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Peer review report

Royal London Hospital and Paediatric Network Clinics

21 May 2015

Fighting for a Life Unlimited

Contents

1. Executive summary

Overview of the service

The paediatric cystic fibrosis (CF) service at Royal London Hospital (RLH) moved to the current new-build site in 2012. However, as growth outpaced staffing levels, it was put under notice of derogation (delay in meeting service requirements) in 2013. The Trust responded with many new recruitments. The benefits of this step-change in staffing levels are now being reaped, facilitating home visiting and the pioneering of innovative practice. The superb new facilities at RLH are spacious, permitting easy segregation and infection control. The model of network care is heavily dependent on Centre input to ensure an excellent standard. To maintain this with the imminent expansion to Whipps Cross, there will be staffing implications, particularly for consultants. There is still no dedicated social worker for CF and room for some improvement in support for the network clinics. However, despite recent upheavals in senior medical staff, in general the service at the Centre is first-class and service-user feedback is excellent.

Good practice examples:

- Ready home and school visiting by multidisciplinary team (MDT) members with better staffing. Even physiotherapy assessments for annual review and psychology assessments have been done at home.
- Attention to organisms in upper airways recovered from sinus washouts in older patients.
- Replacing Glucose Tolerance Test (GTT) with continuous glucose monitoring (CGM) as a more physiological routine annual screening test for CF-related diabetes after 10 years of age.

Key recommendations:

- Phase out respiratory consultant commitment to General Paediatric service.
- Appoint a dedicated social worker to the CF MDT.
- Ring-fence secretarial/administrative support for CF service to improve turnover of letters (particularly annual review reports) and reduce the administrative burden carried by clinical staff, especially the clinical nurse specialists (CNSs).
- Address some staffing issues in network clinics, particularly psychology and dietetic provision.
- Establish service level agreement (SLA) for Queen's.
- Continue to give full care at RLH for the Harlow patients (no need to restore outreach clinic).
- Foster greater transparency from finance managers over the CF tariff income and how it is spent.

Areas for further consideration:

- Include exercise tolerance testing as part of annual review.
- Improve catering provision for inpatients through a voucher system for use in the staff canteen.
- Create a more adolescent-friendly environment and increase facilities for adolescents.
- Look for ways of reducing time spent at clinic appointments by scrutinising the consultation pathway to see if any waste can be eliminated.
- Consider having additional local consultant resource in Colchester to help the existing highly experienced consultant manage the growing number of patients there, which could reach 35 by 2016. This would enable cross-cover for leave and time for Continuing Professional Development (CPD) in cystic fibrosis.

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

Models of care

Summary

- There are currently 119 patients registered to the Royal London Paediatric CF network, of which 31 have shared care with Colchester and 14 with Queen's, Romford. Since retirement of the local consultant at Princess Alexandra, Harlow, 11 patients who used to have shared care now receive full care at RLH giving 74 in full care. A cohort of children transferring their care from Whipps Cross/Royal Brompton is anticipated in the near future.
- Staffing levels at the Specialist Centre have been generally brought up to par for the clinic size with the recruitment drive in 2014, with the notable exception of a social worker.
- Staffing levels in the current two network clinics reflect the nature of how care is shared with the majority of admissions going to RLH, frequent outreach clinics with the whole specialist MDT and very close supervision of all patient management from the Centre. This model of very intensive network support is admirable but may have staffing implications if it is to be maintained with the imminent expansion of the network to Whipps Cross Hospital, which is now part of the same Trust.
- This model certainly meets almost all the requirements for exemplary CF centre care and is providing good care for children in the wider network, although there is not yet a SLA with Queen's.
- There is no local cross-cover for consultants responsible for CF at Colchester and Queen's. In their absence, CF cover is provided by the consultants at RLH. The local consultant in Colchester is responsible for over 30 patients and would welcome having a colleague to share the clinical load. Sufficient clinical input has only been achieved by increasing the frequency of outreach clinics by the centre MDT from two monthly to monthly rather than develop more local support.

Multidisciplinary care

Summary

Clear management protocols, improved staffing numbers and particularly an indefatigable team spirit within the CF MDT appear to have enabled standards of service delivery to be maintained despite recent turnover or absence of key staff, such as senior consultants.

- Medical staffing levels are adequate on paper but had been recently strained by absences beyond anyone's control. Currently, a locum middle grade is covering the grid Specialist Registrar (SpR) maternity leave and the CF fellow post is being re-advertised as there were no suitable applicants when last advertised. (Subsequently appointed in June 2015).
- Although the CF CNS complement may appear generous it is adding huge value to the service by enabling extensive support to the network clinics, enviable access to CGM, home visits, etc. The CNSs are providing the glue to a close-knit clinical network which keeps the show on the road, often undertaking many administrative and social work roles beyond their remit.
- Children who have had CGM subsequently attend the diabetic clinic often with CF consultant in attendance, or sometimes the diabetic consultant attends the CF clinic. Appropriate segregation is greatly facilitated with this model rather than bringing all children with CF-related diabetes to the same clinic.

- Weekly psychosocial meetings are held to discuss CF and other respiratory patients who may be inpatients or outpatients. They are attended not only by the psychologist and other members of the CF team, but by staff from the ward, hospital school, etc making it a larger meeting than the regular CF MDT meeting. Psychology input was reactive but expansion has enabled a more proactive service for all patients, including home visits and inclusion in the annual review assessment.
- The CF pharmacist had just returned from maternity leave and had qualified as an independent prescriber.
- There is no dedicated social worker for CF. Referrals to social services are made in crises, but many of the routine tasks such as help with DLA forms (now replaced by PIP forms which can take up to two hours to complete) are undertaken by the CNSs. This needs to be addressed.

Principles of care

Summary

- Infection control: the spacious environment at RLH facilitates segregation in outpatients and inpatients. All CF inpatients are admitted to individual cubicles with en-suite bathrooms. There are two negative pressure rooms on the respiratory ward generally used for the patients with non-tuberculous mycobacteria. Patients with Burkholderia cepacia are never admitted to the same ward as other CF patients. Personal decontamination between patients can go as far as staff showering and changing clothes after seeing potentially infectious patients.
- Respiratory care generally complies with accepted practices and guidelines. The attention given to monitoring and treating infection of the sinuses and upper airways (an interest of the previous senior physiotherapist) is probably an exemplar to other paediatric clinics for best practice.
- Nutritional and gastrointestinal (GI) care is generally appropriate.
- CGM has replaced GTT at RLH as the routine annual screening test for CF-related diabetes after the age of 10 years. The CF CNSs set up the monitors and the downloaded results are analysed by endocrinologists.

