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Peer review report

University of Nottingham Hospital
Cystic Fibrosis Centre
Adult
20 June 2013

1. Executive summary

1.1 Overview of the service

This is the second peer review of the adult centre at the Nottingham City Hospital NHS Trust, having previously been reviewed in 2008. The dedication and enthusiasm of the multidisciplinary team (MDT) was clearly evident.

The service is going through an exciting period of change with the opening of a new purpose-built CF centre ideally placed within this busy teaching hospital with 16 inpatient beds, a dedicated outpatient area, a gym and a kitchen anticipated in early 2014. There have been some improvements in staffing levels within the MDT since the 2008 review and although the MDT remains under-resourced, further improvements are planned with the opening of the new unit and the expansion in patient numbers. The ward nursing contingent is agreed but the junior doctor cover for the new unit has yet to be defined.

This is one of two centres in the East Midlands, caring for 149 adult cystic fibrosis patients. Although it is anticipated that there will be an exponential increase in patient numbers with the opening of the new unit, in competing with other services there is some uncertainty with regard to this forecast. This may in turn have implications on annual income through the national tariff; it is imperative that this does not pose a threat to planned recruitment to posts.

1.2 Good practice examples

1. Excellent, well-designed, purpose-built, gold standard CF facility under construction within a busy teaching hospital setting with close links to other specialities and allied services.
2. Dedicated, highly experienced and enthusiastic core CF MDT. The social work team and the Ward Manager secondment on Flemming Ward are a clear asset to the team.
3. Excellent future planning in communication and support with webcam support, and planned MDT video conferencing also enabling facilitated group exercise classes.

1.3 Key recommendations

Confirm hospital trust's commitment to new posts – most areas are under-resourced even for current patient numbers.

Specifically:

- Urgent review of the CF physiotherapy service and weekend working with immediate appointment of Band 6 rotational post, confirm permanent 1.0 whole time equivalent (WTE) Band 3 assistant post and consider 1.0 WTE Band 4 assistant physiotherapy practitioner.
- Immediate appointment of a 1.0 WTE clinical psychologist.
- Immediate appointment of a 1.0 WTE CF pharmacist.
- Confirm consultant job plans and commitment to CF on the new CF unit.
- Confirm junior doctor commitment and residency on the new CF unit. Consider speciality doctor/clinical respiratory fellow (CRF) post.
- Reconfirm business case forecast for predicted increase in patient numbers and develop MDT according to the Cystic Fibrosis Trust's 'Standards of Care (2011)' in all areas.
- Convert project manager role to centre manager role on completion of new unit.
- Develop community nursing and physiotherapy service.

1.4 Areas for further consideration

Consider increasing Centre Director's commitment to cystic fibrosis and reducing other commitments. Develop third consultant post according to the Cystic Fibrosis Trust's 'Standards of Care (2011)' and the predicted, rapid increase in patient numbers.

Develop second permanent specialist CF dietician post to cover absence, outpatients and annual review and the predicted, rapid increase in patient numbers.

Develop Fleming Ward Manager and Educator role.

Address patient expense for car parking facilities and patient line.

We recommend revisiting the Nottingham centre a year after the new facilities have opened to review the changes.

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

2.1 Models of care

Summary

Current MDT able to meet standards. Additional resource required for anticipated, rapid increase in patient numbers with the opening of the new unit.

2.2 Multidisciplinary care

Summary

Current MDT able to meet standards and performing well. Additional resource required for anticipated, rapid increase in patient numbers with the opening of the new unit.

2.3 Principles of care

Summary

Issues around outpatient segregation and delay in admission of inpatients will be addressed by opening of the new unit in early 2014.

2.4 Delivery of care

Summary

Current MDT able to meet standards in core disciplines of medicine, dietetic and social work review, but not physiotherapy, clinical psychology or pharmacy. Concern raised that there will be a decline in compliance in the near future with the opening of a new CF unit and the predicted, rapid increase in patient numbers if not matched by immediate increase in MDT resource. Concerns further raised over potential seven-day physiotherapy working reducing physiotherapy input.

2.5 Commissioning

Summary

Prior to the visit, views were sought from East Midlands specialised commissioners. An independent review was undertaken to assess the two units in the region and confirmed that the two units would operate within East Midlands.

On the day of the visit the risk matrix was reviewed, there was no additional evidence submitted so the Clinical Lead and Project Manager were questioned. The matrix identified the RAG rating to be green in all of the commissioning section. The team identified that clinical incidents including medication errors are reported through the hospital trust system but are likely to be attributed to general or respiratory medicine. Additionally, although there were no specific complaints about the service, there were a number of improvements suggested by service users in the patient survey; the main area of concern was that waiting times were too long.

The Trust currently has a caseload of 149 patients, mainly from the Nottingham area. Referrals extend to the east of the region, but the Trust reported that attendance from patients in Lincoln was poor; the reasons behind this were explored.

The Trust has now moved to the national tariff and has an annual income based on the current banding. The service appears to have some gaps in staffing according to the Cystic Fibrosis Trust guidelines (which has been the case since the 2008 review), which should be addressed.

Specialised commissioning should work with the hospital trust to create a clinical network of care

for CF in the region to improve access and improve patient experience. The numbers of expected increase should be reviewed with the hospital trust to ensure the future viability of the new centre with commissioners.

