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British Thoracic Society

BIPRS

Peer review report

Great North Children's Hospital (Royal Victoria Infirmary paediatric)

5 March 2015

Contents

1. Executive summary

Overview of the service

The Newcastle-upon-Tyne paediatric cystic fibrosis (CF) service cares for around 190 children. They have a shared care arrangement with North Cumbria University Hospitals (NCUH) (Carlisle and Whitehaven) and outreach clinics in Sunderland. Recently, there have been significant changes to the service due to consultant turn-over and a reduction in the number of hospitals with whom they share care. The multi-disciplinary team (MDT) is appropriately skilled and experienced but the absence of a psychologist is a significant concern. This was not addressed after the previous peer review and continues to impact on the other members of the MDT as they have to provide psychological support for patients and families, which they are not trained to do. The team is also under-staffed in terms of pharmacy support.

Good practice examples:

- The MDT is experienced, enthusiastic and hard working. There is good communication within the MDTs and all members ensure their knowledge is up to date by regularly attending local, national and international meetings. All members of the MDT are highly regarded and valued by patients and families.
- The facilities available for children with CF are excellent. The purpose-built inpatient wards and outpatient department at the Great North Children's Hospital (GNCH) are clean and child-friendly. The school and parents' accommodation are also especially impressive.
- The team has a strong history of academic research with a good output of presentations and publications. This ethos is present within all the disciplines of the MDT.

Key recommendations:

- There is an urgent need for a psychologist to be employed as part of the paediatric CF MDT. At present, psychological support is provided ad-hoc by other members of the MDT. They are not formally trained to do this and it adds to their already large workloads. This model for psychological support means patients only receive it when a crisis occurs and there is no provision for preventative strategies. This recommendation was made at the previous peer review but no appointment was made. All members of the MDT recognise the advantage of a having a psychologist as part of the team.
- After the last peer review a 0.5 whole time equivalent (WTE) pharmacist was employed by the CF team. The benefits of this post are clear as they have taken on a number of roles and responsibilities. The Cystic Fibrosis Trust's 'Standards of Care (2011)' suggests there should be a 1.0 WTE pharmacist for 188 patients. This increase would allow additional roles to be taken on by the pharmacist, particularly support for the annual review clinic.

Areas for further consideration:

- Children attending the outpatient department have their spirometry performed in the lung function room prior to being placed in an outpatient room, which they stay in for the whole visit. Although clinics are segregated, this presents a possible cross-infection risk and the panel suggests that lung function is performed in the outpatient room (as is already done for the Non-Tuberculosis Mycobacterium (NTM) Clinic).
- Children being admitted to an inpatient ward have to be admitted through A and E. This can sometimes result in significant waits prior to the child being seen. We suggest children are admitted directly to the paediatric assessment area or the ward to prevent this.

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

Models of care

Summary

- Patients are seen more frequently than the minimum recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)'.
- The MDTs at Newcastle-upon-Tyne and NCUH are well staffed and they maintain their continuing professional development (CPD) appropriately.
- There are appropriate referral pathways for other medical and surgical disciplines (all available at the GNCH).
- Microbiology samples are processed appropriately.
- Clear local guidelines.
- Strong history of audit and publications.

Multidisciplinary care

Summary

- The absence of a psychologist and the deficit in pharmacist time at Newcastle-upon-Tyne are the identified deficiencies in the MDT.
- Joint clinics with the paediatric diabetic team are held at the GNCH as recommended in the Cystic Fibrosis Trust's Standards of Care.
- All members of the MDT attend the shared care clinics at NCUH and the outreach clinics at Sunderland.

Principles of care

Summary

- In general, there are good infection control policies in place. Undertaking spirometry for all children in their outpatient room rather than the lung function room would improve this.
- The outcomes for the children in terms of the prevalence of chronic *Pseudomonas aeruginosa*, lung function and BMI are consistently good.
- Manifestations of CF and CF complications are screened for and treated appropriately.

Delivery of care

Summary

- Outpatient clinics are segregated. Facilities are good or excellent. All members of the MDT are available at each visit.
- Inpatient facilities excellent and all rooms are en suite. Inpatients are reviewed regularly by all members of the MDT.
- Significant improvements have been made to the annual review process which is now more robust.

Commissioning

Summary

The paediatric CF service at the GNCH is a well-established service with a cohort of 172 children, with 13 children receiving shared care at North Cumbria University Hospitals NHS Trust.

Band	NuTH	Cumbria	Total
1	64	7	71
1A	9	1	10
2	29	1	30
2A	29	1	30
3	25	2	27
4	2	1	3
∑	159	13	172

The service is funded via the national year of care tariff and it is assumed, though not confirmed, that Newcastle-upon-Tyne Hospital fund the shared care given to the Cumbrian cohort by North Cumbria Hospital staff.

As with most CF services, the level of dedication and skill of the clinical staff and supporting staff is impressive and, at Newcastle, special mention should be made to the quality of the facilities with GNCH. The main area of concern is with regard to staffing levels and, in particular, a shortfall of two consultants.

Areas of good practice:

- The service is funded via national payment-by-results year of care tariffs.
- Good working relationship with local specialised commissioner.

Areas for improvement:

- Shortfall in recommended staffing levels.
- Although staff shortages were flagged in the self-assessed derogation return, only a shortfall in psychology input was raised in the Trust's action plan with a completion date of 31 March 2015. As at 10 April, the Trust has not advised that the action plan has been successfully completed.
- Not unusually, the understanding between the service and the Trust's management team did not appear to be particularly strong. There is no doubt the service and management teams talk and discuss the service, but there was, for example, no inkling that the service understood the level of income and the difference between income and budget, and didn't appear to appreciate that changes in the size of the cohort or case mix should produce sufficient income to meet changes in staffing requirements.
- Previously City Hospitals NHS Foundation Trust provided shared care for children local to Sunderland. Newcastle-upon-Tyne Hospital decided, without consulting the commissioner, shared care would be replaced by an outreach service. Whilst there is no doubt the quality of the service has not been diminished, the actions of Newcastle-upon-Tyne Hospital indicate a disregard for the role of the commissioner and does nothing for staff shortages. Because of the additional travel associated with outreach clinics, such a change must place additional strain on clinical staff.

Recommendations:

- The Trust must revise the derogation action plan to advise the commissioner whether or not the original actions regarding psychology support have been completed, indicate the total staff shortages and how and when the Trust will fill the staff vacancies. The year of care tariff funds the service to full staffing levels and the Trust has an obligation to staff the service to full national standards.