Delivery of care

Summary

- There are good arrangements for managing infants presenting through newborn screening.
- Outpatients at RLH are conducted in spacious facilities adjacent to the lung function laboratory with appropriate segregation. Outpatient clinics at Colchester are now held monthly and at Queens every three months.
- Annual Reviews at RLH: due to the lack of administrative support, much of the organisation of annual reviews falls on the CNSs. Bloods and CGM are done ahead of time and results gathered by CNS before the review. X-rays and scan are done on the day of the review, usually done by a consultant, although it is on the job plan of only one of them. A plan for the year is formulated after an MDT discussion at the end of clinic. Reports are dictated or typed directly and the secretary collates MDT reports. There can be a considerable delay before reports are sent, largely due to the shortage of secretarial support. The results and management plan are discussed at the next appointment.
- Annual Reviews at Colchester: On alternate months CF annual reviews for children under eight years old are done by the RLH MDT in Colchester. The local consultant does a respiratory clinic with CF patient slots in the afternoons in between. Annual review data is sent to RLH for entering onto the registry and data is not viewed separately from the rest of the network.

Inpatients: most parents choose to stay in the spacious cubicles with their children. There are also flats available for parents with sleeping accommodation, kitchen and laundry facilities, which can be pre-booked. Children from Queen's have inpatient treatment at RLH and Colchester patients usually start IV antibiotic courses at RLH.

Homecare: home, nursery and school visits are done by the CNSs. This has only been possible by the recent increase in staffing. The physiotherapists and psychologist have also done some home visits

- Lack of Wi-Fi availability on the wards at RLH was being addressed. (Barts Health Wi-Fi was subsequently established and is now accessible to families.)
- Transition is mainly to London Chest, (which is in the same Trust and now at St Bartholomew's Hospital) although some of Colchester patients may choose to go to Papworth.
- There used to be easily accessible clinical protocols for CF patients. However, two years ago after Whipps Cross and Newham Hospitals came into the Barts Health NHS Trust there was a change in the intranet to ensure compatibility on all the new sites which has resulted in many of the protocols being moved to a separate sharepoint site that is less easily accessible. Unifying IT systems across all the sites is a generic problem which is being tackled.

Commissioning

Summary

- The specialist commissioners put the Trust under notice of a derogation in service because of various staffing shortfalls in July 2013. This resulted in funding being made available for the CF clinical fellow, 1.3 whole time equivalent (WTE) CNS, 2 WTE physiotherapists, 0.5 WTE dietitian, 0.84 Band 8A Pharmacist, 1 WTE psychologist and a CF administrator. These were approved in December 2013 and recruitment began in February/March 2014. Following recruitment to these posts the derogation was lifted in October 2014.
- The budget line for CF care is complex but there appears to be no information available on how the tariff received is being spent and what is top sliced.

This is a well led and proactive service – some aspects of the service identified as red rated in the risk matrix during preparation for the visit were either resolved or in the process of being resolved by the peer review visit.

It was clear that although the clinical lead could calculate the finances coming into the service through the year of care tariff, they had little overall visibility of the proportion of that budget that reached the service. It is accepted that there will always be a level of top slicing for trust overheads but it was not clear what this level is. Although there is a budget line for paediatric CF this only has one post against it and all other costs are spread across a number of other budgets. The General Manager reported that they are working towards service-line reporting and will ultimately have a consolidated budget, but in the meantime they should work with the clinical lead to ensure that there is visibility and complete transparency around the service budget. All elements of the service (different staff groups, therapies, equipment etc) should be visible under the paediatric CF service line so that all income and expenditure can be properly understood. This can then also be used to support business cases, should they be required, for staffing as discussed elsewhere in this report.

The service has shared care arrangements with Colchester Hospital and Queen's Hospital, which is part of Barking, Havering and Redbridge NHS Trust. The level of care delivered locally varies but appears to be resource intensive for the Royal London MDT. SLAs for shared care were not in place for 2014/15, but a draft SLA including tariff split has been agreed with Colchester Hospital which recognises the work done by the local MDT during 2014/15 as well as for 2015/16. The SLA for Queen's Hospital is also being drafted. Again, the process for the transfer of funds to these hospitals is not clear and having a single service line to put these against would assist with this.

It appears that Queen's Hospital also has patients who have shared care with several other paediatric CF services. This is not an ideal situation and raises the possibility of patients receiving an inequitable service as different SLAs are in place with different CF services.

The service was put under a temporary derogation as part of the national service specification compliance process because of staffing levels. The service developed a number of business cases for additional staff and were able to recruit during 2014, after which the derogation was lifted. Apart from a small number of gaps identified elsewhere in this report the service now has a well-staffed and dynamic MDT. The clinical lead feels supported by the immediate management of the service, but this is a large trust with a complex management structure and there appears to be a degree of opacity in the decision making processes.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	111

			Male	Female
FEV_1	Number and % of patients with FEV_1 <85% by age range and sex	0–3 years	0	0
		4–7 years	1 (6%)	1 (7%)
		8–11 years	7 (41%)	5 (36%)
		12–15 years	7 (41%)	8 (57%)
		16+ years	2 (12%)	0

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

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	7 (6%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	6 (86%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	4 (57%)
	Number and % of patients on chronic macrolide without chronic PA infection	34 (33%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

- The paediatric CF service is covered by three consultant respiratory paediatricians at RLH. There is one consultant at Colchester and one at Queens with responsibility for the children with CF there.
- Recent consultant turnover: the moving of a former centre director to another Trust, long-term sick absence of the next most senior CF consultant, appointment of two new consultants and numerous new appointments to the CF MDT all occurred within a relatively short space of time. Stability is gradually being restored. The consultant who had long-term sick leave came back to work on 17 April 2015. Her locum will be staying on to cover some of the maternity leave of one of the newer consultants until August 2015 which should give some continuity to the consultant care. Another locum will need to be appointed thereafter.
- 24-hour consultant on-call cover: there is an informal 1:3 respiratory/CF 'on call' rota mainly for telephone advice, which is made to coincide with the 1:8 formal general paediatric 'on call' commitments. Additionally, an academic respiratory paediatrician covers the inpatients for four weeks of the year. Out-of-hours respiratory/CF work is not written into consultant job plans. If the level of consultant input into the network is to be maintained, let alone extended with imminent incorporation of Whipps Cross into the network, then more consultant time could be released by phasing out the general paediatric commitment.
- Consultant ward rounds occur three or four times a week. A business round is conducted beforehand.
- The CF director who had been on long-term sick leave has just returned, so much of the preparation for the peer review has been done by the acting director.