The service was able to demonstrate a quality CF service – this is achieved with the dedication of the team and should be commended by the review. Consideration should be given to increasing the staffing numbers to meet standards and ensure staff are fully supported.

3. UK CF Registry data

Nottingham		Male	Female
Body Mass Index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	28 (41%)	23 (44%)
	Number of patients and % with BMI <19 split by sex	7 (10%)	12 (23%)

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and median (range) FEV_1 % pred by age range and sex	16–19 years	68.09 (25.97–87.09)	34.93 (26.72–56.52)
		20–23 years	64.62 (30.41–116.07)	55.76 (30.28–108.61)
		24–27 years	61.86 (39.41–94.95)	64.46 (23.3–95.68)
		28–31 years	52.60 (20.27–109.07)	49.65 (34.31–98.29)
		32–35 years	71.00 (33.83–91.86)	55.25 (41.74–78.62)
		36–39 years	87.44 (54.00–107.33)	56.8 (53.8–74.27)
		40–44 years	47.18 (43.16–51.19)	No data
		45–49 years	79.78 (75.74–83.82)	No data
		50+ years	105.97 (105.97)	54.12 (54.12)

Data input	Number of complete annual data sets taken from verified data set	122

Pseudomonas Chronic PA is 3+ isolates between two annual data sets	Number and % of patients with chronic PA infection	93 (76%)
	Number and % of patients with chronic PA infection	81 (87%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	64 (69%) with chronic PA
	Number and % of patients on chronic macrolide without chronic PA infection	4 (14%) without chronic PA

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- The Lead Consultant, Dr Jane Dewar (0.85 WTE, in post for ~9 years) and Dr Andy Clayton (1.0 WTE in post for ~4 years) share responsibility for cystic fibrosis inpatient care on an alternate month basis.
- There are two CF clinics each week run alternately by each consultant.
- There is prospective cover for both inpatient and outpatient duties between the two consultants. When not covering cystic fibrosis on an alternate month basis both consultants part-cover a general medical/respiratory ward looking after 12–15 non-CF patients. In addition, both consultants cover a general respiratory clinic and teaching and Dr Clayton also has a bronchoscopy list.
- Both consultants take part in a 1:11 respiratory take – other duties are cancelled on these days. Neither consultant takes part in the general medical take.
- Currently there is no dedicated cystic fibrosis unit and inpatients are admitted to one of three wards: Fleming (8 side rooms, 4 en suite), Southwell (4 side rooms, 2 en suite) and Nightingale wards (infectious disease ward with negative pressure rooms for patients with *Bulkholderia cepacia*/*Mycobacterium abscessus*). There are currently two consultant CF ward rounds/week.
- The combined input into CF of the two consultants is estimated to equate to ~1.2 WTE. Dr Dewar hopes to reduce hours to 0.8 WTE in the future.
- The Centre Director attends the Cystic Fibrosis Trust Directors meeting and one consultant endeavours to attend either the European CF Society Conference (ECFS) or North American CF Conference (NACFC) each year.

Area of good practice

- Dedicated and experienced consultant team.

Recommendation

- With the opening of the new cystic fibrosis ward and dedicated outpatient area unit and the predicted rapid expansion in patient numbers, consideration should be made to Dr Dewar increasing her commitment to cystic fibrosis and reducing other duties.
- A third consultant should be planned. The Review team is aware that further respiratory consultants are to be appointed and it would be appropriate to provide sessions in cystic fibrosis where appropriate in the meantime.

4.2 Specialist nursing

- Two Band 7 clinical nurse specialists (CNSs) 1.2 WTE
- Two Band 6 CNSs 1.6 WTE
- One Band 3 support worker 0.8 WTE

Areas of good practice

- Established, experienced nursing team.
- Workload appears well-coordinated and organised.
- Established home intravenous antibiotic service with home care IV provider in place.
- Achieve required continuing professional development (CPD) for CF CNS post.
- Achieves recommended targets for CF CNS inpatient and outpatient support/review for patients cared for at Nottingham Adults CF Centre.
- Nurse-led clinics.
- Enthusiastic ward manager on Fleming ward, who has appointed a nurse educator and appears keen for staff to learn the skills and knowledge necessary to care for cystic fibrosis patients.
- Enthusiastic ward manager on Fleming ward who has increased staffing to enhance cystic fibrosis care around intravenous antibiotic administration. Business case developed to increase ward staffing levels further.
- Three nurse prescribers.
- One advanced nurse practitioner.
- Involved in writing protocols for new CF ward.

Areas for improvement

- Lack of community care due to limited resources.
- Adult CF CNS input/support for Nottingham paediatric network patients not equitable to patients solely cared for by Nottingham paediatric services due to lack of adult CNS/team time.
- Limited involvement in audit and research.
- Clinical skills eg site mid lines
- One Band 6 and both Band 7 nurses are prescribers and perform the same duties.