- The Trust cannot change the delivery methodology of the service without consulting with the commissioner. The commissioners commission the service, and the Trust does not sell a service to the commissioner.
- The Trust should involve the service in contract matters and, conversely, the service needs to ensure the management team understands where any service shortfalls are to ensure commissioners are not only advised of non-compliance during peer reviews. The Trust needs to accept year of care tariffs fund a fully compliant service, and there is no discretion about staffing levels and other key performance indicators.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	Total Network 168; Newcastle 150, Whitehaven 3, Sunderland 15

			Male	Female
FEV_1	Number and % of patients with FEV_1 <85% by age range and sex	0–3 years	0	0
		4–7 years	2 (17%)	2 (10%)
		8–11 years	3 (25%)	8 (38%)
		12–15 years	3 (25%)	7 (33%)
		16+ years	4 (33%)	4 (19%)

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	n=7; 2 (29%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	15 (10%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	15 (100%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	3 (20%)
	Number and % of patients on chronic macrolide without chronic PA infection	7 (5%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

Dr Christopher O'Brien (Clinical Lead) and Dr Malcolm Brodlie (Academic Lead) are currently providing the consultant cover for the paediatric CF service. They are both experienced clinicians. Two consultant posts are currently vacant following the early retirement of Dr David Spencer and the generation of a new post. These jobs have been advertised and the interviews are taking place in March 2015. Once these posts are filled, there will be adequate sessions to cover the CF service and allow cover for annual/study leave. There is a paediatric respiratory consultant on-call 24/7 to provide cover for children with CF. A CF MDT ward round (including consultant) occurs twice per week. The Newcastle team have a shared-care arrangement with NCUH (Carlisle and Whitehaven) and do outreach clinics at Sunderland. There are plans to start an outreach clinic at Darlington later this year. Dr Ben-Hamida is the consultant at NCUH and is very happy with the support he receives from the Newcastle team.

Three areas of good practice:

1. Excellent relationship with MDT.
2. Innovative working for patient benefit (e.g. evening clinics).
3. Strong academic record.

Three areas for improvement:

1. Need to fill the two consultant posts.
2. Gaps need to be filled in the MDT: appointment of a psychologist and increase in pharmacist time.
3. There can sometimes be a delay in inpatient bed admission.

Specialist nursing

The staffing levels are 3.6 WTE. The Cystic Fibrosis Trust's Standards of Care recommends two Clinical Nurse Specialists (CNS) to 75 patients.

The panel only met the team from GNCH and did not have the opportunity to explore experiences with staff from the shared care centre, which may have been beneficial. They are members of the Cystic Fibrosis Nursing Association (CFNA) and some are nurse prescribers.

Areas of good practice:

- Well established, experienced CF nursing team with good peer support putting their patient's wellbeing at the centre of service delivery.
- Very good user-friendly inpatient provision with spacious en suite cubicles. Knowledgeable ward staff are well supported by CF nursing team.
- Flexible outpatient clinic appointments to suit microbiology status offering evening appointments too.

Areas for Improvement:

- Out-of-hours patients are admitted through A and E. There is no longer an open access to the ward provision.
- Lung function performed in the same room for each patient. This could be done in the patient's allocated room.
- Psychological input as part of the CF MDT so the service is accessible and seen by the child and family, from diagnosis as an integral component of the CF management.

Recommendations:

- Consider appointing a psychologist.
- Review the out-of-hours admission process.
- Invite shared care staff to next review.

Physiotherapy

The physiotherapy team has excellent relationships with patients, MDTs and the shared care centre and is experienced, forward-looking and innovative. The service is 3.3 WTE broken up as: 0.7 WTE Band 8a, 1 WTE Band 7, 1.3 WTE Band 6 (Newcastle-upon-Tyne) and 0.3 WTE Band 8a (Cumbria). As with the rest of the team, funding for study leave is an increasing issue but members of the team have attended national and international meetings.

Lead of service is the Vice Chair of the Association of Chartered Physiotherapists in CF (ACPCF). There is good cross-cover for absence, although only for inpatients in Whitehaven. The team has a good track record in research and audit, although this is limited by clinical commitments. The team is appropriately involved in all stages of care from diagnosis to transition.

Areas of excellence/good practice:

- Well-staffed, supportive, experienced team in Newcastle and Cumbria with excellent MDT and shared care working relationship. Enthusiasm and knowledge of audit, research and service development.
- Working to national and international standards of care with close involvement with national professional group ACPCF.
- Able to offer wide range of treatment options and equipment in all areas of CF physiotherapy care.

Areas of improvement:

- Lack of protected time for research which is 0.5 WTE of 8a job description.
- More structured MDT annual review process done outside clinic time.
- Erosion of CF specialist physiotherapy clinical time by senior staff working nine-day fortnight to provide cover for Tuesday evening clinic and after school community visits. Band 6 part of seven day working which means lose two weekday days per fortnight; inability to use on-site parking with permit adds considerable time, up to 20 mins each way, to every community visit.

Recommendations:

- Succession planning for outreach clinic post-holder who retires this year.
- Consider alternatives to erosion of specialist weekday service by seven day working.
- Support for clinical lead to enable 0.5 WTE research time.

Physiology report

The service has 1 WTE physiologist for respiratory and all specialties and 0.5 WTE for sleep. It is a small, relatively new service which is innovative and up-to-date. There is excellent support within the MDT and externally from other respiratory physiology services. Staff are able to attend national respiratory physiology meetings. There is cross-cover at the moment but 0.5 WTE post holder is about to go on maternity leave.

Areas of excellence/good practice:

- Enthusiastic, innovative and experienced staff well supported externally and by the MDT.
- Up-to-date equipment and facilities.
- Mainly good practice.

Areas of improvement:

- Best practice exercise testing would be cardiopulmonary exercise test by respiratory physiologist rather than modified shuttle test by physiotherapists.
- Increase in staffing to allow more dedicated time for respiratory.
- Relatively new service and now being used by all specialties.

Recommendations:

- Urgently need to do spirometry in patient's room in outpatient rather than one room due to cross-infection issues.
- Proactive management to ensure small number of staff not expected to take all referrals from all specialties as benefits of respiratory physiology become recognised.

Dietetics

Great North Children's Hospital

- Staffing based on 0.5 WTE. Three paediatric dietitians: Band 8a 0.6 WTE – over 20 years' experience and two Band 6 posts providing 0.6 WTE each service to CF. These dietitians were new to the service in September 2014. All provide cover for each other and cover to other areas of respiratory medicine, which can impact on the CF service.
- Only 8a dietitian is a member of the UK Dietitians' CF Interest Group (UKDCFIG) and has attended meetings. The 8a dietitian has actively participated in numerous European CF conferences and has been a past chair of the European CF Nutrition Group. North-East CF club meetings are attended by all dietitians. Attendance at national/European meetings is limited due to funding issues.
- A dietitian is present at all CF clinics, MDT meetings and ward rounds. Inpatients are seen on a daily basis. A home visiting service (mainly infants) is also provided and the outreach clinic in Sunderland is fully covered. The band 8a attends six shared care (Carlisle and Whitehaven) clinics per year. A dietetic annual review is carried out on all patients.
- Patient information/nutritional care protocols developed by the dietitians are excellent.
- There is active involvement in patient care at all key life stages including transition.
- The band 8a dietitian has extensive experience in research and audit and encourages and supports Band 6 involvement.
- Hospital catering is good with a wide choice of meals/snacks available. The food is a mixture of in-house catering and cook/chill. There are good relationships between the dietitians and catering and a diet chef is available if a special diet is required.

North Cumbria University Hospital (Carlisle and Whitehaven)

- Staffing 0.1 WTE Band 6 (six years' experience, equivalent to 0.44 WTE). The dietitian is not a member of the UKDCFIG, but is applying. Emergency-only cover is provided by a Band 5/6 dietitian with limited CF experience. There are plans to improve this cover.
- Only the North-East CF club has been attended. The dietitian is hoping to undertake an MSc module in CF nutrition in the near future.