Specialist nursing

The Royal London has a team of four CF CNS (3 Band 7 & 1 Band 6) = 2.95 WTE. They have 120 patients on their caseload. If the imminent addition of Whipps Cross patients brings the total near to 150 patients then this would be the nursing complement recommended in the CF Trust Standards of Care (2011). The availability of specialist nurses was helpful when one of the consultants was off sick long term and the nurses took on more responsibility for organising clinics etc. Clinics are held most days of the week and a multidisciplinary meeting is held following each clinic. All nurses have responsibility for all the children on the caseload so all the families get to know every member of the team. Cover for absence comes from within the team. The nurses see patients at home for lung function, home intravenous (IV) antibiotics, education, diagnosis, transition etc. Most courses of (IV) antibiotics are given in hospital as there is good access to beds. The respiratory ward has two negative pressure rooms and all other rooms have ensuite facilities. The CF CNS team provide excellent in-patient support and advice. They visit the ward daily and a psychosocial meeting is held weekly to discuss any in-patient issues. A link nurse, Band 6 from the ward, takes a special interest in CF.

All nurses are members of the national CF Nurses Association (CFNA) and take turns to attend the local and national meetings. One of the nurses is the chair of the regional London and South East CFNA group. They take turns to attend the European CF conference. They also attend CF meetings at the Royal School of Medicine.

The team provide excellent support to the nurses at Queens and Colchester who share care with The Royal London. They continually provide/update any procedures/protocols to ensure equality of care. The team also lead the care for initial diagnosis, annual reviews, transition, end of life care and transplantation (not necessary for many years). The team has very little administrative support. They have someone who changes appointments and types letters but they do most of the organisation of the organising of clinics themselves.

Areas of excellence/good practice:

- Excellent support to the shared care centre. In-patient stays are streamlined and the child attends the hospital school (counts towards their school attendance) and annual reviews are done while they are an in-patient.

Areas for improvement:

- Better access to Wi-Fi

Recommendations:

- More administrative support especially for organising annual appointments

Colchester has a Band 6 Children's Community Nurse (CCN) with a special interest in CF working 22.5 hours per week, 0.6 WTE, but these hours are not just for cystic fibrosis. They provide care for 32 children aged 16 and under. CF Trust Standards of Care (2011) recommend 24 hours of a nurse for 32 patients (0.64 WTE) which indicates a staffing deficit, especially as the CCN's working hours are not just for the CF caseload. Cover for absence is from the other Band 6 CCN's in the team. The CCN keeps herself updated in CF care. She has attended the CF course run by the Brompton and attends local CFNA meetings regularly. She has never had the opportunity to attend a European or North American CF conference. No audits or patient satisfaction surveys have been undertaken specific to CF. These are all done at The Royal London.

The CCN provides care in the community including lung function, education, school/nursery talks and support for home IV antibiotics, but has relatively little input into in-patient care. The care provided is well supported by the CF CNS at The Royal London. They are in very regular email and phone contact and see each other at the joint CF clinics held monthly at Colchester. MDT meetings are held after each of these clinics to discuss patients seen in the clinic and any other causing concerns. The Royal London lead the CF care for newly diagnosed children, they visit the family at home with either the CCN or a Health Visitor and see the child at their centre until all testing and care has been initiated and evaluated, then the CCN follows them up locally. Transition is sometimes done at Colchester by a transition nurse who guides some of their CF children through the transition process starting at the age of 13 years. Some of the children have transition led by The Royal London.

Excellent/good practice:

- CCN works closely with CF CNS's at The Royal London providing a good service to the children.

Areas for improvement:

- Service level agreement (SLA) needs to be done to provide funds for further recruitment of staff.
- Psychology support is needed locally for the CF families.

Recommendations:

- Further CF hours needed for CCN to support CF children in hospital.
- Provide funding to attend the European CF conference.

Queens have a Band 6 CCN with a special interest in respiratory, including CF, who works 15 hours per week = 0.4 WTE, but these are not specifically for cysticfibrosis. They share 10 CF children with The Royal London but also share care with Great Ormond Street, Brompton and Kings so exact nurse–patient ratio is difficult to calculate. Cover is provided by another Band 6 CCN who works 1 WTE, but has no specified CF hours. The CCN is mostly community based and includes support for home IV antibiotics, lung function and education. They do not work on the ward but any CF in-patients are reviewed on a daily basis. They do not have a link nurse as they are based at the end of the children's ward so they are on hand to give advice on CF care. The care given is directed by procedures and protocols provided by the Royal London. The CCN feels well supported by this team. CF clinics are held at Queens three or four times per year, and a multidisciplinary meeting is held after. The CCN team have a few hours administrative support who will type letters/collate figures, but the CCN finds she does most of her own administration for the CF caseload. There is no designated physiotherapist for CF.

The CCN does not attend the CFNA meetings and is not a member. She has not had opportunity to attend the European CF conference. She keeps herself updated by attending study days run by the Brompton. She will be attending the CF course run by the Brompton again, as she did the first course many years ago and feels she needs to redo it for her own personal development. She feels well supported by her trust and senior nursing colleagues and the Royal London CF nursing team.

The Royal London lead the CF care for newly diagnosed children, they visit the family at home with either the CCN or a Health Visitor and see the child at their centre until all testing and care has initiated and evaluated, then the CCN follows them up locally. Transition is started at approximately 13 years of age. The children are invited to joint clinics with the adult teams. When they have had an adult outpatient appointment they then have a goodbye clinic appointment with the paediatric team.