Recommendations

- Harness the enthusiasm of the new ward manager and nurse educator on Fleming Ward now. Consider developing a regular (eg monthly) education session with the aim of improving ward staff's cystic fibrosis knowledge and skills. Consider rolling this out to all wards currently caring for CF patients and where possible include all members of the CF team in this teaching programme. This would be an ideal vehicle for ensuring staff appointed to the new CF ward in 2014 have some existing skills and knowledge to bring to the new service.
- With the opening of the new ward in 2014 and the potential to release CNS time, work towards developing additional transition clinics across the paediatric CF network and reaching out in particular to those patients in the network who are currently lost to specialised adult CF follow-up. This may contribute to increasing patient numbers in line with projected figures.
- With the opening of the new ward in 2014 and the release of CNS time, work towards CNS undertaking nurse-led audit and research.

- With the opening of the new ward in 2014 and the potential to release CNS time, work towards developing a community CF nursing service. CNS to have opportunity to visit other CF centres to inform this area of development in particular.
- Consider ways of utilising advanced nurse practitioner skills.

4.3 Physiotherapy

The adult CF physiotherapy service is staffed by the physiotherapy department and consists of 0.9 WTE Band 8a, 0.75 WTE Band 7, and 1.0 WTE Band 3 assistant (was on a fixed term, should now be a permanent post). The physiotherapy department as a whole is changing to a seven-day service, but without any additional staffing resource. The CF physiotherapy staff are not directly employed by the CF service. Current CF staffing is spread extremely thinly and as neither the 8a or Band 7 are full time, and with time off in the week required if they have worked the weekend, this has resulted in there frequently only being one physiotherapist available to cover the in-patients (approx eight patients), annual reviews and to attend clinic. During annual leave, study leave and sickness absence there is a high risk that on some days no physiotherapists will be available.

A new 1.0 WTE rotational Band 6 physiotherapist has been agreed for when the new unit opens, but there is significant under-resourcing in the current staffing. Currently not all patients (68%) are reviewed by the physiotherapist in clinic and the number of inpatients receiving assisted treatment at weekends is minimal (approx five per cent of inpatients) due to strict prioritisation criteria. There are concerns that the physiotherapy department will request the CF service to cover its own weekend service which on 1.75 WTE would be impossible. The CF physiotherapists are very experienced and dedicated to the service but are aware of the limitations of their service provision due to their severe under-resourcing. They strive to provide a proactive comprehensive service but feel they cannot provide an in-depth service due to poor staffing resources.

A homecare service used to be provided but this has significantly reduced due to the requirements of the inpatient service, although greater numbers of patients are now doing home IV antibiotics.

Good practice

- Highly experienced physiotherapists working in cystic fibrosis.
- Good focus on sinus disease and upper airway management, use of Pari sinus neb with good results, use of Sino Nasal Outcome Test (SNOT) questionnaire in annual assessments.
- Good dedicated physiotherapy time (one hour) at annual assessment.
- Good range of physiotherapy patient leaflets.
- Dedicated exercise sessions for inpatients with Band 3 assistant.

Recommendations

- Urgent review of physiotherapy staffing – confirm Band 3 assistant post permanent, give 1.0 WTE Band 6 rotational post now, before the new unit opens to address current staffing shortfalls – to enable better cover across seven days, and potentially to offer homecare service, although the inpatient service should be prioritised.
- In order to develop the exercise assessment, prescription and provision to patients (in particular for the excellent proposed gym/exercise facilities in the new unit), consider an additional

1.0 WTE physiotherapy Assistant Practitioner (Band 4) post.

- Consider additional physiotherapy staffing in order to develop a CF/Musculoskeletal (MSK) post (0.1WTE) to reduce onward referrals to local MSK services.

4.4 Dietetics

1. The dietitian is a member of the UK Dietitians in CF Interest Group (UKDCFIG) and attends UK CF dietitian specialist interest group meetings.
2. The dietitian attends MDT meetings when scheduled. The dietitian currently does not attend ward rounds due to changes in start times, geographic locations and waiting around for MDT members. She is about to restart attending these ward rounds.
3. A Band 6 renal dietitian covers CF inpatients when the Band 7 CF dietitian is absent. This person has had an induction programme and three months training in cystic fibrosis. However they do not see CF patients on a regular basis to keep up their knowledge or gain more experience and receive very little peer support when the Band 7 dietitian is off. No cover is provided for outpatients or annual reviews. The dietitian also expressed concern for cover if the dietetic department adopts a seven-day working pattern, this is currently being scoped.
4. The dietitian last attended and presented at a European CF meeting in 2011 – funding for conferences/study is difficult and this dietitian has self-funded to attend conferences in the past.
5. The dietitian has been involved in both research and audit, which has included a vitamin D and a pancreatic enzyme replacement therapy (PERT) audit, a Cochrane review of appetite stimulants in cystic fibrosis and a tube-feeding exploration study in cystic fibrosis.
6. The dietitian participates in the transition process and is involved in all key life stages.

Good practice

- Proactive dietitian who works very hard within the current service to provide good patient care.
- Has invested a lot of time and effort to try to improve hospital catering and food/snack provision available to inpatients. These include provision of microwave meals for out-of-hours, extra snacks from catering, a tuck shop and provision of tinned soups/spaghetti and bread on the ward. However not all inpatients will have access to these provisions. Plans for new CF unit include a dedicated kitchen and chef. However, patients on outlying wards will not have access to this service.
- Participation in research and audit.