- Monthly CF clinics and MDT meetings are attended and home visits are offered.
- Patient literature is shared with Newcastle-upon-Tyne.
- Newly diagnosed infants are seen in Newcastle-upon-Tyne, so experience in this area is limited. There is no formal arrangement for transition.

Areas of good practice:

- Proactive and dedicated dietetic team with quality assurance measures in place and excellent provision of clinical supervision for Band 6 dietitians in Newcastle-upon-Tyne.
- Excellent patient information and care protocols, shared by all.
- Ability to provide home visiting support to patients throughout the network.

Areas for improvement:

- Improved education for all Band 6 dietitians by attendance at national and European conferences and sharing educational opportunities within the team, especially with the dietitian in North Cumbria.
- Improved cover for the dietitian in North Cumbria.
- Protected time for research and audit for Band 8a dietitian. Better facilities for research/audit for all dietitians e.g. electronic patient data/records.

Recommendations:

- The Band 6 dietitians in Newcastle-upon-Tyne and the dietitian in North Cumbria to join the UK DCFIG.
- Increased development opportunities for all Band 6 dietitians. The dietitian in North Cumbria should visit and shadow the dietitians in Newcastle-upon-Tyne.
- Protected time for research and audit for all dietitians.

Pharmacy

All children in the region are looked after by the team at GNCH. The team visit Sunderland Royal Hospital to provide outreach care for patients in the south of the region and Carlisle/Whitehaven to the west but this does not include pharmacist support. The CF care team identified 0.5 WTE pharmacist time, this is currently Band 7, and the pharmacist works full time, with the other 0.5 WTE of their role being general paediatrics.

There is ward-based support from a medicines management technician (MMT). The pharmacist is able to attend weekly MDT meetings and support the team with homecare provision and writing medicines related guidelines. The pharmacist is a member of the CF pharmacists group (CFPG) and attends the group's annual study day when possible and contributes to the CFPG forum. They have attended the European CF conference in the past and attend the local CF meetings for the north region.

Standards:

Number of patients	Staffing standards for CF pharmacist
188	1 WTE

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

Funding is already in place for 0.5 WTE Band 7, so increased staffing for 0.5 WTE 8a plus small increment to uplift current band.

Inpatient Services

- When the patients are admitted, they are seen and a formal medicines reconciliation is performed, but this is a relatively small cohort of patients.
- There is support from an MMT on the respiratory ward only. Patients admitted to other wards do not receive this service.
- In-hours there is good availability of pharmacist time to answer queries and provide medicines management support.
- Outliers are hard to flag, but the other paediatrics pharmacists will flag difficult patients (e.g. those with NTM) to be seen by the CF specialist pharmacist.
- Patients do not have their IVs provided via in-house CIVAs when on the ward, but are able to access this for home IV courses.

Outpatient Services

- Patients are not routinely seen by a pharmacist at annual review clinics or other clinic appointments.
- Home IVs are provided by the in-house manufacturing service for Newcastle-upon-Tyne patients and by Bupa for ten patients in the Sunderland area.
- Bupa provide delivery of high-cost treatments. All prescriptions are screened by the CF pharmacist.

Other

- Finance reporting is limited by lack of available time.
- Paediatric CF pharmacist is lone worker and relies on access to UK e-mail forums for support.
- Pharmacist is a qualified prescriber.
- Not involved in transition currently.
- Has been involved in CF specific audit/research in the recent past.
- There is no back-fill for absences.

Areas of good practice:

- Pharmacist has a good working relationship with the rest of the CF MDT.
- Pharmacist attends MDT meeting when possible.
- Is still able to screen and organise IV and high cost medicines prescription. This identifies errors and reduces excess spend.
- Pharmacy technician support allows better use of skill mix.
- Pharmacist maintains good level of CPD.

Areas for improvement:

- Insufficient staffing is having a significant impact on the service the pharmacist can provide. There is a significant shortfall against the Cystic Fibrosis Trust's Standards of Care and, as a consequence, the pharmacist is not able to provide the expected level of service at annual review.

Recommendations

- Improve staffing levels to the Cystic Fibrosis Trust's Standards of Care, i.e. 1.0 WTE Band 8a highly specialist pharmacist. The cost for this could be counterbalanced with savings made in drug expenditure by better medicines management.
- Improve liaison between adult and paediatric pharmacist to provide disease specific support and CPD.

Psychology

Areas of good practice:

- There is clinical psychology support for patients who require a transplant.
- There appears to be enthusiasm in the CF team for clinical psychology sessions.

Areas for improvement:

- Recruit one full-time clinical psychologist – recommended Band 8a and 0.1 WTE Band 8c to offer provision for setting up the service management and supervision.

Social work

Newcastle-upon-Tyne has two very experienced social workers in post that have a vast amount of knowledge and experience. They are very highly thought of by all the professionals within the MDT and by the ward staff. They both work 0.5 WTE, making the 1.0 WTE which is meeting the required standards.

They are based in Barnados, a short distance from the hospital. The positives of this are they have the guidance and support on a daily basis from a social work team. This enables them to see patients outside the hospital setting and they are able to see patients within their own homes. There is a good referral system by email or telephone contact and are able to respond in a timely manner.

They feel fully integrated in the MDT and attend MDT meetings on a regular basis. Their priority is to see patients due to the demands on their service. Both social workers are able to offer both practical support, in the form of advice on benefits/employment/housing/form-filling and emotional support.

It is clear they are having to support psychology issues. Paul receives psychological support within his adult CF social worker role and has seen how this has been very positive for the patients and the MDT. Jill leaving will place added pressure until a new person is integrated into the team.

The social work team is not able to attend annual reviews, but have produced a specific questionnaire and have leaflets to advertise their service. This is not ideal and it would be good to show a proactive approach to gaining relationships before a need arises. It will be important to assess the effectiveness of this approach.

It is clear the social work team is staffed to the Cystic Fibrosis Trust's Standards of Care, however the service is busy and resources are stretched. Paul is trying to meet the demands of the adult CF team which is not staffed to the guidelines, which will be addressed within the peer review forum.

Strengths and areas of good practice:

- A committed and experienced team who know families well and have a wide knowledge of cystic fibrosis.
- The team seeks appropriate support from the safeguarding children teams and local resources in the appropriate areas.
- Very good social work outreach support and home visits.