Areas of excellence/good practice:

- CCN works closely with CF CNS's at The Royal London providing a good service.

Areas of improvement:

- Identify CF link nurse on ward – attend (CFNA) meetings – need CF designate physiotherapist.

Recommendations:

- Attend the European CF conference.

Physiotherapy

Delivery against professional standards/guidelines not already assessed

- Additional funding was sought in 2014 which has led to an increase in physiotherapy staffing from 1 WTE band 7 to 2.0 WTE Band 7 physiotherapists and 1.0 WTE rotational band 6. The lead band 7 physiotherapist left his post earlier this year with his replacement already working part time within the team and is due to start full time at the beginning of June. The other newly appointed Band 7 is on maternity leave with cover arranged to start imminently. Since peer review the full-time post is now occurring and the maternity leave has been covered
- The newly appointed Band 7 is a member of the Irish CF physiotherapy group with plans to join the ACPCF.
- All physiotherapists in the team regularly access local, national and international opportunities for training.
- Audit and research is strongly encouraged and supported both within the physiotherapy and CF teams.

- All staff are fully involved within the MDT attending weekly inpatient, post clinic and psychosocial meetings. It is clear they are fully integrated and work very well with the wider CF team.

Areas of good practice:

- All patients are seen by a physiotherapist in clinic and receive a physiotherapy annual review.
- The physiotherapy staff have completed projects looking at the collection of nasal washouts and compared microbiology findings with sputum and cough swabs and found a strong correlation. With this in mind they have introduced clear guidelines for collecting nasal washouts at annual review and for eradicating pathogens found.
- With changes to the working patterns staff are able to offer treatment twice daily throughout the week and weekends with opportunity to access the gym, outdoor play area and indoor play areas or exercise sessions.

Areas for improvement:

- Because of staffing shortages the team haven't been able to offer as much community support as they aspire to providing. The physiotherapy team have highlighted those patients they feel would benefit from support and plan to offer outreach soon.

Recommendations:

- All permanent band 7 staff should become member of the ACPCF. It was great to hear that links with other local CF staff are already in place. It would be great for this to continue and to be extended to the other band 7 staff both covering leave and staff on their return from leave.
- To introduce the use of exercise tolerance testing at annual review.
- To further develop the shared care network by providing support and educational opportunities. This could be achieved by having a network educational CF study day or by offering shadowing opportunities at the Royal London.

Colchester physiotherapy service

- The CF service is covered by an experience and enthusiastic 0.4WTE of a Band 7 and 0.2WTE Band 5 with some cover from a Band 6 for leave.
- The physiotherapy team attend a joint CF clinic monthly with the Royal London physiotherapy staff.
- The lead physiotherapist seeing CF patients at Colchester is a member of the ACPCF and attends local specialist interest group meetings and study days

Areas of good practice:

- Inpatients are able to be seen twice a day during the week and at weekends. Inpatients also have the opportunity to attend gym sessions during their stay. However the majority of patients receiving some of their care in Colchester would have their IV's when needed at the Royal London.
- Staff working at Colchester work closely with the Royal London in an established system of outreach clinics.
- Information leaflets and MDT clinic sheets are shared between the Royal London and Colchester.

Areas for improvement:

- All airway clearance equipment is supplied by the Royal London with no funding streams currently available locally – there seem to be good systems in place to send out or arrange for patients to have replacement pieces of equipment. However this may be something that could be discussed between the Royal London and Colchester and developed further.

- Local resources are limited. Further resources would allow more support locally with the possibility of community visits or the opportunity to review patients outside of normal clinics thus supporting staff at the Royal London.

Recommendations:

- There is already a good mechanism for joint clinics, but the further development of local services within this CF Network may be useful. The physiotherapy staff at Colchester should therefore be supported to spend time shadowing staff at the Royal London and have opportunity to attend joint study days when arranged. Over time this may support the development of more local support both for in- and out-patients attending Colchester and for local community support.

Dietetics

Royal London Hospital (RLH)

- Staffing: 0.6 WTE band 7 (1.5 years in post years) and 0.4 WTE band 6 (two years in post). Total 1.0 WTE. This would be the recommended dietetic provision if the acquisition of additional patients from Whipps Cross brings the total number near to 150. Both work full time, cover other areas of dietetics and provide cover for each other. During periods of leave the CF service is reduced, with inpatient reviews and outpatient clinics being prioritised
- Both dietitians are members of the UK Dietitians' CF Interest Group (UKDCFIG). The Band 7 has attended one group meeting; the Band 6 is yet to attend. The Band 7 dietitian has also attended the North American CF Conference in 2014 and is to attend the European CF Society Conference (ECFSC) in 2015. Both have continuous professional development (CPD) opportunities to attend local CF meetings. The Band 7 post subsequently completed the specialist CF course at the Brompton.
- A dietitian is present at all CF clinics, post clinic MDT meetings, weekly psychosocial meetings and they attend ward rounds at least twice weekly. There was 80 percent adherence to twice weekly inpatient reviews on the risk matrix; the dietitians are working to improve this situation. A home/school visiting service was set up following increased funding secured in 2013. The dietitians attend shared care clinics at Colchester and Queen's in Romford (see below)
- There is active involvement in patient care at all key life stages including diagnosis and transition (joint clinics with Bart's staff). Newly diagnosed patients are seen monthly with phone contact in between.
- Both dietitians are involved in audit eg CF-related diabetes (CFRD) screening methods, resulting in the development of a screening protocol using continuous glucose monitoring as the screening tool. The audit will be presented at the 2015 ECFSC.
- The patient surveys indicate dissatisfaction with the hospital catering provision; with comments that the food is too healthy and not focussed on the needs of people with CF. The dietitians feel that catering has improved recently with new menus and a better provision of snacks.

Areas of good practice:

- Proactive and dedicated dietetic team with succession planning arrangements in position.
- Supportive MDT with good working relationships and a strong psychosocial focus, enabling improved patient rapport and adherence. Good support from specialist acute paediatric dietetic service eg gastroenterology and endocrinology.
- Good support to the dietitian at Colchester and patients at Colchester and Queens.
- Ability to provide home/school visiting support to patients throughout the network.

