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Peer review report

Glenfield Hospital, Leicester Adult Cystic Fibrosis Centre

17 June 2015

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1. Executive summary

Overview of the service

The Glenfield cystic fibrosis (CF) unit has grown slowly over the years and remains a relatively small service, providing care to 84 adults. The multidisciplinary team (MDT) is experienced and extremely dedicated, providing high-quality care despite significant under-resourcing and gaps in the MDT, and the service is highly valued by its users. The service has now reached a critical point in its development and in order to continue to provide safe and effective care, investment in staffing levels is essential in order to meet the necessary standards of care.

Good practice examples:

- Patient-focused and personalised service with highly dedicated staff.
- Strong approach to transition with bi-monthly joint transition clinics with paediatric colleagues.
- Excellent user feedback.

Key recommendations:

- The service is significantly under-resourced and there is an urgent need to address staffing levels across the whole MDT. Note is made of plans to appoint a psychologist, but further investment across the whole team is now necessary to meet current standards and allow for service growth.
- The service is now at tipping point and the shortfall in staffing across the team is further exacerbated by pressure to cross-cover other services within the division. Measures will need to be put in place to allow the CF MDT to focus on CF service delivery and to continue to deliver high-quality care for their patients.
- Review staffing infrastructure across respiratory physiotherapy to allow for the provision of a weekend physiotherapy service.
- Consideration should be given to the longer term strategy and development of the service. Pressure on other CF services across the region offers the opportunity to expand the service with appropriate resourcing.

Areas for further consideration:

- Consideration should be given to the grading of staff within disciplines to ensure a robust framework for professional leadership, service development and research.
- Consider provision of homecare drugs (intravenous [IV] antibiotics +/- high cost drugs) via a homecare provider to release capacity within the pharmacy team, particularly if plans to repatriate high-cost drug provision back to secondary care occur.
- Continue to progress plans for outpatient clinics and clinic segregation. As the service grows the introduction of a second clinic may be necessary and plans to allow capacity for this activity will need to be reviewed.
- As the team grows it will be necessary to clearly define the responsibilities of each role, including those of existing team members who have previously taken on additional roles to fill service gaps, to maximise effectiveness of the broader MDT.

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

Models of care

Summary

The service is well organised with appropriate referral links, protocols and provision of both inpatient and outpatient care. All patients are offered an annual review assessment, and for those who chose not to attend, tests are arranged during an alternative hospital attendance where possible. The team have a monthly annual review MDT meeting to discuss the results, but due to the significant pressures on consultant time a formal report is not achieved for at least half of all patients. As the service grows it will be important to ensure a robust approach to capturing all patients is in place.

Multidisciplinary care

Summary

Overall the strong and committed core MDT provide a high standard of care despite shortfalls in staffing across the team and, notably, the lack of a psychologist and social worker. Whilst some psychosocial support is picked up by the specialist nurses and other team members, this is largely achieved out of goodwill and by team members being willing to 'go the extra mile' for their patients. This is commendable but not sustainable as the service grows.

The bi-monthly transition clinics are highly valued and the introduction of a joint CF-related diabetes (CFRD) clinic and MDT has further strengthened the service, although concerns have been raised about ongoing funding to support this.

Principles of care

Summary

The service now has high standards for managing infection control. While clinics are not completely segregated, all patients are isolated in individual rooms with appropriate cleaning and there is no communal waiting area. The centre has a separate clinic for *Burkholderia cepacia* and has recently also introduced a separate clinic for patients with Nontuberculous Mycobacterium (NTM). Molecular microbiological sputum surveillance is ongoing to inform further cohorting of clinics. Pressure on clinic space and the need to ensure appropriate isolation will need to be considered as the service continues to expand.

The number of patients with chronic pseudomonas on regular nebulised anti-pseudomonal antibiotics appeared low in the 2013 UK CF Registry data. Further review demonstrates that all eligible patients are assessed and prescribed nebulised therapy appropriately.

Delivery of care

Summary

The service receives excellent feedback from its users. While the shortfalls in staffing highlighted throughout this document mean that the service is not able to achieve recommended standards in all domains (weekend physiotherapy, availability of dietitian and physiotherapist at all clinics, specialist pharmacy input and psycho-social support) the MDT should be commended for their commitment to providing a high standard of care despite this. This will not be sustainable unless significant investment to resourcing the service is addressed.

Commissioning

Summary

The service is relatively small and has grown organically over a number of years, but is now at a tipping point with respect to its ability to manage current and future caseload as the number of patients and case complexity increase.

The service has a number of deficits in key posts, notably consultant time, psychology support, a senior pharmacist and physiotherapy. This means that, while the service is compliant with minimum standards, it relies on a significant amount of goodwill with staff often working beyond what might reasonably be expected in order to ensure high-quality care.

The Divisional Management Team are supportive of the service and see it as a key part of their plans for the future development of tertiary services. The team have identified resources to address some of the identified deficits and have supported the recruitment of a service coordinator and additional physiotherapy support. Proposals have been developed to address other priority issues such as psychology support. The management team are also exploring the options to free up more dedicated consultant time for the service.

As the team expands it will be necessary to clearly define the responsibilities of each role, including those of existing team members, in order to maximise their individual effectiveness and that of the broader MDT.