Identified areas for development or improvement:

- The social workers meet families at diagnosis. As an opportunity for proactive engagement, it will be important to review the effectiveness of recent annual review developments.
- Psychological support needs to be explored to ensure added pressure is not put on the social work team.
- When the team change over to electronic notes, the possibility to be explored that social work team can access and write on notes remotely.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	12	8	12	1
Female	15	3	5	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	46	3	1	0
From the ward staff	27	13	0	1
From the hospital	33	12	3	0

Areas of excellence:

1 Accessibility – approachable/flexible.

2 Cleanliness – always clean.

3 Communication – caring wanting the best for your child.

Areas for improvement:

1 Outpatient waiting times – 4-5hrs waiting.

2 Food – no additional snacks/processed food.

3 Car parking – no concessions.

4 Out of hours – through A and E not through ward.

6. Appendices

Appendix 1

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

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

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

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

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

Hospital name

Great North Children's Hospital

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	
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	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	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	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of 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	Need to do spirometry in child's outpatient room not the lung function room.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Red Plan to run extra clinics to meet this	Green	Processes not in place to ensure this is met.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red Discussed routinely not documented	N/A	Clear documentation needed.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Amber	Amber	Some delays in clinic letters being sent out.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Amber	Amber	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red Not allowed to recruit a dedicated psychologist	Red	Urgently need to appoint a clinical psychologist.
	% availability of a clinical psychologist for inpatients	100%	Red	Red	See above.
	% availability of a social worker at clinic	100%	Green	Green	
	% availability of a social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Green	Amber	Pharmacist not able to give input at annual review clinics due to lack of time. Increasing pharmacist time to 1.0 WTE in keeping with the Cystic Fibrosis Trust's Standards of Care would address this.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0		
5.2	Number of clinical incidents reported within the past 12 months	<1%	2%		
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Red Still being clarified	Red	SLA need to be established with shared care centres and outreach centres.

Appendix 2

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Great North Children's Hospital
Consultant 1	0.5	1	1	0.4 WTE
Consultant 2	0.3	0.5	1	0.4 WTE
Consultant 3			0.5	Vacant
Consultant 4 (transplant)				0.2 WTE
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	1 WTE
Specialist nurse	2	3	4	3.6 WTE
Physiotherapist	2	3	4	3 WTE
Dietitian	0.5	1	1.5	1.8 WTE
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	1 WTE
Pharmacist	0.5	1	1	0.5 WTE
Secretary	0.5	1	2	1 WTE
Data manager	0.4	0.8	1	0.54 WTE

Appendix 3

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre – Great North Children's Hospital	
Number of active patients registered (active being patients within the last two years)	188 total network
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	Total Network 168; Newcastle 150, Whitehaven 3, Sunderland 15
Median age in years of active patients	8
Number of deaths in reporting year	0
Median age at death in reporting year	n/a

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	0–3 years	39 (26%)
	4–7 years	34 (23%)
	8–11 years	25 (17%)
	12–15 years	29 (19%)
	16+ years	23 (15%)

Genetics	
Number of patients and % of unknown genetics	9 (6%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)	
Patients with a BMI percentile <10th centile on supplementary feeding	n=7; 2(29%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	2 (17%)	2 (10%)
	8–11 years	3 (25%)	8 (38%)
	12–15 years	3 (25%)	7 (33%)
	16+ years	4 (33%)	4 (19%)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	39
	4–7 years	34
	8–11 years	25
	12–15 years	29
	16+ years	23
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	9
	16+ years	6

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	1 (0.7%)
Number and % of *cenocepacia*	1 (0.7%)
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (0.7%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	17 (11%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	17 (11%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	9 (6%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH; 1(0.7%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	1
Number of patients referred for transplantion assessment in previous three years	2
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	90
	4–7 years	107
	8–11 years	164
	12–15 years	296
	16+ years	224
Number of days of home IV therapy in reporting year split by age group	0–3 years	30
	4–7 years	54
	8–11 years	187
	12–15 years	357
	16+ years	271
Total number of IV days split by age group	0–3 years	120
	4–7 years	161
	8–11 years	351
	12–15 years	653
	16+ years	495

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
Percentage of patients aged 5–15 years on DNase	n=78; 26 (33%)
If not on DNase, % on hypertonic saline	3 (4%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	15(10%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	15(100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	3(20%) with chronic PA; 7(5%) without chronic PA

Appendix 4

Patient survey

Great North Children's Hospital

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	12	8	12	1
Female	15	3	5	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	44	7	1	1
Communication	39	9	2	1
Out-of-hours access	23	15	4	2
Homecare/community support	38	6	0	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	33	15	2	1
Waiting times	16	14	11	4
Cross-infection/segregation	28	14	6	3
Cleanliness	40	9	0	1
Annual review process	31	8	4	0
Transition	10	2	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	19	14	4	2
Cleanliness	25	12	2	1
Cross-infection/segregation	21	10	2	0
Food	11	8	13	6
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	33	4	2	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	27	5	5	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	27	0	1	1
Availability of equipment	33	6	1	0
Car parking	8	12	11	6

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	46	3	1	0
Of the ward staff	27	13	0	1
Of the hospital	33	12	3	0

Comments about CF team/hospital

"The CF team at the GNCH is great for both my son, who is in the children's department, and also my daughter, who is in the adult section, quick response from both teams. Listen to us with any problems when they arise. Excellent service in and outside of the hospital."

"The wards struggle with lack of staff and therefore has a knock-on effect to us. We often get stuck on other wards when we are waiting for a bed and the other wards have little or no CF knowledge. We are treated as the cuckoo in the nest."

"Since my son was born six weeks prematurely in the GNCH, the care we have received has been nothing short of amazing. Always there to help and always made to feel like an individual rather than a number. My son always says he is going to the hospital to see his friends."

"We feel very privileged to be in the care of such an exceptional CF team. Everyone you come into contact with is extremely professional and cares so much about their patients. Couldn't be in better hands."

"My son has received fabulous treatment from such dedicated staff; from his consultants, CF nurses who we as a family have grown up with over the years and consider them as great friends, they all are such an excellent team, every single one of them."

"Everything about our son's care at the GNCH has been excellent. Having moved from care at the Royal Aberdeen Children's Hospital the contrast is unbelievable – in a good way! Free parking at Aberdeen was nice. In a recent 16 day stay at GNCH parking cost us a fortune!"

"We have recently been transferred to the CF team at the GNCH from Sunderland and the CF care has improved greatly. The Sunderland team were good but the CF consultant we now see is a specialist in this field. In Sunderland we saw a respiratory specialist and my son's care has improved greatly. It is a chore to go to the GNCH when you live in Sunderland, but mainly because we have another child and we find it hard to arrange care for her when he is in hospital. SRH was more accommodating."

"All outreach clinics in the Durham area were stopped almost two years ago, this means Newcastle GNCH is the only place anything is done. In my opinion, they cannot cope with the workload and it is very inconvenient having to travel to Newcastle for everything."

"We feel so lucky to be under the care of the CF team at the GNCH and to live so close to the excellent facilities they have."

"Provide excellent care. Always approachable."

"I can't comment on inpatient services as no admission for 10 years. Have had IVs at home over past 10 years which have worked well for us. Can be some delay in pharmacy providing Tobramycin."

"Waiting in clinic is bad sometimes we wait four to five hours in clinic. I also feel sad that parents and children are kept apart at clinics when it is a small area and bugs are about anyway. Sometimes we have waited half hour between consultants, physios etc, however my daughter does receive great care."

"The CF team always make us all feel like an individual. You never feel that they are rushing you or are busy. They make you feel like you are the only person they need to see. They always remember small details about our son to chat to him about. They are so friendly and make everything always seem alright."

"Hospital very good and could not ask any more of the CF doctors, nurses, physios. The help we received and treatment is second-to-none. They do a fantastic job – we are so grateful to them all."