Areas for improvement:

- Education and development opportunities for Band 6 dietitian
- Clinical documentation/information systems to improve ability for research and audit, this will also help to improve the visibility of service, especially within London.
- The catering provision.

Recommendation:

- Band 6 dietitian to have the opportunity to attend UKDCFIG meetings and an ECFSC.
- Development of electronic based documentation and protected time for audit/research including benchmarking with other paediatric CF centres exploring areas to improve profile.
- Ongoing review of catering including increased use of diet chefs when the catering system doesn't provide for needs. Consideration of a free voucher system for one meal a day from the staff canteen. Continued training of domestic staff in portion sizing and presentation.

Colchester Hospital

- Staffing 0.2 WTE band 6 (1.5 years' experience) for 32 patients, equivalent to approximately 0.5 WTE/75 patients. This dietitian is currently acting up to cover a diabetes maternity leave; she does not feel that this has had a negative influence on the CF service she provides. However, she is currently only providing one full days cover to CF a month and is therefore not providing the funded service. The dietitian is not a member of the UKDCFIG, but is applying. Emergency-only cover is provided by a band 5/6 dietitian with limited CF experience. There are plans to improve this cover.
- The dietitian has not had the opportunity to attend a ECFSC but has attended CF educational meetings in London.
- Monthly CF clinics are attended with one of the dietitians from the RLH. There are very few inpatients admitted to Colchester, but those who are receive a daily dietetic review.
- Annual reviews on patients under the age of five years are carried out jointly with the RLH dietitians at Colchester, those on patients over this age are carried out at the RLH.
- Newly diagnosed infants are mainly seen at the RLH, so experience in this area is limited. There is no formal arrangement for transition at Colchester. Patients transitioning to Barts go through the RLH programme, some patients chose to transition to Papworth. This process is driven by the nurses at the RLH.
- Hospital catering is 'in house' with a good choice of meals/snacks available. A diet chef can cater for specific dietary needs. Patients are also given vouchers to use in the staff canteen.

Areas of good practice:

- Supportive MDT and good supportive working relationships with dietitians at the RLH.
- The catering service.

Areas for improvement:

- Limited capacity to support patients with heavy reliance on dietitians at the RLH.
- Cover for periods of leave.

Recommendations:

- Ensure the CF service receives the 0.2 WTE funded time.
- Band 6 dietitian to join the UKDCFIG and have the opportunity to attend group and other national CF meetings. Improve knowledge by shadowing the dietitians at the RLH. Joint network clinics would also help to improve the CPD of all dietitians involved in CF care.
- Training of a second dietitian to provide cover during periods of absence.

Queen's Romford

The 12 patients who share care with the RLH are seen by the RLH dietitians. Outpatients are seen in three-monthly clinics at Queens and inpatients are usually admitted to the RLH, with the exception of one patient who receives inpatient care at Queens. Annual reviews are carried out by the RLH dietitians at the RLH

Recommendations:

- Improved provision of dietetic support to patients attending Queens.

Pharmacy

Areas of good practice:

- Pharmacist cover over establishment including robust plans for cover for maternity leave and annual leave ensuring continuity of care.
- Majority antibiotic courses offered as inpatients facilitated by access to dedicated beds – treatment often started within 24–48hours. This reduces costs and inconvenience associated with home IV's and improves access to the MDT.
- Excellent medicine information provided in the format of CF guidelines which are updated regularly by the pharmacy team and CF patient information leaflets.

Areas for improvement:

- Self-medication administration policy in place but no access to individual locked medicine cabinets in the rooms meaning medications occasionally left unsecured.
- The Royal London has the benefit of a Lloyd's pharmacy and pharmacy manufacturing unit (CIVA) so could make savings by dispensing high-cost inhaled therapy and preparation of home/inpatient IV antibiotics on site.
- There was a CF centre cost code with its own section in the monthly pharmacy report for inpatient and outpatient prescribing. The only medications used out of the ward budget were IV antibiotics due to logistical issues. However there needed to be increased accountability of the cost of the CF service.
- Pharmacy services at the shared care sites were not assessed as part of the peer review process and currently are not in a position to deliver a service fully in line with the CF Trust Standards for Pharmacy.

Recommendations:

- Purchase keypad operated individual medicine lockers for each side room.
- Establish cost savings by using Lloyd's and hospital (CIVA) service.
- Create a specific cost centre for CF patients allowing all medications to be issued to individuals hence providing an annual CF medication cost separate from respiratory.

Psychology

Royal London

The service has a very experienced 0.4 WTE band 8c Clinical Psychologist (CP) with the recent addition of a 0.6 WTE band 8a CP. This level of staffing is in line with CF Trust 'Standards of Care (2011)' recommendations. Both CPs are registered with the Health & Care Professions Council, and are members of the UK Psychosocial Professionals in Cystic Fibrosis (UKPP-CF) group. The 8c post holder has attended previous European conferences, having spoken and presented posters. The 8a post holder has attended the most recent UKPP-CF study day.

There is a well-attended weekly psychosocial multidisciplinary team (MDT) meeting. In addition the CPs will attend ward round when relevant to their caseload. All patients receive a psychology annual review (AR) assessment. All newly diagnosed patients meet one of the CPs in clinic. When requested, or relevant to their caseload, the CPs will become involved in key life stages such as transition and end-of-life care. Annual leave is coordinated to ensure cover over holiday periods, and in the event of unavoidable absences, urgent referrals are dealt with by a duty CP.

Areas of good practice:

- There is excellent flexibility and availability to both patients and members of the MDT.
- There is excellent responsiveness to referrals, seeing inpatients within 24 hours, and outpatients within two weeks.
- There is a wide breadth of therapies on offer to patients, including cognitive, behavioural and narrative therapies, and hypnosis.

Areas for improvement:

- Participation in audit and research has been limited due to clinical demand. With the recent increase in psychology time, this may be an area for future development.
- The service may benefit from an increase in teaching and training on psychosocial issues to the MDT.

Recommendations:

- With the recent increase in psychology provision, the CP service may now feel more able to participate in service development initiatives, teaching and training, and audit and research projects.
- The service may benefit from more formal coordination with shared care centres. This may take the form of consultation, supervision, or training, by the CF CPs at RLH to those professionals who are working with the psychosocial issues of the patients in the shared care centres.