Recommendations

- The current staffing level is within current recommendations of 1.0 WTE dietitian for 150 patients; however limited cover is provided in this post's absence. The nutrition and dietetic department and CF team need to explore this along with succession planning and for the predicted growth in patient numbers. A consideration could be the development of a part-time training post as part of another specialty.
- The dietitian has worked hard to improve the catering provision within the hospital. However, equal catering provisions are not available to all CF inpatients and they will vary according to which ward the patient has been admitted to.

4.5 Pharmacy

Current pharmacy service

- As was the case during the last peer review, there is currently no formal funding for a CF pharmacist for the Nottingham adult CF service. Despite this the CF service receives a very good level of pharmaceutical support from the specialist respiratory pharmacist who is an active member of the UK CF Pharmacists Group and attends national/international CF meetings.
- Inpatients are always reviewed by a pharmacist and receive level 2 medicines reconciliation.
- Although a pharmacist is not able to be present on ward rounds or in clinic, any medicines related queries generated from these are answered by the specialist respiratory pharmacist.
- A number of other senior pharmacists and technicians also provide support to the CF service (infectious diseases, homecare and high-cost drugs) ensuring efficient access to medicines.

Other areas of good practice noted:

- A CF-specific guide for administering IV antibiotics to inpatients is currently being developed. Past practice, (as per hospital trust recommendations) has been to give almost everything as infusions; however CF patient feedback has shown that bolus injections are preferred.
- UNH has a self-medication policy (that works) in place which enables CF patients to take their own medicines if/when they are admitted (this isn't the case in all hospitals).
- Pharmacy input into design of the new CF unit has ensured the drug storage and administration areas will be suitable, in terms of space and meeting legal requirements.
- All patients get pre-mixed antibiotics from an external company for home use.

Pharmacy service compared to the Cystic Fibrosis Trust's 'Standards of Care (2011)'

- According to the Cystic Fibrosis Trust 'Standards of Care (2011)' the service should have 1.0 WTE specialist pharmacist.
- Funding has been agreed as part of the new CF centre for 0.5 WTE at Band 7. However it is not clear when the funds for this post will be made available (ie dependent on achieving a pre-defined number of patients or just when the new centre opens).
- Ideally, a CF specialist pharmacist should be banded at 8a level for the person in post to be able to meet the requirements set out in the Cystic Fibrosis Trust's 'Standards of Care (2011)'.
- The pharmacy department at Nottingham has decided to utilise the existing respiratory medicine Band 8a pharmacist (who currently provides as much pharmacy input to the CF service as she is able) to support and lead the work of the Band 7 CF pharmacist. This does give the potential added benefit of the pharmacy being able to provide cross cover when the CF specialist is on leave.

Recommendations

- Cystic fibrosis pharmacist to be appointed as soon as possible.
- Review the agreed funding for the CF pharmacist to 1.0 WTE as per Cystic Fibrosis Trust recommendations for patient numbers. This will become more pressing as numbers increase.

Once in post, the new CF pharmacist will need to review and expand the existing CF pharmacy service in line with Cystic Fibrosis Trust recommendations. It may be useful for this person to

shadow an experienced adult CF pharmacist at another large CF centre. Priorities for early implementation would be pharmacist involvement in:

- Annual review and outpatient clinics.
- Ward rounds.
- Pharmacist review of IV antibiotic homecare prescriptions prior to ordering. These are currently reviewed after the order is placed, usually within 24–48 hours, but can be after manufacture/ delivery to patient. This presents both a clinical and financial risk.

4.6 Psychology

- There is currently no clinical psychologist in the service so it is not possible to comment on areas of best practice or improvement.

The service plans to appoint a full-time (1.0 WTE) clinical psychologist (included in the service's business plan). This would be in line with the recommended CF-dedicated time as outlined by the staffing guidelines in the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

- This post is essential for the service to provide adequate psychological support to its patients.
- The clinical psychology post is currently in the planning stage and guidance is available from the UKPPCF, which can provide advice and guidance on the competencies, credentials and job plan a clinical psychologist would require to fulfill this specialist role.

Once appointed, the clinical psychologist's roles will include – (as outlined by the Cystic Fibrosis Trust's 'Standards of Care (2011)': assessment in the annual review process; providing psychological therapy; 'gate-keeping' for onward referrals and liaising with other agencies; coordinating urgent psychiatric assessments; providing consultation and training for the team; and research and audit roles.

- The clinical psychologist could provide input at key life stages including diagnosis, transition, end-of-life care, transplantation, planning families etc.

4.7 Social work

One full-time equivalent social worker (SW) post job-shared by two social workers. The post was funded by Barnardos for 20 years until it withdrew its support in 2012. The social workers then negotiated the continuation of the service, within the NHS. They moved into the CF unit last year and successfully integrated social work provision into the existing CF services.

Good practice:

- Fully staffed as per guidelines and working to the the Cystic Fibrosis Trust's 'Standards of Care (2011)'.
- Highly knowledgeable workers with many years experience of cystic fibrosis between them.
- Developed specific working tools that could be adapted for use by other CF SW services – an Annual Review form and a secure electronic system for SW recording.
- Close links with paediatric team, contributing to development of the transition process.

Provision:

48-hour target for responding to referrals so response times are usually much shorter than as per guidelines (ie, within one week under normal circumstances).

Annual reviews:

Attending approximately 85% of annual assessment clinics, plus carrying out a further 5–10% of SW annual reviews outside of this formal framework.