The current plan should be the starting point for more detailed planning and the development of a strategic plan for the service. There is a strong sense that the service has concentrated its efforts on coping with current demand with the resources that it has available and does not have a clear vision for the future and a plan for how it will cope with the projected growth in activity. The service sits within a large respiratory medicine department that delivers a wide range of other tertiary services and therefore offers opportunities for sharing resources.

The service should explore opportunities for changes to the current service model to enable it to cope with future growth including for instance the option of increasing outreach. The service should look for examples of good practice from other larger services to inform its plans. The management team outlined future plans for the Glenfield Hospital site and the opportunities that this might offer for overcoming some of the environmental challenges that the service currently faces, particularly for ambulatory and day-case activity.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	78

			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	4; 90.98 (64.75–107.05)	3; 61.48 (38.88–95.91)
		20–23 years	15; 67.66 (19.93–101.65)	12; 70.73 (27.33–116.54)
		24–27 years	4; 39.35 (27.88–74.8)	5; 50.36 (26.34–64.37)
		28–31 years	2; 62.49 (36.31–88.66)	7; 65.57 (38.7–107.87)
		32–35 years	2; 50.1 (45.78–54.42)	5; 68.82 (32.95–134.99)
		36–39 years	2; 72.24 (63.81–80.66)	3; 44 (42.61–85.33)
		40–44 years	3; 58.77 (17.86–85)	1; 74.36
		45–49 years	2; 38.49 (28.53–48.44)	1; 110.14
		50+ years	3; 103.96 (66.72–116.39)	2; 75.08 (55.68–94.47)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=38); 20 (53%)	(n=40); 16 (40%)
	Number of patients and % with BMI <19 split by sex	7 (18%)	12 (30%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	40 (51%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	24 (60%)

Macrolides	Number and % of patients on chronic macrolide with chronic *Pseudomonas aeruginosa* infection	24 (60%) with chronic PA
	Number and % of patients on chronic macrolide without chronic *Pseudomonas aeruginosa* infection	13 (34%) without chronic PA

4. Delivery against professional standards/guidelines not already assessed

Consultants

Both CF consultants have considerable experience in Cystic Fibrosis and are highly committed to the service. They attend national and international meetings and the service lead is a senate member for the national CF Clinical Reference Group (CRG). Each has 0.3 whole-time equivalent (WTE) allocated for cystic fibrosis in their job plans (standards recommend 0.5 and 0.3 WTE for 75 patients), but they are stretched with commitments to general respiratory medicine, a large non-CF bronchiectasis service and participation in the general respiratory take. In addition, they both have non-clinical commitments (service lead for respiratory medicine and medical education) and in reality the actual time they have available for the CF service is around 0.4 WTE in total. While there is some junior doctor support for the service on the ward, specialist registrar input is only available around 40% of the time due to cross-cover arrangements with respiratory medicine and on-call rotas. The service is completely dependent on the excellent specialist nursing team to bridge the gap in the shortfall in medical staffing, but the specialist nurses are both working above capacity and undertaking multiple roles to support the team, which is not sustainable.

The consultants provide cross cover for each other and out-of-hours advice is available via the respiratory on-call rota. With the limited time available for CF, the focus has been on delivering a safe clinical service that is consultant led, but it is clear that the team are stretched and at capacity. There is a weekly MDT meeting and the team have committed to delivering an exemplary transition service. However, little time is available for service development, research and audit, and in order to take the service to the next level investment in these areas will be necessary as the service continues to grow. Pressure on capacity in other CF services in the Midlands may provide an opportunity to further expand the service, but at the current level of service provision this would put considerable strain on existing resources.

The service is predicted to continue to grow by around three to five patients per year and without creating capacity for the CF consultants to commit more time to the CF service it will not be possible to continue to provide a robust clinical service. There is a recognition that the service is under resourced in a number of areas, notably psychology, social work and pharmacy support, although pressure on dietetic and physiotherapy time also impact on service delivery. The consultant team are working closely with management to address these issues.

Areas of good practice:

- A committed and experienced consultant team who provide a consultant-led service.
- Willingness to be involved in research and clinical trials despite pressures on time and resources.

Areas for improvement:

- Service development and longer term strategy, audit.

Recommendations:

- Release capacity (0.4-0.5 WTE minimum) within CF consultant job plans by backfilling time for general respiratory work to allow an increased commitment to the CF service in line with standards and to allow for service growth.

Specialist nursing

There are two (1.9 WTE) Clinical Nurse Specialists (CNS) (Band 7) providing adequate provision for their number of patients. However there is no cover when one of them is on leave or when they had to additionally cover for another team. The CNS provide extended contact hours to patients and are available to ward staff for advice out-of-hours.

Both CNS take turns to attend regional and national meetings and are members of the Cystic Fibrosis Nursing Association (CFNA). They also attend international conferences every other year, using a charitable fund to help with costs.

There is good team working, with the CNS supporting ward staff and the wider team.

Unfortunately, staff shortages have meant the nurses have had to pick up some of the workload from other disciplines. This has resulted in the CNS not being able to complete an e-learning package they were designing or complete/update audits and policies.

Apart from their weekly CF outpatient clinic, they provide a CF adolescent/transition clinic and a diabetes nurse-led CFRD clinic (presently under threat due to funding) both run on alternate months. They have recently started a monthly NTM clinic and they intend from August to start a consultant-led CFRD clinic, on alternate months.