"I love our CF team. They couldn't be better. The waiting times during appointments can be long but I expect that."

"Great team who listen and give excellent advice."

"We are lucky to have a strong experienced team at GNCH who know the patient well. My only uncertainty is there is a lot of chop and change at registrar level so always a relief to see the consultant on most of our visits."

"I cannot fault any of the children's CF professionals. Only concern I have is waiting times at outpatient appointments e.g. 5.30pm but not seen until one hour later."

"Always willing to help – no problem in dealing with hospital CF team. Great support every time they are needed."

"Doctors, nurses and physio are excellent."

"CF team are excellent, always there when need help etc."

"They are a wonderful team."

"The team are always professional and caring. The waiting times can be excessive, however."

"The paediatric CF team at the GNCH are excellent, but from personal experience, I think it would be so much easier if my children were seen by the same doctor each time who knows them and their history. I also think CF nurses should be more available for home visits even just for advice and guidance."

"Very happy with our CF team. Do not like admissions into wards where they have no CF experience (due to errors made)."

"Have felt fully supported through the whole process, always there for advice and a home visit if needed."

"The CF team go out of their way to do anything that makes it easy for my child. I couldn't ask for a better set of people to be looking after my child and his health."

"First class service at GNCH received at all times."

"Feel CF team care about our son. Are very knowledgeable about what is going on in his life/care needs. Very pleased with care we get."

"Never had to stay as inpatient. The CF team at the GNCH are great and we cannot thank them enough for the help and support they give."

"Our daughter ate our food not the hospital's. Most care brilliant, but on weekend child is ill but not very ill it's vague. There is a lot of consistent excellent care."

"Very knowledgeable team, work well together, worked with our family closely to ensure smooth transition from previous hospital as my son found it difficult to accept."

"Fantastic team, however the open access we were told about to ward six on diagnosis was great until the introduction of a news system/pathway. We now access ward six via A and E making a 20-30min appointment/assessment last up to four hours."

"The CF team have been nothing short of excellent and thorough, and I have never had any cause for complaint."

The doctor usually requests to see my son in six weeks from clinic, but there are hardly ever any available more eight weeks then they sometimes get cancelled. Making it ten weeks before he's seen again. Six week appointments are ideal especially getting regular swabs to check for bacterial growth. Ten week appointments are frustrating!

Appendix 5
Parent/patient interviews

Parent A felt segregation at outpatient clinic is really good and children are kept separated from one another. She described good use of hand gel and equipment being wiped down between patients. She felt the CF MDT definitely listen to her and make things easy for her to understand.

Parent A and her son see all of the CF MDT most of the time, although sometimes they do not see the dietitian or physiotherapist. This is dependent on patient need. Parent A added the social worker from Barnardos telephones to catch up and makes home visits on occasions.

Parent A takes prescriptions from outpatient clinic to her local pharmacy/GP surgery.

Inpatient care (ward): Not applicable

Annual review: Parent A's child is offered annual review every year and has recently had this year's assessment. She explained all annual review assessments take place at the GNCH, where they see all of the CF MDT. The outcome of the annual review is reported back to her by letter and if urgent information included, by telephone.

Home care: Parent A's child only has a home visit from a member of the CF team if her son has a chest infection.

Good practice:

- "Flexible appointment booking times."
- "Always clean at the CF Centre."
- "The CF team listen well and explain things well."

Areas for improvement:

- "Provide concessions for car parking which is very expensive."

Parent B is happy with segregation measures at the GNCH. She and her son see all of the CF MDT, though not necessarily the dietitian. This, however, does not concern the parent as she added, "she's there if needed." It was explained a social worker is available, but parent B has never seen a clinical psychologist. She felt the pharmacy waiting experience is a 'bone of contention', with the increased potential risk it presents in terms of waiting and cross infection.

Inpatient care (ward): Parent B's son could not be admitted to the CF/respiratory ward for most recent admission in the last year and so had to be admitted to the neurology suite. However, she felt it caused no problem and was in fact far less of an infection risk.

Parent B felt the ward nursing staff's knowledge of cystic fibrosis was absolutely fine, she had no concerns with the timing of medications and her son was happy with the food provided on the ward – she was very satisfied. Parent B added physiotherapy is provided twice daily, seven days a week.

Annual review: Parent B's child is offered annual review every year, including this year. His annual review is staggered through the year, seeing at different times the whole of the CF MDT. A copy of the annual review outcome is sent to the parent although parent, felt explanations were at times insufficient – e.g. onset of Aspergillus and what it meant.

Home care: Clinical nurse specialist and physiotherapist have visited when necessary – e.g. when her child had a cough, they came to listen to his chest and take a cough swab. They currently do not have home delivery of medications but believed these were 'in the pipeline' for DNase from hospital pharmacy.

Good practice:

- "Can't fault the CF team. They're approachable and flexible."
- "More professional."

Areas for improvement:

- None mentioned

Parent C felt segregation measures at outpatient clinic do not work, adding they arrive and wait in a 'small area' where there is coughing, before being directed to a side room. In the side room the parent and child feel lonely and isolated. Parent C questioned the effectiveness of cross-infection measures, referring to one patient replacing another straight after in the consultation room and her perceived cross-infection risk this causes.

Parent C felt the CF team do not listen to her and she has been annoyed at what she described as 'the time wasted waiting on arrival at clinic, sometimes clinics taking two-and-a-half hours.'

She and her child normally see the whole CF MDT, although not always the dietitian. They have seen one of the Barnardo's team, but have never seen a clinical psychologist and are unsure if there is one.

Parent C waits for one or two hours at the pharmacy in what she described as 'a small, enclosed area.' Her concern is the cross-infection risk at pharmacy.

Inpatient care (ward): Parent C felt it was not easy to get her child admitted to the ward – a two day delay in admission. She described the food as 'horrible, processed and not fresh', criticising its appearance and suggesting 'they ask children what their favourite food is.' She added the food at the café is nice. Parent C takes shop food into the hospital for her child, adding "there are no additional snacks."

Parent C explained physiotherapy is offered twice daily, during the week, on the ward; once daily at the weekend. She takes on responsibility for her child's physio for the second session at the weekend and added her child has no other exercise she is aware of on the ward. She felt the ward staff's knowledge and attitude is poor and medication hand-outs are slow and IVs never on time. Parent C asked ward staff if she could 'do the medications', but it was explained to her this wasn't allowed. Parent C felt parents should be allowed more involvement in their child's care.

Annual review: Parent C's child is offered annual review each year. They don't always see the dietitian and sometimes see a physiotherapist, though always see the doctor and nurse. She thought this was "because the physiotherapist was too busy, on the ward or on annual leave." Annual review is reported back to this parent by letter and she added communication from the CF team is usually good, especially from the CF CNS. All their annual review assessments take place on the same day.

Home care: The clinical nurse specialist visits to carry out port flushes. They have pre-mixed IV antibiotics delivered by Bupa and Heparin pre-mixed by the Great North Children's Hospital. DNase and Colobreathe also being delivered now by Bupa – a service she is happy with, citing just one incident where an error was made, she felt, by Bupa.

Good practice:

- "Care is the best; fantastic CF care."
- "Hospital is nice and clean."