Outpatients:

Attending approximately 80% of review clinics, plus covering CF/diabetes clinics and transition clinics where possible – inherent limitations due to clinic overlaps.

Inpatients:

Available to see inpatients and attending MDT meetings and ward rounds.

Strengths:

Meeting most targets as per the Cystic Fibrosis Trust's 'Standards of Care (2011)' guidelines.

Difficulties:

Limitations in research opportunities and in meeting desired targets for dealing with referrals, providing clinic cover, community visiting and the level of input with vulnerable adults are due to staffing levels, ie, the existence of only one SW post and absences due to annual leave and training. Also constraints to the physical environment (office space, interview room, admin support) that will be resolved when the new CF unit opens.

Points for development:

The current roll-out of the government's extensive programme of welfare reform is having an increasing impact on the CF population. This is leading to a growing demand for SW support at a time when community-based advice services are shrinking due to funding cuts. It is essential to continue monitoring the impact of these reforms on CF adults, to ensure that the SW service can continue to be responsive to the increased demands that it is likely to face.

Recommendations

- Protection of current SW staffing ratios so the SW service continues to meet agreed guidelines – ie, ensure SW provision increases inline with projected growth of the adult CF service, which includes factoring-in any increased demand linked to welfare reform.
- Training – continued access to essential SW training as NHS employees.
- Alternative resources to replace the newsletter for the patient community previously produced with Barnardos' support.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	0	0	6	5	2	0	1
Female	1	0	8	4	1	1	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	17	12	1	0
From the ward staff	8	16	2	0
From the hospital	6	20	2	0

Areas of excellence

1. Overall care from the MDT
2. Outpatient – cross-infection and cleanliness
3. Annual review process

Areas for improvement

1. Out-of-hours access
2. Waiting times – outpatients and inpatients
3. Car parking

6. Appendices

Appendix 1

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

Reported and actual compliance below follows a Red, Amber, Green rating defined as the following:

Green = Meeting all the Cystic Fibrosis Trust's 'Standards of Care (2011)'

Amber = Failing to meet all the Cystic Fibrosis Trust's 'Standards of Care (2011)' with improvements required

Red = Failing to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)' with urgent action required

Hospital name

University of Nottingham Hospital

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% patients seen at least once a year by the specialist centre for an annual review.	90%	Green	Green	Agreed
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry.	90%	Green	Green	Registry data
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review.	90%	Green	N/A	No shared care patients

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include annual review).	95%	Green	Green	Confirmed by Centre Director & MDT
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	Agreed safe but needs additional immediate resource into MDT.
	% of MDT who receive an annual appraisal.	100%	Green	Green	Confirmed by Centre Director & MDT
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months.	100%	Green	Green	Confirmed by Centre Director & MDT
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	Confirmed by Centre Director & MDT
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	Confirmed by Centre Director & MDT
	Are there local operational guidelines/policies for CF care?	100%	Green	Green	Follow Cystic Fibrosis Trust guidance with local policies under development
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust standards.	100%	Green	Green	Confirmed by Centre Director & MDT
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Green	Confirmed by Centre Director & MDT
	% patients with CF-related diabetes (CFRD) reviewed at a joint CF/diabetes clinic.	100%	Green	Green	Confirmed by Centre Director & MDT

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	16-bed purpose-built CF unit under construction.
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Red	Red	Currently staggered appointment slots. Will be addressed with opening new dedicated CF outpatient area.
3.2 Monitoring of disease	% attempted eradication of 1st isolates *Pseudomonas aeruginosa* in the previous 12 months.	100%	Green	N/A	No patient presented with 1st isolates *Pseudomonas aeruginosa* in the previous 12 months.
	% patients admitted within seven days of the decision to admit and treat.	100%	Red	Red	16-bed purpose-built CF unit under construction.
3.3 Complica-tions	% aminoglycoside levels available within 24 hours.	60%	Green	Green	Confirmed by Centre Director & MDT
3.4 Cystic fibrosis-related diabetes (CFRD)	% patients >12 years of age screened annually for CFRD.	100%	Green	Green	Confirmed by Centre Director & MDT
3.5 Liver disease	% patients >5 years of age with a recorded abdominal ultrasound in the last three years.	100%	Green	Green	Confirmed by Centre Director & MDT
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Green	N/A	Adult service

3.7 Reduced Bone mineral density (BMD)	% patients >10 years of age with a recorded bone density scan (DEXA) scan in the last three years.	100%	Green	Green	Confirmed by Centre Director & MDT

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% patients seen by a CF consultant a minimum of twice a week while inpatient.	100%	Green	Green	Confirmed by Centre Director & MDT
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/shared care consultant/patient or carer, within 10 days of consultation.	100%	Green	Green	Confirmed by Centre Director & MDT
	% dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	Confirmed by Centre Director & MDT
	% patients reviewed by a CF Clincal Nurse Specialist (CNS) at each clinic visit.	100%	Green	Green	Confirmed by Centre Director & MDT
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Green	Green	Confirmed by Centre Director & MDT
4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Amber	Amber	Additional 1.0 WTE physiotherapist agreed
	% patients reviewed by a physiotherapist twice daily, including weekends.	100%	Red	Red	Additional 1.0 WTE physiotherapist agreed
	% availability of a CF specialist dietitian at clinic.	100%	Green	Amber	Need to develop 2nd post
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay.	100%	Amber	Amber	Need to develop 2nd post
	% availability of clinical psychology for inpatients and at clinic.	100%	Red	Red	1.0 WTE clinical psychologist post planned. Needs confirmation.
	% availability of social worker for inpatients and at clinic.	100%	Green	Green	Confirmed by Centre Director & MDT
	% availability of pharmacist for inpatients and at clinic.	100%	Red	Red	1.0 WTE CF pharmacist post planned. Needs confirmation.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	Confirmed by Centre Director & MDT

4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life.	75%	Red	Green	All patients offered palliative care input. Often choose not to accept.