Queens

There is no funded CP for this service. Outpatients and inpatients can be referred to the paediatric liaison child and family psychotherapist from the local Child and Adolescent Mental Health Service. Outpatients can also be seen by the RLH CPs either within the patient's home, or at RLH.

Recommendations:

- The MDT and psychotherapist may benefit from more formal consultation or network training by the specialist CF CPs.

Colchester

- There is no funded CP for this service. However, outpatients and inpatients can be referred to the CP who is funded by the diabetes service. Outpatients can also be seen by the RLH CPs either within the patient's home, or at RLH. All patients over five years old receive a psychology AR at RLH, however patients under five years old who have their AR at Colchester do not have a psychology AR.

Recommendations:

- The specialist CF CPs may choose to consider whether their shared care patients would benefit from the CPs either attending the monthly MDT joint clinics, or providing a psychology satellite clinic at Colchester, in order to offer an AR to the under five age group, and to offer more flexibility to their shared care patients.

Social work

Currently there is no social worker in post in the CF team. In the meantime, the social work role falls on CNS team and the psychologist to offer their experience and skills to perform the tasks usually carried out by a social worker. The team is supported by the nurse practitioner lead for child protection and she links into the hospital generic Social Work team.

For all other social work-related issues the CNS team cover these with the knowledge that they have in areas such as benefits, housing, employment and annual reviews to name just a few. This will not be in any way comprehensive enough to support a large group of paediatric CF patients, amongst whom will be patients with complex needs requiring considerable support as the nurses have their own roles and responsibilities to meet. Ultimately there are issues that the nurses are unable to deal with either due to time constraints or other pressures. In these cases, patients are signposted to the appropriate professionals outside the team. This is the same for the shared care centres.

This CF service would benefit from a dedicated 1 WTE social worker, as recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)' as an integral part of the CF team, bringing with it time and expertise that are considerably more difficult to provide from other under-resourced areas within the team.

Recommendations:

- Recruitment of qualified social worker as per the Cystic Fibrosis Trust's 'Standards of Care (2011)' to contribute to development of transition, annual assessment and specialist key life skills
- Consultation with other centres in the local area on how to achieve this.

In the meantime, careful thought and close management need to be given regarding social work issues to ensure that the patients are properly supported.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	8	2	4	1
Female	6	5	5	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	19	6	1	0
From the ward staff	13	6	2	0
From the hospital	13	9	2	0

Areas of excellence:

1 Accessibility – always available.

2 Communication – on hand with advice and support.

3 Cleanliness (outpatients).

Areas for improvement:

1 Car parking.

2 Food.

3 Waiting times out patients.

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

Royal London Hospital

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red Joint clinic being established	Red	However, CFRD is managed well and segregation difficulties in a joint CF-diabetes clinic avoided by having CF consultant attend diabetes clinic or vice versa.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	Delays have occurred with levels sent from Colchester.
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	Screening with continuous glucose monitoring from 10 years.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red 32/56 age >10yr had DEXA.	Red	A major catch-up drive since the submission may have increased compliance from 57% to about 80%.

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%	Unable to audit	Amber	Ought to be audited and likely to be suboptimal for same reasons delaying discharge summaries.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Red Electronic discharge 99% Dictated summary 49%	Red	Demonstrates need to ring-fence more clerical and administrative support for cystic fibrosis.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	Working hours have been extended which may enable twice daily review on weekends
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Green	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Green	Amber	Psychology provision for Colchester and Queens patients not equivalent to RLH.
	% availability of a clinical psychologist for inpatients	100%	Green	Green	As majority of admissions are to RLH at least to start off.
	% availability of a social worker at clinic	100%	Red Referral safeguarding team	Red	Appointing a SW dedicated to CF is a key recommendation.
	% availability of a social worker for inpatients	100%	Red Referral safeguarding team	Red	Appointing a SW dedicated to CF is a key recommendation.
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Amber	Amber	As most IV courses are at least instigated at RLH and relatively small numbers have home IV this should be easily addressed.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	Green	Has not been required but palliative advice is available.

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%	None	
5.2	Number of clinical incidents reported within the past 12 months	<1%	11	11	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green To be submitted in due course.	Amber	SLA with Queen's being drafted and will need to be signed.

Appendix 2

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Royal London Hospital 116 patients
Consultant 1	0.5	1	1	0.5 WTE
Consultant 2	0.3	0.5	1	0.4 WTE
Consultant 3			0.5	0.4 WTE
Staff grade/fellow	0.5	1	1	1.0 funded
Specialist registrar	0.3	0.5	1	0.8 WTE
Clinical Nurse Specialist	2	3	4	2.95 WTE
Physiotherapist	2	3	4	2.5 WTE
Physiotherapist assistant				0.5 WTE
Dietitian	0.5	1	1.5	1 WTE
Clinical psychologist	0.5	1	1.5	1 WTE
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.84 WTE
Secretary	0.5	1	2	0.6 WTE although often given extra duties
Admin assistant	0.4	0.8	1	0.75 WTE

Appendix 3

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre – Royal London Hospital	
Number of active patients registered (active being patients within the last two years)	116
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	111
Median age in years of active patients	9
Number of deaths in reporting year	0
Median age at death in reporting year	NA

Age distribution (ref: 1.6 'Annual Data Report 2013')		
Number and % in age categories	0–3 years	17 (15%)
	4–7 years	30 (27%)
	8–11 years	33 (30%)
	12–15 years	26 (23%)
	16+ years	5 (5%)

Genetics	
Number of patients and % of unknown genetics	Nine patients with one missing mutation; one patient with two missing mutations

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2013')	
Patients with a BMI percentile <10th centile on supplementary feeding	5

FEV_1 (ref: 1.14 'Annual Data Report 2013')			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	1 (6%)	1 (7%)
	8–11 years	7 (41%)	5 (36%)
	12–15 years	7 (41%)	8 (57%)
	16+ years	2 (12%)	0

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	17
	4–7 years	30
	8–11 years	33
	12–15 years	26
	16+ years	5
Number of patients with chronic PA by age group	0–3 years	1
	4–7 years	1
	8–11 years	3
	12–15 years	2
	16+ years	0

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

Complication (ref: 1.16 'Annual Data Report 2013')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	14 (13%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	8 (7%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH 2 (2%) with no PH

