree Ward: Rooms have desks.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Basins in the bathrooms to be used for this, sinks in rooms for hand washing only.
What facilities are provided for those with MRSA?		Admitted to rooms in Belvoir Ward.
What facilities are provided for those with B.Cepacia?		Admitted to rooms in Belvoir Ward.
What facilities are provided for those with other complex microbiology?		Admitted to rooms in Belvoir Ward.
Are patient information leaflets readily available on ward?	Yes	Available on request.
Transition patients – can they get a tour of ward facilities?	Not normally	Visit possible on request.

Additional comments

- All patient notes are kept locally for instant access in a central office near the CF team office.
- Allen Ward side rooms: Good sized rooms. TVs, basin with good en-suite facilities.
- There are supposed to be two parent rooms for use off Allen Ward. However, these have not been renovated and door access to these makes them unusable at present. There is potentially the facility of a kitchen area and two bedrooms.
- Belvoir Ward: A smaller ward, although has larger side rooms.
- Patients have the telephone numbers of the nurses for 24/7 contact if needed. They can also call ward nurses at any time.
- The newborn screening doctor service covers the whole of Northern Ireland.
- There is sometimes an issue with the waiting time for admission for IVs.
- Treatment room: This is shared with gastroenterology. There is a diary used for booking both; this system works well. Large, well-equipped, bright room with TV for use with DVDs for distraction.

Environmental walkthrough: other

	Hospital name	The Royal Belfast Hospital for Sick Children
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Inpatient families can request a free pass from staff.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, e.g. radiology, pharmacy, bone mineral density (DEXA) scanning?		X-ray waiting times are an issue. It is reported this is due to understaffing.
Do patients have to wait at the pharmacy for prescriptions?		The pharmacy is in the main building. Prescriptions are sent via a pod and the patients wait for them in the ward, although this can be a long wait. Outpatient prescriptions are prescribed by GP.
Patient information		
Is the patient advice and liaison service (PALS) well-advertised – leaflets, posters?	PALS is not used within NI	There is a complaints procedure and department.
Are there patient comments/ feedback boxes?	No	

Additional comments

- Car parking: This is a single-storey car park. There are only 83 spaces available. It can sometimes take one-and-a-half hours to get a parking space, and patients/parents have to queue for these spaces. There is an inadequate number of disabled spaces, although these are free.
- Travel expenses: The office for travel expenses has now closed. Some parents cannot afford to come to clinic due to the slow refund process. Staff use petty cash to cover expenses for families.

Appendix 7

Panel members

Dr Siobhan Carr*	Consultant
Sue Wolfe	Dietitian
Mandy Bryon	Psychologist
Amanda Bevan	Pharmacist
Elaine Dhouieb	Physiotherapist
Sandra Hall	Clinical Nurse
Ursula Peaple	Commissioner
Angela Mills	Social Worker
Lynne O'Grady	Head of Clinical Programmes
Sophie Lewis	Clinical Care Adviser

*Clinical lead for peer review panel

Appendix 8

Additional information

Hospital managers met with the peer review team to discuss current funding arrangements, the line management structure of the cystic fibrosis service, strengths and weaknesses. The Northern Ireland funding comes as a block contract for the Children's Hospital, with no ring fencing of monies for any individual services. However, they have a good two-way communication around development of services with the commissioners, and the aim for the next financing round was to prioritise the cystic fibrosis service. Areas of the service that have a single-handed element were highlighted, as these have been recognised as priority areas in the past.

The CF service appeared to have several areas that will need review around succession planning, and consideration given to removing the onus on individuals running them single-handedly. There is a newborn screening service for Northern Ireland that is run by one doctor and one nurse specialist. It has a rapid response time with good contact with families who have infants screened for suspected CF. Although the service has been an excellent example for many years, it is vulnerable because of a lack of depth of staffing.

There is a unique post in microbiology that also provides both microbiological surveillance and input into various databases for cystic fibrosis. Again, future planning will need to take place to allow cross-cover or review of provision of this service in the future.

There was universal praise for the administrative staff (clerical and secretarial) from the team.

cysticfibrosis.org.uk