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months.	<1%	0	0	No known complaints. Check not included in respiratory medicine.
5.2	Number of clinical incidents reported within the past 12 months.	<1%	0	0	No known incidents. Check not included in respiratory.
5.3	User survey undertaken a minimum of every three years.	100%	Red	Red	To undertake once new unit opened.

Appendix 2

Staffing levels

	75 patients	150 patients	250 patients	University of Nottingham NHS Foundation Trust 148 patients
Consultant 1	0.5	1	1	0.85 including other duties
Consultant 2	0.3	0.5	0.5	1.0 including other duties
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	1
Specialist registrar	0.4	0.8	1	1
Specialist nurse	2	3	5	3.8
Physiotherapist	2	4	6	2.75
Physiotherapy assistant				
Dietitian	0.5	1	2	1
Clinical psychologist	0.5	1	2	0
Social worker	0.5	1	2	1
Pharmacist	0.5	1	1	0
Clinician's assistant				
Secretary	0.5	1	2	1
Admin assistant				
Database coordinator	0.4	0.8	1	0
CF unit manager				

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the 'UK CF Registry Annual Data Report 2011', available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2011	
Demographics of centre	
Number of active patients (active being patients with data within the last two years) registered	134
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2011')	122
Median age in years of active patients	25.5
Number of deaths in reporting year	2
Median age at death in reporting year	40

Age distribution (Ref: 1.6 'Annual Data Report 2011')		
Number in age categories	16–19 years	11
	20–23 years	38
	24–27 years	23
	28–31 years	20
	32–35 years	15
	36–39 years	6
	40–44 years	4
	45–49 years	3
	50+ years	2

Genetics	
Number of patients and % of unknown genetics	22 patients (18%) with one unidentified mutation; 36 (30%) patients with two unidentified mutations

Body mass index (BMI) (Ref: 1.13 'Annual Data Report 2011')		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	28 (41%)	23 (44%)
Number of patients and % with BMI <19 split by sex	7 (10%)	12 (23%)

FEV_1 (Ref: Figure 1.14 'Annual Data Report 2011')		
	Male	Female
Median FEV_1% pred at age 16 years split by sex	0	0
Number and median (range) FEV_1 % pred by age range and sex		
16–19 years	68.09 (25.97–87.09)	34.93 (26.72–56.52)
20–23 years	64.62 (30.41–116.07)	55.76 (30.28–108.61)
24–27 years	61.86 (39.41–94.95)	64.46 (23.3–95.68)
28–31 years	52.60 (20.27–109.07)	49.65 (34.31–98.29)
32–35 years	71.00 (33.83–91.86)	55.25 (41.74–78.62)
36–39 years	87.44 (54.00–107.33)	56.8 (53.8–74.27)
40–44 years	47.18 (43.16–51.19)	No data
45–49 years	79.78 (75.74–83.82)	No data
50+ years	105.97 (105.97)	54.12 (54.12)

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas Aeruginosa* (PA)		
Number of patients in each age band	16–19 years	11
	20–23 years	38
	24–27 years	23
	28–31 years	20
	32–35 years	15
	36–39 years	6
	40–44 years	4
	45–49 years	3
	50+ years	2
Number of patients with chronic PA by age band	16–19 years	7
	20–23 years	29
	24–27 years	19
	28–31 years	17
	32–35 years	11
	36–39 years	4
	40–44 years	2
	45–49 years	3
	50+ years	1

Burkholderia Cepacia (BC)	
Number and % of total cohort with chronic infection with BC complex	4 (3%)
Number and % of cenocepacia	2 (2%)
MRSA	
Number and % of total cohort with chronic infection with MRSA	2 (2%)
Non-Tuberculosis Mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complications (Ref: 1.16 'Annual Data Report 2011')	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	16 (13%)
CFRD	
Number and % of total cohort requiring chronic insulin therapy	51 (42%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	11 (9%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis with no PH	4 (3%) patients with no PH 1 (1%) patient with PH

Transplantation (Ref:1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	6
Number of patients referred for transplant assessment in previous three years	2008–2010 = 14
Number of patients receiving lung, liver, kidney transplants in last three years	2011 = 2; 2008–2010 = 3

IV therapy (Ref:1.21 'Annual Data Report 2011')		
Number of days of hospital IV therapy in reporting year split by age groups	16–19 years	27
	20–23 years	544
	24–27 years	560
	28–31 years	217
	32–35 years	132
	36–39 years	97
	40–44 years	0
	45–49 years	42
	50+ years	21
Number of days of home IV therapy in reporting year split by age groups	16–19 years	0
	20–23 years	624
	24–27 years	743
	28–31 years	457
	32–35 years	420
	36–39 years	51
	40–44 years	42
	45–49 years	14
	50+ years	24
Total number of IV days split by age groups	16–19 years	27
	20–23 years	1168
	24–27 years	1303
	28–31 years	674
	32–35 years	552
	36–39 years	148
	40–44 years	42
	45–49 years	56
	50+ years	45