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

IV therapy (ref: 1.21 'Annual Data Report 2013')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	54
	4–7 years	129
	8–11 years	392
	12–15 years	363
	16+ years	24
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	12
	8–11 years	63
	12–15 years	7
	16+ years	17
Total number of IV days split by age group	0–3 years	54
	4–7 years	141
	8–11 years	456
	12–15 years	369
	16+ years	41

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=77); 59 (77%)
If not on DNase, % on hypertonic saline	4 (6%)

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2013')	
Number and % of patients with chronic PA infection	7 (6%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	6 (86%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	4 (57%) with Chronic PA 34 (33%) with no Chronic PA

Appendix 4

Patient survey

Royal London Hospital

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	8	2	4	1
Female	6	5	5	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	21	9	0	0
Communication	19	11	0	0
Out-of-hours access	7	12	5	1
Homecare/community support	15	9	3	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	16	11	2	0
Waiting times	6	11	8	2
Cross-infection/segregation	15	11	2	0
Cleanliness	16	12	0	0
Annual review process	12	13	0	0
Transition	2	4	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	9	10	2	0
Cleanliness	10	9	2	0
Cross-infection/segregation	7	7	4	1
Food	2	4	3	10
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	15	6	0	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	5	11	4	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	2	1	0	0
Availability of equipment	7	10	3	0
Car parking	0	3	1	14

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	19	6	1	0
Of the ward staff	13	6	2	0
Of the hospital	13	9	2	0

Comments about CF team/hospital

"Would be useful to have written information for us on physio, do's and don'ts, meds instructions. For family and friends – do's and don'ts eg smoking, hand washing, mud/sand/water specifics. Would be better to have more notice of clinic dates – though our outreach hospital have now done this."

"CF team is always there to be reached. Problem is to contact consultant out of hours, switchboard do not transfer the line to registrar!"

"CF team are fantastic group of very caring and supportive people, always available and helpful only disappointments are with the hospital itself – smoking at entry door to hospital, no access or car parking – poor food."

"My daughter is blessed to have a great team behind her. I mainly contact team via email and pager (more important issues). They always respond promptly and resolve any problems/concerns that I may have regarding my daughter's wellbeing and medication. They are kind, friendly and reassuring."

"The CF team is excellent; experienced, accessible, friendly. Experience's with ward staff during admission not as good. Lack of experience, ward not designed to cater for teenagers."

"Home care/community support was rated poor as we don't get home visits. The food in the hospital isn't great as not many calories/fat in them and son doesn't eat much of the food. It was great when given vouchers for café but that stopped."

"We feel very lucky to have a team so intimately involved in our daughter's wellbeing, it is a Rolls Royce service: accessible (nothing is too much trouble), thoughtful (they fully engage with every new health challenge), individual (they know her really well). Positive (keeping her and us looking forward even when things look grim). This applies particularly to her outpatient team but on the ward the same generally applies. Inpatient experience has dramatically improved in last few years. Cross-infection hard to say; segregated for most of the clinic but for weight etc patients may enter room and touch equipment just vacated by another person with CF."

"Well done keep up with the good work, carry on working hard, very pleased with the CF team and co."

"The CF team are very good and helpful. Although I recently had an appointment for my sons CF scan at Barts Hospital only to be told that they only do adults there and the children's CT scan was at Royal London where he's based at anyway. So we were like yoyo wondering why we were sent to Barts when Royal London had the facilities."

"Support from the CNS staff is amazing. Staff turnover at Consultant level seems high – ill health etc causing changes but docs friendly, expert and engaged. Elevator access without HEPA filter is crazy when cross-infection is a worry."

"We are extremely happy with the service provided by the CF team at the Royal London Hospital. We are grateful for their dedication."

"The team at Royal London are always on hand with advice and support. The CF CNS in particular are outstanding – wouldn't know what to do without them sometimes."

Appendix 5

Parent/patient interviews

Parent A

Parent A's child attends Royal London for full CF specialist centre care. She is happy with segregation measures at outpatient clinic, where they are directed straight into a consultancy room, only leaving it for occasional blood tests.

Parent A feels hygiene measures – hand washing and wiping down equipment between patients – is very good and she is happy with the interaction with the CF team at appointments, normally seeing the full multi-disciplinary team (MDT) and being involved in joint decisions with the CF team on her child's treatments. Parent A has little experience of hospital pharmacy; prescriptions faxed to the GP to be processed locally.

Inpatient care (on ward)

Her child's last admission was in winter 2014, when her child waited a couple of days for admission. Parent A feels that of the five or six staff nurses, half of them are "brilliant", but the remainder not so knowledgeable and experienced. Parent A made the suggestion that a CF nurse specialist be present at time of patient admission. She is pleased that the CF nurse is trying to implement a care plan for the ward.

Parent A feels that food on the ward is not of suitable quality for children with CF, adding "They're trying to be too healthy, and not many high calorie snacks." Mother brings in ready meals to ensure daughter is eating well.

Parent A feels that physiotherapy coverage twice daily is better during the week as it is carried out by experienced physiotherapists. She added, by contrast that the physiotherapy assistants are not as good and referred to weekend physio as "maintenance". Parent A is happy with the cleanliness and hand hygiene on the ward.

Annual Review

Parent A's child is offered annual review each year and has had annual review in the last 12 months. At annual review appointment they see the MDT, but neither a psychologist nor social worker. All annual review assessments take place at the Royal London Hospital, annual review outcome reported back via letter and at clinic appointment.

Home care

Parent A explained that the clinical nurse specialist (CNS) will readily make a home visit and the physiotherapy team have started home care services in the last year. They have experienced two home physio visits. The community nurse team make a home visit to take Tobramycin levels. Fresenius provide home deliveries of Gastrostomy home feed and equipment, but parent A feels that their service is substandard in its delivery coordination. By contrast, she feels that the BUPA home delivery service for nebulised and IV treatments is of better standard, including text notification of deliveries.

Transition

Parent A feels that transition was handled brilliantly, as compared with endocrinology. Her child has attended two transition clinics and describes transition as "very smooth running" thus far. Parent A added that CF nurses are readily available to make school visits, if necessary.