About half of their patients are seen as ward attenders for their annual reviews, with the remaining seen in clinics in order to best capture all patients. A coordinator has been appointed recently to help with administrative tasks and the CF Registry.

Areas of excellence/good practice:

- Excellent CNS-led daycase review service. They're both prescribers and know their patient base well, starting them on home IVs and providing follow up both in hospital and at home. This gives patients individualised care and knowledgeable support.
- Nurses are very passionate and flexible in their approach to providing excellent patient care. Their dedication to the service must not be underestimated.

Areas of improvement:

- Consideration must be given to their lack of protected non-patient time, due to staff shortages resulting in them not being able to carry out more proactive work.
- Considerable thought must be given to the expansion and development of the service.

Recommendations:

- The CNS should have their time protected from the bronchiectasis service as this is currently filled with a short-term secondment. This would endanger the quality of current service. Likewise, it is vital that resources are allocated to fill pharmacy, psychology and social work posts, as these directly impact their workload and capabilities.

Physiotherapy

A total of 1.9 WTE physiotherapists and 0.2 WTE physiotherapy assistant time care for 82 patients (standards of care recommend 2.19 WTE five-day working), equating to a 0.3 WTE shortfall. The 1.9 CF physiotherapists participate in a Trust-wide seven-day working model, further reducing physiotherapy time dedicated to the CF service.

In addition, there is a requirement to provide support to a very busy bronchiectasis service. This has the impact of reducing dedicated physiotherapy provision to the CF service further, average loss 0.55 WTE (range 0.3 – 0.8). In total physiotherapy provision to CF care has a shortfall of 0.85 WTE (range 0.6 – 1.1) from standards of care recommendation. This excludes the time lost through the implementation of a Trust-wide seven-day working model. The physiotherapists are working at approximately half the recommended staffing levels dedicated to CF.

Areas of good practice:

- A very motivated, expertly lead physiotherapy team that is integrated with both the wider specialist respiratory physiotherapy teams at Glenfield Hospital and the CF physiotherapy team at Nottingham, allowing cross fertilisation of skills and expertise.
- Active regional and national Association of Chartered Physiotherapists in CF (ACPCF) engagement, including presentations. Presentation at the European Cystic Fibrosis Conference (ECFC) 2014.
- An innovative, bi-weekly, 6-week exercise start-up programme, including support to both patients and gym staff with in-community gym settings.

Areas of improvement:

- Grading of staff means that there is a lack of physiotherapy-specific professional leadership to facilitate both professional and specialist service development and research. As the centre grows this will become an increasing issue. The highest graded physiotherapist is a Band 7.
- The small team size and staffing shortfall has had an adverse impact on OPD service provision. Strategies to manage a recurrence of this in the future need to be considered.
- Only 19% of patients are seen by a physiotherapist twice a day over weekends.

Recommendation:

- Physiotherapy staffing shortfall should be addressed now and continue to follow nationally recommended staffing levels.
- Consider the grading of the senior staff to provide a robust framework of professional leadership, specialist service development and research as the centre grows.
- Develop processes that will help to increase the uptake of weekend physiotherapy provision.

Dietetics

The service currently has a 0.4 WTE Band 6 dietitian. The remainder of the post holder's time (0.6) is spent covering general respiratory, adult cardiac surgery and ITU. All inpatients are seen twice weekly, and the dietitian attends the weekly CF outpatient clinic and MDT meeting. All patients who attend for annual review are seen by the dietitian and she attends the diabetes specialist nurse led CFRDM clinic and transition clinic. However there is no cover for the dietitian when she is on leave/absent, and she is expected to cover for departmental colleagues on a regular basis which has a significant negative impact on CF caseload. The support of a dietetic assistant for two sessions a week has recently been withdrawn and there are no plans to replace this role. Audit and developmental work tends to be completed in her own time.

Patient feedback regarding food service provision is generally good, however the food service can be reduced over weekends. The hospital provides a plated menu but there is a Diet Chef available until 2pm, Monday to Friday, who can provide additional food choices. CF patients can also access the children's menu, and in addition the dietitian has implemented a programme of high-calorie snack provision that can be accessed daily. In addition, there is an allowance of up to £15 per day, per inpatient that can be spent at any of the hospital food outlets. There are plans for a diet kitchen to be built and the dietitian will be involved in menu planning and recipe development. All patient rooms have fridges.

The dietitian is a member of the UK CF Dietitians Interest Group and has shadowed and been mentored by CF-specialist dietitians from larger centres in order to gain experience and assess competencies for Band 7. She has completed the MSc Module in CF dietetics. Her background is nutrition support and she is currently developing an Adult CF Enteral Feeding Care Pathway for Discharge. She leads the service on vitamin supplementation and is currently undertaking an audit of Vitamin D levels. Median CF BMI has improved since her appointment.

Areas of Good Practice:

- Dietitian working towards Band 7 competencies, with support from Leeds and Papworth specialist dietitians.
- Audit being undertaken and policies developed.
- Dietitian is fully integrated into MDT.

Areas for Improvement:

- Current dietetic establishment under CF Standards of Care, and patient numbers increasing with increase in complexity of cases.
- CF dietetic time not protected.
- No provision for home visits.