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1 % pred <85% (ie, below normal) on DNase	(n=94) with FEV_1 <85% 53 (56%) on DNase
If not on DNase % on hypertonic saline	12 (13%)

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	93 (76%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	81 (87%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	64 (69%) with chronic PA; 4 (14%) without chronic PA

Appendix 4

User survey results: Nottingham

Other hospitals attended

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	0	0	6	5	2	0	1
Female	1	0	8	4	1	1	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/a
Accessibility (appointments/advice)	13	13	3	0	0
Communication (verbal/written)	11	15	2	1	0
Out-of-hours access (via phone or ward)	5	7	7	5	5
Home-care/community support (appointments/advice)	10	10	4	0	5

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/a
Availability of team members (who you need/want to see)	12	14	3	0	0
Waiting times	8	6	9	4	0
Cross-infection/segregation	16	8	5	1	0
Cleanliness (room)	15	11	4	0	0
Annual review process	12	13	4	1	0
Transition (paediatric to adult)	4	4	1	2	16

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/a
Admission waiting times	6	9	4	7	3
Cleanliness (cubicle/bathroom)	9	10	7	0	3
Cross-infection/segregation	12	11	3	0	3
Food (quality/quantity)	7	8	7	4	3
Exercise (gym equipment/facilities)	6	10	7	2	4

How would you rate:

	Excellent	Good	Fair	Poor	N/a
Home intravenous (IVs) antibiotic service	17	6	3	0	2
Availability of equipment (physiotherapy aids/nebuliser parts)	17	7	2	1	2
Car parking (availability/ease of reach)	1	5	10	10	2

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/a
Of your CF team	17	12	1	0	0
Of the ward staff	8	16	2	0	3
Of the hospital	6	20	2	0	1

Comments about CF team/hospital

"Waiting times can be a long time on clinic appointments – two hours."

"Red tape has become a barrier in most interactions these days. Also the attitude/manner of certain members of the team leaves a lot to be desired! We patients do know what we're talking about and in most cases know our illness better than they do."

"Good, reassuring service. Sometimes lots of waiting."

"There are some excellent and extremely experienced staff members in the CF team and on the wards, however the environment which they have to work in brings the service down. When admitted to a busy respiratory ward the needs of the CF patients are not always met due to lack of staff. The sooner the CF centre is built here the better."

"Feel very safe in hands of caring people which have always been incredibly supportive."

"Shortage of beds for those needing a bed. Unfortunately I know, virus not kept out can lead to serious repercussions. One does their best in all situations as human beings."

"My CF team at Nottingham is always there for me when I need them or if I just need to talk. Can't wait for our new CF unit!"

"I don't use City hospital anymore as I didn't like being near the Pseudomonas patients and didn't like how the appointment system altered."

"I think the CF team at Nottingham City Hospital offers excellent and compassionate care."

"I feel that the CF team work very hard to help with any problems you may have at any time."

"I always feel well looked after and safe in the care of the CF team."

"Communication between CF team and my GP is frustrating – neither seems to take responsibility (eg prescriptions changes or blood tests required and results sent) and I always have to chase it myself."

"My CF team are very good and always do whatever they can to help me and tend to my needs. It will be much better for all of us once we have our own new unit."

"Going to NUH since 16 yrs old; before to Bassetlaw and Sheffield."

"The enthusiasm and attitude of the young nursing staff was a tonic in itself."

Appendix 5

Patient/parent interviews

Nottingham adults CF service peer review, City Hospital

Patient 1

Male, 16 years old. He has started an IT apprenticeship and is looking forward to getting back to work. A charming young man who explained that he self-evaluates every situation into a positive situation.

This is his first admission to an adult ward and he has been in hospital three days. He is finding the adult ward very different to the paediatric ward, which is usually very noisy which he liked. He is not finding the transition easy. The adult ward is very quiet and he is isolated in his room with no TV. He cannot afford Patient Line. He has the use of his laptop. He does not think that patients should have to pay to watch TV.

He is keen to use the gym today for the first time and informed us that yesterday he played football with his physiotherapist which he enjoyed.

The patient said that the parking facilities were OK but he thinks that inpatients should not have to pay full price due to the long stay period, this also works out expensive for visitors. His mother, who does not own a car, has difficulty visiting regularly due to expensive public transport fares.

He thinks that there is a lack of choices on the food menu; his father has been bringing him food from outside. He did say that the quality of the food is what he would expect in hospital – not very good.

He thinks that the staff are very nice and friendly.

Patient 2

Female, 38 years old. This was a very interesting interview with lots of ideas regarding alternative therapies. She practices as a naturopath; is trained in Chinese medicine, reflexology, iridology and colonic irrigation and lives her life using these.

She does not eat dairy, eggs or wheat and says that she dictates what she eats to the staff. She has had a bad experience when staff cooked at her request but this has improved now. She believes the staff should be better trained with alternative foods. Patients are not allowed to go in the kitchen. She is happy to have her own fridge in her room.