Areas for improvement:

- "More distracting activities for the children in the clinic and ward."
- "Hand hygiene could be improved – I've had to ask doctors, physiotherapists and nurses to clean hands, especially on the ward."
- "Speed up clinic times."
- "Provide more television in the patient ward rooms (there's a Wii Fit in the play room)."

Parent D described the outpatient clinic in terms of "different waiting areas, labelled red and green." Her concern was not knowing who else is waiting in the waiting room, before being directed into a consultancy room. Her child's spirometry takes place in the same consultancy room or in another room. She referred to "good use of hand gels and wiping down of equipment between patients." Parent D felt the CF MDT always discuss decisions on treatments with her and her child particularly. They see all of the CF MDT at outpatient clinic appointments, adding she thinks they would be able to see a clinical psychologist and social worker if need be. Her son has recently found it hard attending transition clinic – i.e. leaving the familiarity of his paediatric team.

Inpatient care: Not applicable. Parent D's child has not required inpatient treatment.

Annual review: Parent D's child is offered annual review each year and has had last annual review within last 12 months. All the annual review assessments take place at GNCH, where they see all of the CF MDT, before a report back of outcomes at clinic. Parent D happy with the communication from the CF team. She has the CNS's telephone number and pager.

Home care: The CNS flushes her child's portacath every six weeks at home or at CF clinic. She also takes Tobramycin levels and takes needle out, either in the home or at clinic.

Good practice:

- "CNS, doctor, dietitian and physiotherapist are really caring and wanting to do the best for my child."

Area for improvement:

- "Wish there was more awareness of CF."

Parent E felt segregation measures at outpatient clinic were "o.k. – not the best", adding "more parents should be aware of it and its importance". She explained parents/children are not told to sit separately from others. On arrival at evening clinic they are directed straight into a consultancy room, but at day clinics parents/children sit together in an open area.

Parent E described the consultancy as 'shared decision making' and she sees good use of hand gels and wiping down of equipment between patients. They see all of the CF MDT at clinic, adding that they've seen the Barnardo's social worker (Paul Forbes) for a long time. Parent E also explained BUPA provide home delivery service of Tobramycin, Colobreathe and DNase, which she is very happy with.

Inpatient care: Not applicable – her child has not required inpatient care in the last year.

Annual review: Annual review is offered to Parent E's child each year and this year's annual review has taken place, with all the MDT in attendance, with the exception of a psychologist and social worker. All assessments take place at the GNCH, apart from the bone mineral density (DEXA) scan which takes place at the Freeman Hospital. After each clinic, parent receives a reported outcome in a letter, as she does for annual review too, as well as discussion at next clinic appointment. Parent E felt telephone communication from the CF team is normally very good – they respond quickly.

Home care: The CNS performs the port flush in the home and a physio visits home at least once a year to provide support.

Good practice:

- "Excellent service – very accommodating and team explain things well in layman's terms."
- "The team treat my son like an adult and explain things well to my son."

Area for improvement:

- "It is clean at the CF unit, but could be cleaner."

Parent F felt segregation measures at outpatient clinic are "alright", adding "They started putting us in different areas and then directing us to a side room where we stay, apart from for lung testing." She felt there is good use of hand gels and wiping down of equipment between patients, adding "they wash their hands all the time."

Parent F described the decision-making process around changes to treatments as: "they tell you what you have to do. It's explained pretty well; some explaining better than others." Parent F and her child usually see the whole CF MDT at clinic, seeing the social worker for the first time this year. However, she didn't know about the existence of a clinical psychologist. She usually attends late clinic with her child and so waiting at pharmacy is not an issue in terms of cross infection risk.

Inpatient care (ward): Parent F explained they usually book their child in in advance for inpatient treatment, then receive a call from the ward at short notice to advise that a bed has become available. She described physiotherapy on the ward as twice daily, though there are not so many physios available at the weekend. Parent F felt ward staff nurses are pretty good in terms of their understanding of cystic fibrosis, adding "medications are usually on time, although they took all medications off the child/parent last time." She described the ward food as "chips, chips, chips," so mother takes a lot of food into the hospital for her child. Her daughter is offered crisps and cola on the ward too. For exercise, her child is taken to the hospital gym or goes for a walk in the grounds with her mother.

Annual review: This annual review is her daughter's first at the GNCH. Annual review assessments are staggered throughout the year and she attends the Freeman Hospital for her DEXA scan;

Home care: Parent F's daughter has home delivered, pre-mixed IVs from BUPA, which she describes as a reliable service.

Good practice:

- "Lovely hospital; new and clean."
- "Very nice team."
- "Segregation has been sorted."

Areas for improvement:

- "Since they closed our local clinics we have to go to Newcastle all the time – two hour journey by bus or one hour by car. I'd like to be able to go to Darlington clinic. We have to leave at 6am for oral glucose tolerance test in the morning at 8am and be there until 5pm late clinic." – i.e. parent would like to see a more local service provided for her daughter who attends clinic every six weeks.
- "Care is no better since local clinics shut. We still don't see a 'proper' doctor, nor do we see the proper consultant often." – i.e. parent would prefer to see familiar, experienced consultant more often.

Patient Interviews – Newcastle Paediatric Peer Review Day

Patient G

Fourteen-year-old male patient who has a two hour journey to the hospital by car. He previously attended Carlisle until he became very ill with lung failure, now he attends the GNCH as he has more trust in the care there. He has been admitted for a two week stay, his mother stays with him most of the time.

Areas of Excellence:

- The rooms are fantastic, comfortable and clean.
- There are a wide assortment of snacks available, crisps, pop, energy drinks, bacon butties and the big cooked breakfast available in the mornings.
- On admittance, his mother was given an envelope containing money, this is from a charity and is to help with costs during his stay.

- Schoolwork is sent from his school. He can go to the in-house Bridges School, which gives him a change of scenery.
- He has good contact with the team. He can call the CNS or the ward. If it is an emergency he will call an ambulance, however he does not like to be admitted this way due to cross-infection.
- His next admittance is pre-booked six weeks ahead.

Areas for improvement:

- Food, ready meals, he is accustomed to having fresh food at home.
- A friend drives him to hospital and drops him off due to the problems with parking. He believes there are concessions for inpatient stays, however he is unsure of the rate and discount.
- Wi-Fi – there is no free service. His family have to pay £15 for the use of Wi-Fi for two weeks. He would love the internet access.
- TV is free 6am–7pm, after which time they pay £30 top up for use during his two week stay; a family friend pays for this.
- They never see a psychologist and the mother feels that the parents would benefit from counselling at times, but the social worker is very good.

Patient H

Mother with five-year-old daughter who is an only child and has CF. They live 10–12 miles from the hospital and travel in by car from Durham. They get dropped off at the hospital and never use the car park and they are unsure of the concession rates available. They travel in by train for outpatient appointments. The mother works, and fortunately, her employers are very accommodating when the child is admitted or for hospital appointments. The mother stays in with the child throughout the two week stay and she will bring in a work pack from the child's school.