Recommendations:

- Increase dietetic post to 0.5 WTE to meet CF Trust Standards of Care, and progression of post to Band 7 upon completion of Band 7 competencies.
- Discontinue the use of CF dietetic time to cover other specialties.
- Provide cover for CF service during periods of dietetic leave.

Pharmacy

Prior to February 2015 the CF clinical pharmacy service was provided by a 0.1 WTE Band 8a CF lead and respiratory pharmacist, which did not meet the minimum recommendation of a 0.5 WTE for 75 CF patients. In February the Band 8a pharmacist left and the post remains vacant. The pharmacist was extremely dedicated, experienced and an integral member of the MDT. He attended weekly MDT meetings, provided a comprehensive clinical ward pharmacy service and full medication review, was actively involved in writing clinical guidelines, research, completing audits (Fosfomycin audit/poster on adherence), and regularly attended/presented at regional and national meetings, ECFS conference and NACFC. Due to time restraints the CF ward round was attended on an ad-hoc basis and annual reviews were not undertaken.

The CF service is currently overseen by the respiratory consultant pharmacist who works four days a week. She is unable to take on the role as the CF lead pharmacist due to her extensive role, other work commitments and competing pressures. Therefore, the service provided previously cannot be maintained. A basic clinical ward pharmacy service is provided by an experienced Band 7 pharmacist, but with limited CF experience/expertise. This pharmacist will start attending MDT meetings, but not ward rounds. During their absence a junior pharmacist covers the wards. Queries/issues that cannot be dealt with by the junior/Band 7 pharmacist are directed to the consultant pharmacist, or the CF team contact her directly. In her absence they are dealt with by medicines information or other pharmacists who may not have CF expertise/experience. Where possible, new clinical guidelines are written by the consultant pharmacist; however, there is no time to update clinical guidelines.

A self-administration scheme operates on the wards. There is a medicines management technician (MMT) who covers the respiratory ward, including the CF inpatient beds, for approximately two hours a day. Medicines reconciliation and checking of patients' own drugs is undertaken by the pharmacist, or MMT. Patients can receive IV antibiotics at home that are supplied by pharmacy, which they make up themselves. Only patients with particular issues receive elastomeric devices through a homecare company. Currently Ivacaftor, Bramitob, Colobreathe, Mannitol, and TOBI Podhaler are provided by a homecare company, with all other homecare medicines provided by the understaffed Trust's pharmacy, further increasing the workload and pressure.

The pharmacists are working very hard and under a lot of pressure to continue to provide the best service to the CF team and patients.

Areas of Good Practice:

- Consultant pharmacist overseeing service in the absence of a senior CF lead pharmacist.
- Provision of a home IV antibiotic service.

Areas for improvement:

- Clinical pharmacy service to be provided by a senior pharmacist with CF expertise and knowledge.
- Annual medication review by a senior CF/respiratory pharmacist in clinic.
- Regular attendance at ward round, MDT, CF meetings and national and international conferences.

Recommendations:

- For pharmacy to meet the areas for improvement, re-instate the excellent service prior to the vacancy, and further improve and develop the service, the following is required:
- Appointment of a 0.4 WTE Band 8a pharmacist ring-fenced for CF (0.1 WTE to be provided through the appointment of an 8a respiratory pharmacist with an approximate start date of September 2015).
- The provision of all homecare through a homecare provider, particularly if the repatriation of high-cost drugs back to the Trust for CF patients occurs.

Psychology

There is currently no clinical psychologist within the Leicester adult CF service, and the team have not had any dedicated clinical psychology service to date. Recommended staffing for a unit their size would be 0.5 WTE clinical psychologist based within the CF team. Therefore, the service does not currently meet standards of care in this respect.

Lack of clinical psychology service means that other members of the CF team, notably the clinical nurse specialists, are attempting to provide the psychological care for the CF patients. While a great deal of support and advice is clearly offered and valued, patients do not currently have access within the team to the appropriate evidence-based specialist psychological therapies (eg cognitive behavioural therapy) for psychological problems most commonly experienced by people with cystic fibrosis. Referral to community psychology services is made as required, but with variable access, and such services are not integrated with CF care. Liaison psychiatry is also accessed as required, as are hospice services for palliative/end-of-life care issues. Clearly great effort is made to meet the psychological needs of patients in the service, but significant gaps in provision are recognised by the CF team, and demands on the CF specialist nurses time (in trying to cover multiple CF team roles) seem high.

A CF clinical psychologist would provide a specialised psychological therapy service (including for complex/severe emotional health problems) integrated with CF care, and with detailed knowledge of CF specific problems. In addition, a CF clinical psychologist (at recommended staffing level) could lead on service development for psychological care in the CF service as a whole, and through expert screening, early intervention and psychological work on adaptation to coping with CF, would take a more preventative approach to emotional health disorders. They could also provide expert intervention for problems to do with managing physical health, including adherence to treatments, and help support the CF team in their demanding work.

Members of the Glenfield team seem well aware of the need to have an integrated CF clinical psychology service and are keen to develop this. A possible route to some initial clinical psychology sessions has been identified but the unit will require the hospital trust's support in funding/securing such a service. Provision below recommended levels will need to be carefully planned to decide which possible roles for the CF clinical psychologist should be prioritised. Further advice regarding the competencies and roles of a CF clinical psychologist is available from the UKPPCF on request.