She says that she feels very lucky to have her own room, especially as she has a good view from her window, which she really appreciates.

She worries regarding cross-infection as some other patients leave their doors open and would like everyone to keep their doors closed. She is also concerned when walking down the ward and sometimes has to pass other patients as she thinks it might be a risk.

She thinks that the team was very nice and friendly and felt that they understood her views and opinions. She believes that patients should be touched more; she says that there is no ‘hands-on’ contact and would like more. She had, however, received massage from the physiotherapist, which she found useful. She would like to see yoga and meditation offered in the future.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Nottingham (Adults) City 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	No waiting rooms always available
Do patients spend any time in waiting room?	No	Patients are taken to the clinic rooms on arrival and do not wait in waiting area.
Is there easy access to toilets?	Yes	Although these are shared at present
Where do height and weight measurements take place? Is this appropriate?		Takes place before appointment time at annual review clinic in a large room.
Where are lung function tests done for each visit?		In individual clinic rooms.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Wi-Fi access for use with own equipment
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Patients are seen in the joint diabetes clinic (Dundee House)
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	

Additional comments

New purpose-built CF unit with dedicated outpatient area, with eight consultation rooms under construction, with anticipated opening early 2014.

Environmental walkthrough: ward
Ward name: Nottingham adults (City Hospital) Fleming Ward (Respiratory/CF Ward)
Microbiology status: All microbiology except *M. abcessuss* and *B. cepacia* and *cenocepacia*

		Nottingham (Adults) City Hospital	
		Yes/no/ number/ N/A	**Notes/comments**
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Suitable, not dedicated to CF, shared with respiratory.
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?		Yes	Only if patient required a bath, which would be arranged for them.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Each patient has a lockable locker to store own medication.
Can you use mobiles?		Yes	
If there is a television, is the service free?		No	Patient Line available. Not currently a free service.
If no, are there any concessions for CF patients?		No	
Are there facilities to allow parents, carers/partners to stay overnight?		Yes	There are limited rooms in the hospital trust and also Z beds are available.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Protected meal times, however are flexible for CF patients.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	Access to a fridge, not a microwave.
What facilities are provided for teenagers?			There is a link with the school. The social worker is exploring what can be offered for extended learning by contacting the colleges as required.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is exercise equipment in the rooms. Limited access to the gym and access to grounds for outdoor exercise sessions.
What facilities are there to help with school and further studies?		Wi-Fi available. Use bedside table as desk.
Is there a relatives' room?	Yes	Sitting room on ward
What internet access is there?		Wi-Fi
What facilities are there to enable students to continue work and study?	Wi-Fi	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Yes
What facilities are provided for those with Meticillin-resistant staphylococcus aureus (MRSA)?		The patient would be segregated in own room.
What facilities are provided for those with *B.cepacia*?		The patient would be admitted to Nightingale Ward for (infectious diseases) and segregated in own room.
What facilities are provided for those with other complex microbiology?		These patients would be admitted to Nightingale Ward and segregated in own room.
Are patient information leaflets readily available on ward?	No	Many leaflets, but not CF information leaflets. These are distributed by nurses on request.
Transition patients – can they get tour of ward facilities?	Yes	

Additional comments

Nightingale Ward - admits patients with infectious diseases.

The ward has 13 side rooms, 6 of which are negative pressure rooms, where CF patients are admitted. These rooms are not dedicated to CF patients.

Nightingale Ward has the same available facilities as Fleming Ward.

Patients do not share any bathroom facilities in Nightingale Ward.

Nottingham has two patients with *Burkholderia cepacia*, two *cenocepacia* and two *Microbacterium abcessus*.

Southwell Ward is occasionally used for overflow patients.

The wards visited, Fleming and Nightingale, had a good standard of cleanliness.

New purpose-built 16-bed CF unit under construction with anticipated opening early 2014.

Environmental walkthrough: other

	Nottingham (Adults) City Hospital	
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	Ample parking spaces. Only free to blue badge holders at present Charges for: 0–2 hours – £3–£10; 4–24 hours – £5–£60
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg, radiology, pharmacy, DEXA scan?	Yes	Radiology has a large, seated waiting area. Patient appointment times are always staggered.
Do patients have to wait at pharmacy for prescriptions?	No	Outpatient prescriptions are collected by support workers. In patient prescriptions are delivered to patients.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?		
Are there patient comment/ feedback boxes?	Yes	All patients are given patient feedback forms. The feedback boxes are kept on ward reception.

Appendix 7

Panel members

Ian Ketchell*	Consultant	Cardiff and Vale UHB Hospital
Helen Willimott	Pharmacist	Norfolk and Norwich Hospital
Nicola Reid	CF Specialist Psychologist	Manchester Adult Cystic Fibrosis Centre
Sandra Bott	CF Clinical Nurse Specialist	Sheffield Children's NHS Foundation Trust
Sarah Collins	CF Specialist Dietitian	Royal Brompton Hospital
Penny Agent	CF Specialist Physiotherapist	Royal Brompton Hospital
Anne Gray	Social Worker	Heartlands Hospital
Sandra Tribe	Commissioning	Croydon Primary Care Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust

*Clinical Lead of Peer Review Panel

Appendix 8

Other information

cysticfibrosis.org.uk