Areas of Excellence:

- Contact with the team is good and personal. All are on first name terms and the team know the family background. The CNS will also visit at home.
- Admission has never been a problem. The mother can phone on the Tuesday after receiving results and her daughter will be admitted the next day.
- The child enjoys her inpatient stay where toys are brought to her room and the availability of painting and crafts with the play assistants.
- She is taken to the gym for physiotherapy.
- The teachers visit her in her room regularly.
- There is a good choice of food and snacks available. She can have a cooked breakfast with toast, cereal and yoghurt.
- The mother was given an envelope containing money from a charity on admission, to help with expenses during the stay. She will go to a local supermarket and purchase microwavable meals for herself which she can keep in the ward kitchen fridge.
- Play park at outpatients, where the child likes to go.
- Cinema showing films on Wednesdays and Saturdays.

Areas for improvement:

- There is no Wi-Fi and the mother has to leave the ward to get a signal for her own 3G. She was not aware that Wi-Fi is available by payment.
- There could be more information given to parents prior to treatments such as line insertion and the use of gas and air. The mother felt the team assumed she knew about the procedure. Same applied to the ward facilities. The mother wanted to change her daughter's bed and was not aware of where the bedding was kept.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Great North Children's Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Five–six waiting areas.
Do patients spend any time in waiting room?	Yes	Sister polices as to where the patients wait, or they will be directed to the clinic room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	In each clinic room.
Where are the lung function tests done for each visit?		Dedicated room where equipment is cleaned in between patients
Are clinic rooms appropriately sized?	Yes	All rooms are of a good size, clean, modern and are well equipped. All surfaces are cleaned in between patients.
For annual review patients, are any distractions provided?	Yes	No toys in rooms. Team arrange activities.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Joint clinic, diabetes nurses will attend clinic.
Transition patients – can they get tour of outpatients' facilities?	N/A	Newly diagnosed are seen on the day unit, then during home visits they will be informed of the clinic structure.
Transition/new patients – do they get information pack?	Yes	CNS gives an information pack.

Additional comments

- Twelve to fifteen patients are seen at each clinic. Clinics are held on Tuesday evenings and Friday mornings. The evening clinic works well and suits working families and they have use of all rooms for this clinic. All toys are removed from the rooms at clinic. The rooms have a one hour wash out period in between patients.

Environmental walkthrough: ward

Ward name: 2

Microbiology status: General Respiratory

		Hospital name	Great North Children's Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		23	All rooms have full en-suite facilities and are set up for negative pressure.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		No	Patients have their own named drug box which is stored by the CNS in the clean utility room.
Can you use mobiles?		Yes	Not in high dependency unit (HDU).
If there is a television, is the service free?		Yes	Watershed at 7pm. Older patients can pay for further use.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	All rooms have a pull down bed. Crawford House, which is on the same site, is an overnight facility.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Opening visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	The kitchen has both a microwave and fridge for use.
What facilities are provided for teenagers?			DVD player.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is a paediatric section in the physio gym. Older children can use the adult gym. Wii-Fit for room use.
What facilities are there to help with school and further studies?		The Bridges School is very impressive and has achieved an outstanding Ofsted report. Teachers are available term time and will visit a child's room.
Is there a relatives' room?	No	Waiting area with tea/coffee facility.
What internet access is there?	None	No patient general access. The school computers do have internet.
What facilities are there to enable students to continue to work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in rooms.
What facilities are provided for those with MRSA?		No patients; would be barrier nursed and follow hospital policy.
What facilities are provided for those with *B. cepacia*?		One patient; barrier nursed and follow hospital policy.
What facilities are provided for those with other complex microbiology?		Eight patients with NTM who are admitted to ward 1A; barrier nursed and follow hospital policy.
Are patient information leaflets readily available on ward?	Yes	General leaflets.
Transition patients – can they get a tour of ward facilities?	Yes	At transition clinic, which starts at 14 years. Patients are familiarised with team and facilities.

Additional comments

- With approximately 180 patients, the GNCH was built about four years ago where three hospitals amalgamated to have all children's facilities in one area. The ward is located on level three and the ward corridors are bright, modern, clean and spacious with child-orientated artwork on the walls.
- The Bridge School is a dedicated and impressive facility which has achieved an outstanding Ofsted report. There are in excess of four teachers and further assistants. The large school room has multiple desk spaces and five computers with school Wi-Fi, there are also laptops available for use. The children would benefit if Wi-Fi were generally available throughout the hospital to continue their studies.
- The physiotherapy department use the corridor to exercise test patients. The paediatric gym has trampets, bikes, therapy bed, steps and exercise balls. 3D (amazing interactivities) images on screen to use for activity and exercise. The adult gym for the older children, is a large, well equipped room with cross trainers, bikes and a good variety of equipment for use.

	Hospital name	Great North Children's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Outpatients can get a reduced rate if their appointment is over one hour. Inpatients can get free parking in the multi storey car park.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To both outpatients and ward
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	Pharmacy - electronic boards indicating prescriptions in progress. X-ray – appointments are policed by team. DEXA scan – by appointment.
Do patients have to wait at pharmacy for prescriptions?	No	Patients can sit in corridor area or go away and return; there is a large café area nearby. Parents usually take prescription for collection after clinic. Evening patients are issued FP10 prescriptions or can go to GP. Inpatient drugs are delivered to ward.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Clearly visible open office area.
Are there patient comment/ feedback boxes?	Yes	Parent user satisfaction feedback. Staff survey. 'Friends and family' at outpatient clinic. Suggestion box at main reception. Feedback station at physiotherapy waiting area.

Additional comments

- On arrival there was a long queue from the car park barrier onto the road. There is a ground level car park and also a multi-storey car park.

West Cumberland Hospital, Whitehaven

Overview summary

The MDT at University Hospitals of North Cumbria (UHNC) is appropriately staffed and they have a good level of experience. The UHNC MDT have a good relationship with the Newcastle MDT who all attend the local clinic. The facilities are good and the patient feedback was positive.

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	
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	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	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	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	N/A RVI	N/A	CFRD clinic is run at Newcastle

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red Sent to RVI takes 48hrs	Red	No easy solution to this

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	RVI	RVI	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red Able to refer with fast track	Red	No psychologist
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red	Red	Social worker in Newcastle can be contacted
	% availability of a social worker for inpatients	100%	Red	Red	
	% availability of pharmacist at clinic	100%	Red Have access to paediatric pharmacist	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	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%	Green	Green	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	West Cumberland Hospital
Consultant 1	0.5	1	1	1 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	15hrs a week
Physiotherapist	2	3	4	0.3 WTE
Dietitian	0.5	1	1.5	7.5hrs a week
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	4hrs per week
Admin assistant	0.4	0.8	1	5hrs per week

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre – West Cumberland Hospital, Whitehaven	
Number of active patients registered (active being patients within the last two years)	188 total network
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	3
Median age in years of active patients	1
Number of deaths in reporting year	0
Median age at death in reporting year	n/a

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	0–3 years	3 (100%)
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)	
Patients with a BMI percentile <10th centile on supplementary feeding	0

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	0	0
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	3
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	0
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

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

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
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	0
	16+ years	0
Total number of IV days split by age group	120	0
	161	0
	351	0
	653	0
	495	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
Percentage of patients aged 5–15 years on DNase	0
If not on DNase, % on hypertonic saline	N/A

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	N/A
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0