Recommendation:

- A CF clinical psychology service should be developed as soon as possible, as standards of care are not currently met in this respect.

Social work

Areas of good practice:

- There is no CF social worker in the team, but the team are very patient focused and aware of patients having psychosocial needs and would like to provide a professional service for this.
- The specialist nurses and centre coordinator try to help patients with social issues and provide whatever support they are able to, within the time and skills they have.
- The specialist nurses have been keen to find out more about how a social work post could be obtained and funded, and are keen to lobby for this.

Areas for improvement:

- The team is small and under-resourced, patient growth is limited though steady, so resources for a social work post may be limited.
- The CF team staff members appear to struggle already to have protected time/sufficient staffing for their CF roles so a specialist social work role purely in CF would be a new concept in the hospital, where CF social work has no history.
- The CF team are used to managing with what they have, but will need the full range of staffing at adequate levels in order to meet standards of care as their service grows.

Recommendations:

- The CF team need to formulate a plan for the increase in staffing and include proposals for psychosocial professionals to be employed as part of this.
- It appears that there is limited knowledge of the role of a social worker within some areas of the team – the UKPPCF can provide further information about this.
- That the CF team take advantage of the Peer Review as a positive force for change, and an opportunity to move towards the Standards of Care psychosocial requirements.

Summary:
There is no CF social work post in the Leicester team. The Standards of Care requirements specify that for approx. 80 patients a post of approx. 0.5 WTE would be needed. Leicester is unusual in never having had any psychosocial professionals in the team, and this should be part of the allocation of CF staffing resources.The Peer Review provides an opportunity to learn more about the psychosocial roles, investigate resources and move towards creating the necessary posts.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	1	1	6	1	2	2	1
Female	0	0	2	3	1	0	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	17	3	0	0
From the ward staff	8	6	1	0
From the hospital	12	5	2	0

Areas of excellence:

1. The CF team – accessibility to appointments/advice
2. Outpatient clinic – very good/excellent outpatient experience
3. Inpatient care – admission waiting times, segregation, cleanliness

Areas for improvement:

1. Annual review – 25% of respondents felt it was only 'fair'
2. Food – patient accounts are varied
3. Weekend physiotherapy support on ward – patient accounts are varied

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

Glenfield 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%	Red	Red	While most patients either attend for annual review or have annual review tests performed ad hoc, only 43% had a discussion and action plan. This is largely due to pressures on consultant time.

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?	Yes/No	Safe service, however not effective due to staffing deficiencies.	No	The service is safe but significant under-resourcing of staff makes the service vulnerable and impacts on effectiveness.
	% 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	With insufficient staffing resource there is limited time and capacity to update develop new guidelines and update existing resources.
	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 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%	Red	Amber	The service has separate Non tuberculous Mycobacterium and *B. cepacia* clinics. The team have plans to further segregate outpatient clinics according to microbiological status. Currently all patients are isolated in outpatients in single rooms with appropriate cleaning after each patient use.
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	% of patients aged >12 years screened annually for cystic fibrosis-related diabetes	100%	Green	Green	

3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years.	100%	Amber Repeated DNA (did not attend) patients	Amber	All patients are offered liver ultrasound scan appropriately but high did-not-attend rate
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%	Amber Significant did-not-attend	Red	All patients offered scans. High did-not-attend rate and local Trust policy means patients under age 21 are not accepted for bone mineral density scan.

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 at each clinic visit.	100%	Green	Green	
	% of patients with access to a CF clinical nurse specialist during admission (excluding weekends).	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit.	100%	Amber	Amber	
	% of patients reviewed by a physiotherapist twice daily, including weekends.	100%	Green	Amber	Shortfall in staffing and lack of cover for annual leave impacts on the ability of the physiotherapists to meet this standard. Access to weekend physiotherapy is extremely limited.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a CF specialist dietitian at clinic.	100%	Amber	Amber	Shortfall in staffing, pressure from general respiratory services and lack of cover for annual leave impact on the ability to meet this standard.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	Note no cover for annual leave and loss of dietetic assistant post will affect ability to meet this standard.
	% availability of a clinical psychologist at clinic.	100%	Red	Red	Currently no psychologist.
	% availability of a clinical psychologist for inpatients.	100%	Red	Red	Currently no psychologist.
	% availability of a social worker at clinic.	100%	Red	Red	No social worker aligned to the service. The nurse specialists provide some social work support.
	% availability of a social worker for inpatients.	100%	Red	Red	As above
	% availability of pharmacist at clinic.	100%	Red	Red	Currently no specialist CF pharmacist.
	% availability of a pharmacist for inpatients.	100%	Green	Green	Currently no specialist CF pharmacy support, but service is supported by ward pharmacist and consultant pharmacist.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
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%	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	5	5	The service has an appropriate and rigorous approach to incident reporting.
5.3	User survey undertaken a minimum of every three years	100%	Red	Green	
5.4	Service level agreements in place for all	100%	N/A	Green	

Appendix 2

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Glenfield Hospital (83 patients)
Consultant 1	0.5	1	1	0.3 WTE
Consultant 2	0.3	0.5	1	0.3 WTE
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.4	0.8	1	Rotating
Specialist nurse	2	3	5	1 WTE 0.9 WTE
Physiotherapist	2	4	6	1 WTE 0.9 WTE 0.2 WTE band 2 assistant
Dietitian	0.5	1	2	0.4 WTE
Clinical psychologist	0.5	1	2	0
Social worker	0.5	1	2	0
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	0.1 WTE
Database coordinator	0.4	0.8	1	1 WTE
Consultant Microbiologist				0.5PA (1PA shared with Paediatric Team)
Diabetes Nurse Specialist				Bi-monthly nurse-led clinic? 0.1WTE
Consultant Diabetologist				0

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 – Glenfield Hospital, Leicester	
Number of active patients registered (active being patients within the last two years)	78
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	78
Median age in years of active patients	25
Number of deaths in reporting year	2
Median age at death in reporting year	22.5

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	7 (9.5%)
	20–23 years	28 (36%)
	24–27 years	10 (13%)
	28–31 years	9 (11%)
	32–35 years	7 (9.5%)
	36–39 years	5 (6%)
	40–44 years	4 (5%)
	45–49 years	3 (4%)
	50+ years	5 (6%)

Genetics	
Number of patients and % of unknown genetics	12 (15%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=38); 20 (53%)	(n=40); 16 (40%)
Number of patients and % with BMI <19 split by sex	7 (18%)	12 (30%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	7 (100%)	11 (92%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Medium FEV_1% predicted at age 16 year split by sex		0	0
Number and medium (range) FEV_1 %n predicted by age range and sex	16–19 years	4; 90.98 (64.75–107.05)	3; 61.48 (38.88–95.91)
	20–23 years	15; 67.66 (19.93–101.65)	12; 70.73 (27.33–116.54)
	24–27 years	4; 39.35 (27.88–74.8)	5; 50.36 (26.34–64.37)
	28–31 years	2; 62.49 (36.31–88.66)	7; 65.57 (38.7–107.87)
	32–35 years	2; 50.1 (45.78–54.42)	5; 68.82 (32.95–134.99)
	36–39 years	2; 72.24 (63.81–80.66)	3; 44 (42.61–85.33)
	40–44 years	3; 58.77 (17.86–85)	1; 74.36
	45–49 years	2; 38.49 (28.53–48.44)	1: 110.14
	50+ years	3; 103.96 (66.72 – 116.39)	2: 75.08 (55.68 – 94.47)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	7
	20–23 years	28
	24–27 years	10
	28–31 years	9
	32–35 years	7
	36–39 years	5
	40–44 years	4
	45–49 years	3
	50+ years	5
Number of patients with chronic *P. aeruginosa* by age group	16–19 years	3
	20–23 years	14
	24–27 years	9
	28–31 years	5
	32–35 years	4
	36–39 years	2
	40–44 years	1
	45–49 years	2
	50+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	1 (1%)
Number and % of *B.Cenocepacia*	0
Meticillin-resistant *Staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	6 (8%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	5 (6%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	19 (12%)
Cystic fibrosis-related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	24 (31%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	8 (8%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (1%) with PH 4(5%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	5
Number of patients referred for transplantion assessment in previous three years	9
Number of patients receiving lung, liver, kidney transplants in previous three years	2

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	36
	20–23 years	629
	24–27 years	528
	28–31 years	64
	32–35 years	100
	36–39 years	83
	40–44 years	129
	45–49 years	0
	50+ years	8
Number of days of home IV therapy in reporting year split by age group	16–19 years	74
	20–23 years	400
	24–27 years	356
	28–31 years	157
	32–35 years	91
	36–39 years	66
	40–44 years	41
	45–49 years	94
	50+ years	2
Total number of IV days split by age group	16–19 years	113
	20–23 years	1029
	24–27 years	884
	28–31 years	2221
	32–35 years	191
	36–39 years	149
	40–44 years	170
	45–49 years	94
	50+ years	10

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1, % predicted <85% (ie below normal) on DNase	(n=59); 27 (46%)
If not on DNase, % on hypertonic saline	10 (17%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	40 (51%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	24 (60%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	24 (60%) with chronic *P. aeruginosa*; 13 (34%) without chronic *P. aeruginosa*

Appendix 4

Patient survey

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	1	1	6	1	2	2	1
Female	0	0	2	3	1	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	15	5	0	0
Communication	11	8	1	0
Out-of-hours access	9	6	2	1
Homecare/community support	9	3	0	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	13	6	1	0
Waiting times	12	5	1	0
Cross-infection/segregation	16	3	0	0
Cleanliness	16	4	0	0
Annual review process	12	4	4	0
Transition	7	2	1	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	10	5	0	0
Cleanliness	10	3	1	0
Cross-infection/segregation	10	4	0	0
Food	7	4	2	2
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	10	4	0	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	6	1	5	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	8	7	0	0
Availability of equipment	9	5	1	0
Car parking	9	5	5	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	17	3	0	0
Of the ward staff	8	6	1	0
Of the hospital	12	5	2	0

Comments about CF team/hospital

"Excellent team in every way"

"Could not ask for better. CF team do a brilliant job."

"The on demand support the CF team provides to people like me is really great and the team goes out of their way to provide care and attention. Very encouraging and supportive and makes a huge difference to our well-being. Well done."

"The best care I could possibly get. I travel 40+ miles to the hospital. There is a closer hospital but the service I get now is so good I wouldn't move."