Patient survey

West Cumberland Hospital

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male				
Female	1			

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	1	0	0	0
Communication	0	1	0	0
Out-of-hours access	1	0	0	0
Homecare/community support	1	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	1	0	0	0
Waiting times	0	1	0	0
Cross-infection/segregation	0	1	0	0
Cleanliness	0	1	0	0
Annual review process	0	1	0	0
Transition	0	0	0	0

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	1	0	0	0
Of the ward staff	1	0	0	0
Of the hospital	1	0	0	0

Comments about CF team/hospital

"Paediatrics at the West Cumberland Hospital is under review, services may be moved to the Cumberland Infirmary in Carlisle, the panel is very concerned about the effect on CF care."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Whitehaven (West Cumberland)
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	Yes	Limited time spent in the waiting area before being ushered into their own consultation rooms.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight done in an open corridor area (low cross-infection risk).
Where are the lung function tests done for each visit?		In own consultation room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		The majority of patients have their annual review investigations carried out at NCUH e.g. bloods, CXR, U/S scan and Physiotherapy assessments; results are sent to the RVI team who collate the information over the year, for the annual review letter, after clinical assessment.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Seen in a separate diabetes clinic at the GNCH.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No	Information on transition is given verbally. Contact numbers for the MDT are given at a planned home visit to the transitioning patient.

Environmental walkthrough: ward

Ward name: Fairfield

Microbiology status: All

		Hospital name	Whitehaven (West Cumberland)
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Not a dedicated CF ward	Suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Three	
Do the en suites have:	**Toilets?**	Yes	One room has full en-suite, the other two have a toilet and sink.
	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	Staff keep all medication.
Can you use mobiles?		Yes	Very poor signal strength.
If there is a television, is the service free?		Yes	Free between 7am and 9pm.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Zed beds in rooms.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Opening visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Parents room/kitchen.
What facilities are provided for teenagers?			Designated teenager room – DVD players, video games.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Access to a gym and physiotherapist uses a movable trampette for use in own rooms.
What facilities are there to help with school and further studies?		Teachers liaise with schools when necessary.
Is there a relatives' room?	Yes	
What internet access is there?	None	Hospital does not have Wi-Fi. The new build that the service is about to be moved to will have full Wi-Fi access for patients.
What facilities are there to enable students to continue to work and study?		As above, teachers liaise with schools when necessary.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Patients are provided with a separate washing bowl for this purpose and there is also a steam steriliser available.
What facilities are provided for those with MRSA?		Barrier nursed where required.
What facilities are provided for those with *B. cepacia*?		Barrier nursed where required.
What facilities are provided for those with other complex microbiology?		Barrier nursed where required.
Are patient information leaflets readily available on ward?	Yes	Cystic Fibrosis Trust leaflets.
Transition patients – can they get a tour of ward facilities?	Yes	Given tour of the facilities.

	Hospital name	Whitehaven (West Cumberland)
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free parking permit given to families.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Not a dedicated CF ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Staff collect medication for patients so no waiting in pharmacy areas. Radiology department phone when they are ready for patients so there is no waiting. Bone density scanning also has to be carried out at the GNCH.
Do patients have to wait at pharmacy for prescriptions?	No	See above.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Alongside PALS, an internal national patient experience system is used to monitor patient experience/feedback.

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Carlisle
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	Yes	Separated in different areas.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight room. Room cleaned between patients but possible risk of air borne cross infection.
Where are the lung function tests done for each visit?		Lung function is measured in a medical lab. One patient is tested at a time.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		The majority of patients have their annual review investigations carried out at NCUH e.g. bloods, CXR, U/S scan and physiotherapy assessments; results are sent to the RVI team who collate the information over the year, for the annual review letter, after clinical assessment.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	No diabetics	Would be seen in a diabetic clinic at the GNCH, Newcastle.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No Packs	Patient information booklet provided.

Environmental walkthrough: ward

Ward name: Children's Ward

Microbiology status: All

		Hospital name	Carlisle
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	General paediatric ward but suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		4	
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)			Lockable cupboards are currently on order.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service between 7am and 9pm.
If no, are there any concessions for CF patients?		As above	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Zed beds
Visiting hours – are there allowances for CF patients/families out of normal hours?			Opening visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?			Teenagers room – TV, Xbox, Playstation, Wii, board games, DVDs.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapists take patients to the gym for exercise.
What facilities are there to help with school and further studies?		No teachers, but school room with computers.
Is there a relatives' room?	Yes	Relatives room with couches and kitchen facilities.
What internet access is there?	None	The hospital trust are not currently willing to spend money on the provision of Wi-Fi.
What facilities are there to enable students to continue to work and study?		School room with computers.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Washed in own room using own steriliser.
What facilities are provided for those with MRSA?		Barrier nursed where required.
What facilities are provided for those with *B. cepacia*?		Barrier nursed where required.
What facilities are provided for those with other complex microbiology?		Barrier nursed where required.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	Carlisle
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free car parking for inpatients. Space and availability of parking is poor.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Not a dedicated CF ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	Patients do not have to wait in any other areas of the hospital.
Do patients have to wait at pharmacy for prescriptions?	No	Medication is collected by staff when required.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

Sunderland Hospital is now closed to CF patients and all now attend Great North Children's Hospital

UK CF Registry data 2013	
Demographics of centre – Sunderland Hospital	
Number of active patients registered (active being patients within the last two years)	188 total network
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	15
Median age in years of active patients	10
Number of deaths in reporting year	0
Median age at death in reporting year	n/a

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	0–3 years	0
	4–7 years	2 (13%)
	8–11 years	7 (47%)
	12–15 years	5 (33%)
	16+ years	1 (7%)

Genetics	
Number of patients and % of unknown genetics	2 (3%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)	
Patients with a BMI percentile <10th centile on supplementary feeding	n=1; 1(100%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	0	0
	8–11 years	1 (33%)	0
	12–15 years	2 (67%)	0
	16+ years	0	1 (100%)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	0
	4–7 years	2
	8–11 years	7
	12–15 years	5
	16+ years	1
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	0
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	1 (7%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	2 (13%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	1 (7%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH; 2(13%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	5
	12–15 years	14
	16+ years	0
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	51
	12–15 years	14
	16+ years	0
Total number of IV days split by age group	120	0
	161	0
	351	56
	653	28
	495	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
Percentage of patients aged 5–15 years on DNase	n=14; 6(43%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	N/A
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0

Panel members

Dr Francis Gilchrist*	Consultant	University Hospital North Staffs
Amanda Bevan	CF Specialist Pharmacist	Royal Brompton Hospital
Michele Puckey	CF Specialist Clinical Psychologist	Royal Brompton Hospital
Vicky Williams	CF Clinical Nurse Specialist	Royal Wolverhampton Hospital
Sue Wolfe	CF Specialist Dietitian	Leeds Children's Hospital
Elaine Dhouieb	CF Specialist Physiotherapist	Royal Hospital for Sick Children, Edinburgh
Clare Oliver	CF Social Worker	Southampton General Hospital
Peter Dixon	Commissioning	Cumbria, Northumberland
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	Quality Assurance and Control Manager	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for Peer Review

cysticfibrosis.org.uk