"The CF team are very good in doing their best to support me, but they are so busy and at times it's hard to get a response. There is no support or access at weekends so this makes things difficult if I have problems over the weekend or am admitted on a Friday. The restaurant is not open at weekends and the food is terrible. I always resort to having food brought in for me. The CF ward is based by a respiratory ward and the CF corridor is accessed by members of the public and other patients. Also, people are not stopped from smoking outside the CF unit and the smoke comes into rooms affecting me."

"Access to the two specialist nurses is superb, but doctors with CF specialism not always available. Unit needs to expand also."

"Glenfield Hospital CF team are excellent in providing care, support and advice when required - a hard working team."

"I couldn't live without our CF team – ie consultants, CF nurses and physio. I don't really go to the dietitian for advice. Also, we really miss our pharmacist since leaving."

Appendix 5

Patient/parent interviews

Patient telephone interviews

Patient A

Outpatient clinic

Patient A felt that segregation measures at outpatient clinic were fine. He's directed straight to his own, separate consultation room on arrival at clinic where he is weighed and measured; spirometry equipment is wheeled into this room so that the patient doesn't have to leave the room.

Patient A found the hand hygiene measures fine, adding that he believed everyone seems to use the gel dispensers at appropriate times.

Patient A explained that he has a mild form of CF and so does not need to have discussions with the CF team about changes to treatments. He attends the CF service for annual review only.

Inpatient care

Not applicable to this patient.

Annual review

Patient A explained that he has a chest x-ray every two years, full lung function test each year and pancreatic function assessment every five years. He explained that his annual review reports show comparisons between previous years.

Patient A's annual review outcome is fed back at the annual review appointment itself and in a written letter to the GP, a copy of which letter he also receives.

In broader communication terms, Patient A has the email address of each member of the CF team. His first point of contact is either the clinical nurse specialist or Dr Range's secretary.

Home care

Not applicable to this patient.

Good practice

- "All of the CF team are very friendly and easy to talk to. Wish my GP was the same."
- "Very thorough at late diagnosis, especially Dr Range."
- "Holistic approach by the CF team and they articulate it well to the GP."

Area for improvement

Patient A didn't feel qualified, in his words, to suggest areas for improvement.

Patient B

Outpatient clinic

Patient B felt that segregation measures at outpatient clinic were good, adding that he is directed straight to a consultancy side room on arrival. He explained that there is a gel dispenser at the entrance to the clinic and further down the corridor. He was happy that the hand-hygiene measures were being adhered to.

At outpatient clinic Patient B saw each member of the CF specialist multi-disciplinary team and he knew how to access psychosocial support, if required. He felt fully involved in decisions made in respect of his treatments and changes to treatments. At pharmacy he felt the waiting time was "pretty good" adding that he "just hears coughing sometimes."

Inpatient care

Patient B's most recent admission within the last 12 months was a trouble-free admission – he added that admissions always have been easy and referred to the CF unit as "the best unit in the hospital." Patient B felt the ward nurses were superb, but was less positive when reflecting on the ward food, adding that he thought the meals were "dire and bland" so he ate baguettes from the shop, using the daily £15 voucher his is given.

Patient B felt the physiotherapy support on the ward was "brilliant". He explained that if he has back ache the CF physiotherapists will ask him to come to see them. He did not know what exercise equipment or opportunities there were for inpatients.

Annual review

Patient B is offered annual review each year and has had this year's annual review. All his annual review assessments take place at Glenfield Hospital and he receives the outcome of the review in a written report which includes what aspects of his treatments and results have changed. Patient B called his annual review letter "comprehensive."

Home care

Patient B's social worker has made a home visit to him. All his nebulised treatments are prescribed locally and he has to collect all these from his local chemist. Patient B did not have any other home visits or home care.

Good practice

- "I couldn't speak highly enough of the CF service, even the cleaners. I've had no problems in four or five inpatient stays."

Areas for improvement

- "I can rarely get a parking space, even with a blue badge."

Patient peer review day interviews

Patient A

Patient A is a 24-year-old female who lives just ten minutes away from the hospital. She transitioned to this service from the paediatric service at the Leicester Royal Infirmary. Patient A is admitted to hospital for two weeks IV antibiotic treatment every month.

Areas of excellence:

- Car parking hasn't been a problem so far as she has a blue badge so is able to use the disabled parking areas.
- The food served from the ward menu is poor but the voucher system where patients are issued a daily £15 voucher enables her to get food from the hospital canteen which she feels is of much better quality.
- The team are always very accessible and she is always seen by the same members of the MDT.
- There is never any waiting time for hospital admission.
- Patient A sees a physiotherapist twice a day.

Areas for improvement:

- Patient A doesn't use the TV service as it is too expensive (free standing TVs are provided but the signal is very poor, she sometimes uses the TV to watch DVDs). Purchasing Wi-Fi access is also expensive considering the amount of time she spends in hospital and the limited sites she is able to browse.
- Patient A would like the rooms to be brightened up and made more homely.

Patient B

Patient B is a 22-year-old female. She lives in Hinckley; the journey to the hospital takes around thirty minutes. She transitioned from the paediatric service at Leicester Royal Infirmary at around 17 years.

Areas of excellence:

- Patient B considers the service and quality of care she receives to be very good. She is admitted to the hospital for IV antibiotics treatment three to four times each year.
- The £15 daily subsistence allowance is good as she feels the food on the ward is terrible so she uses the voucher system to get food from the hospital canteen.
- Time for admission is within 24 hours
- The MDT are very friendly and always easy to get hold of.
- The annual review process is very smooth.

Areas for improvement:

- Car parking is sometimes problematic; weekly permits are available but these are still on the expensive side.
- The nursing team currently help with any social-work related issues. Patient B feels that input from a psychologist would be beneficial, especially in the future as she may encounter more problems.
- Internet access is expensive.
- Patient B would like more nurses who are trained in specific CF care; administering IV antibiotics and flushing ports for example.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Glenfield 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	Patients are shown into individual rooms on arrival to clinic. We are in the process of segregating clinics according to microbiology status.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	Male and female toilets in clinic.
Where do height and weight measurements take place? Is this appropriate?		Treatment room in clinic. Equipment is wiped down after each patient.
Where are the lung function tests done for each visit?		In individual rooms.
Are clinic rooms appropriately sized?	Yes	Yes. All rooms have a sink for handwashing and a couch for examination.
For annual review patients, are any distractions provided?	No	Patients usually bring in own laptops/tablets/ books.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Previously no	Joint CF/diabetic clinics are in the process of being set up and will follow the same process as CF clinics as above.
Transition patients – can they get tour of outpatients' facilities?	Yes	Paediatrics and adults on different sites. We hold a joint adolescent clinic at Glenfield alternate months. Patients are shown around the CF unit and other departments.
Transition/new patients – do they get information pack?		We have information that is given to new patients. We have transition documentation for patients to work through but not always used.

Additional comments

Approximately 280 patients, 270 and fourteen currently transitioning.

Three clinics, held on Monday, Wednesday and Friday, one of which is an evening clinic. Clinics are segregated depending on microbiology. Patients are segregated and seen at different clinics for *Pseudomonas*, *non-Pseudomonas* and *M.Abscessus*, who are seen at end of clinic. All rooms are not reused after complex microbiology attendance and are 'Chlor' cleaned nightly. The lung function lab is located near to the clinic.

Environmental walkthrough: ward

Ward name: 16

Microbiology status:

		Hospital name	Glenfield Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			Ward 16 had five dedicated side rooms for CF patients. Patients with B. cepacia are nursed on an adjacent ward (we only have two patients with *B. cepacia*). All rooms are en suite.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?			Nine (five dedicated for CF)
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	There is a lockable medicine cabinet inside each room.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Each room on the CF unit has a TV, however reception is very poor. Mainly used to watch DVDs. There is internet access which is chargeable.
Are there facilities to allow parents/ carers/partners to stay overnight?			In the patient's room, they have use of a recliner chair. For longer stays there are chargeable relative's accommodations available on site.
Visiting hours – are there allowances for CF patients' families out of normal hours?			CF patients have open visiting.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?			There is a fridge in each room on the CF unit. There is a microwave for use but patients are not allowed in the kitchen for infection control reasons. There is no separate patient kitchen.
What facilities are provided for teenagers?			

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Gym on the CF unit. Some exercise equipment available for the rooms.
What facilities are there to help with school and further studies?		
Is there a relatives' room?	No	Use of a quiet/retreat room.
What internet access is there?		Wi-Fi available but is chargeable.
What facilities are there to enable students to continue to work and study?		Patients bring in own lap tops.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes/no	There is a sink in each side room. There are no sterilising facilities. Patients can bring in their own.
What facilities are provided for those with MRSA?		As per CF unit. Separate spirometer.
What facilities are provided for those with *B. cepacia*?		These patients (2) are nursed on an adjacent ward. Facilities are the same. Separate clinics/treatment rooms/spirometer for these patients.
What facilities are provided for those with other complex microbiology?		Same gym at different times. We are in the process of looking at patients with Non Tuberculous Mycobacterium (NTM) and inpatient facilities. Separate clinics/treatment rooms/spirometer for NTM patients.
Are patient information leaflets readily available on ward?	Yes	In CF treatment rooms to prevent cross-infection.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	Glenfield Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	1) Disabled parking. 2) Half-price monthly pass. This is used for patients that are coming into the hospital frequently over a short period of time. However not many patients will use it as many have a disabled badge and others will park in the free 20-minute drop-off zone (even though they will be longer).
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes/no	Only from one entrance.
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	We don't send more than one patient to pharmacy or radiology. DEXA scanning is on a separate site
Do patients have to wait at pharmacy for prescriptions?	Yes	We do not allow more than one patient in pharmacy at any time.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	On the ward and in clinics.
Are there patient comment/ feedback boxes?	Yes	On the ward and in clinics.

Appendix 7

Panel members

Dr Caroline Elston*	Consultant	Kings College Hospital
Mahinaz Harrison	CF Specialist Pharmacist	Royal Brompton Hospital
Helen Oxley	CF Specialist Clinical Psychologist	UH South Manchester Hospital
Alan Peres	CF Clinical Nurse Specialist	Royal Brompton Hospital
Elizabeth Glennon	CF Specialist Dietitian	Birmingham Heartlands Hospital
Susan Johnson	CF Specialist Physiotherapist	UH South Manchester Hospital
Anne Dealtry	CF Social Worker	Nottingham Hospital
Jon Gulliver	Specialist Commissioning	East Midlands
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	Quality Assurance and Control Manager	Cystic Fibrosis Trust

*Clinical lead

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