Good practice:

- "CF nurses hold the service together; two very experienced nurses of the four who provide continuity and pull together."
- "CF nurses are readily available and the first port of call."
- "The physiotherapy team and dietitian are very good."

Areas for improvement:

- "Inpatient/ward staff and peripheral staff."
- "The ward is geared up towards little children, but not teenagers – no Wi-Fi and school is an issue."
- "Ordering food on the ward and some staffing on the ward."
- "Lack of continuity amongst consultants – three newcomers who don't know my child as well."

Parent B

Parent B's child receives full CF care at Royal London Hospital, attending every two months. She feels that segregation measures at outpatient clinic are very good, adding "We never meet up with others." She explained that a wristband identification system had been muted, which she'd be happy with, though for her as a parent to wear, rather than labelling her daughter.

On arrival at clinic, they are directed straight to a consultancy room where they see the full MDT. They had an introductory meeting with the psychologist, but no meeting since. They are unaware of social worker support, adding though that the CNS performs this role and that they do not require this currently.

Parent B feels that the CF team make decisions on her child's treatment, jointly with mother and she described the relationship as reassuring and helpful with CF and treatments explained well.

Parent B has little experience of hospital pharmacy, getting prescriptions faxed to the GP and processed locally.

Inpatient care (on ward)

Not needed as yet.

Annual Review

Parent B's child is offered annual review each year and has had annual review in the last 12 months. They see the full MDT at annual review, the outcome of which is reported back in clinic as part of the routine post-clinic summary letter, a couple of weeks after annual review. Parent B feels more generally that communication from and with the CF team is good; email response within two hours and quick response to more urgent telephone queries and concerns – ie immediate ring back or within a few hours from the CNS.

Home care

Parent B's child has a school visit and home visit performed at school, as one. The physiotherapists visit home to instruct on airway clearance techniques and use of PEP mask.

Good practice:

- "Friendly and reassuring CF team who don't rush you, but listen to you."
- "The CF team explain things well – a thorough team who are proactive at preventative measures and willing to try new things. I'm appreciative."

Areas for improvement:

- "Duration of clinic could perhaps be shortened or streamlined."

Parent C

Parent C's child attends Royal London Hospital for full CF care. They find segregation measures are very good; never waiting in an open area. They also find hand hygiene very good and mother is pleased with joint decisions with the CF team on her child's treatments. They see the whole CF MDT, with a clinical psychologist available if needed, although mother was unsure of availability of a social worker. Prescriptions at outpatient clinic are faxed to the doctor at her local surgery.

Inpatient care (on ward)

Not applicable currently.

Annual Review

Parent C's child is offered annual review each year, her last review back in summer 2014. They see all of the CF MDT and outcomes are reported back via letter copied into GP, as well as in clinic consultation on annual review day. More generally, Parent C finds communication from the CF service good, though not always quick, although the CF nurses liaise with the doctors and answer the parent same day.

Home care

Parent C's child does not require routine home visits currently. They referred to the BUPA home delivery service of Dnase (Pulmozyme) as "okay, but difficult to communicate with them and get delivery at the right times. The packaging is bulky and so difficult to take on the London Tube."

Good practice:

- "New, well designed, well organised hospital, with good, clean facilities."
- "We get to see a doctor who is willing to listen when we need to."

Areas for improvement:

None specified.

Parent D

Parent D's child receives full CF care at Royal London Hospital. They are allocated a side room on arrival at clinic, so at no point is there contact with other children with CF. Mother expressed concern though about her child being weighed and measured soon after another child with CF has used the same room.

At clinic they see all of the CF MDT, but mother wasn't sure how to access the clinical psychologist and was unaware of whether a social worker for the team existed. Mother felt that decisions made on her child's treatments were made with her views taken into consideration, referring to it as an "extraordinarily inclusive process, but where I can talk privately with team members too about issues sensitive to my daughter."

Prescriptions for parent D's child are processed locally via their GP surgery, but urgent prescriptions at clinic appointments can be processed by the CNS.

Inpatient care (on ward)

Last admission last winter was an easy admission, admitted to the ward four or five days after referral from outpatient clinic appointment, as a non-emergency. Mother feels that the ward staff nurses have a good understanding of CF, a lot of experience and are careful with her daughter's care in terms of segregation and well briefed in the safety required in nursing children with CF. Mother added that in the inpatient experience "has been transformed since the new facilities were built". She described three-times-daily, high-quality physiotherapy from an enthusiastic physio team during the week, which includes teaching airway clearance techniques and taking

her daughter to the hospital gym. At weekends parent D feels physiotherapy coverage is more "haphazard", so she covers it herself if the physio doesn't. Mother referred to the ward food as "not that great, but it has improved, though dished up in an Oliver Twist style. Often my daughter will not eat the food, so I get food in for my child which she'll eat."

Home care

Occasionally the CNS will make a home visit to talk through new equipment. Parent D's child enjoys home visits from the physiotherapist. Her daughter has BUPA home deliveries of Dnase and inhaled antibiotics; a service she describes as "slightly less convenient than the previous system of deliveries direct from hospital pharmacy in terms of convenient delivery timings."

Good practice:

- "High calibre of the CF team – no problem is too small for them. My daughter wouldn't have the same quality of life without them."
- "We feel very lucky to have all the treatments for free."
- "Facilities at the new hospital are very good."

Areas for improvement:

None specified.

Parent E

Parent E's child receives full care from the Royal London Hospital after previously having shared care with Harlow Hospital – this service has now apparently ceased. She is happy with the segregation measures in place at Royal London Hospital which they attend every eight weeks. On arrival at clinic they are allocated a side room and stay there throughout clinic, leaving it just when being weighed and for blood tests.

Parent E feels that decisions made by the CF team are made jointly with her in an inclusive way. They see the whole CF MDT, although they only see the clinical psychologist at annual review (referral at any other time) and they believe the CNS performs social work tasks.

Inpatient care (on ward)

Not needed currently.

Annual review

Parent E's child is offered annual review each year, the last annual taking place in the last 12 months. They see the full MDT at annual review, except a social worker. Blood tests and x-rays are performed prior to annual review day, so the full annual review outcomes can be discussed at annual review clinic and feedback be received in a routine clinic letter, copied to the GP.

Home care

Parent E's child had home visits initially from the CNS and physio, but these stopped when funding stopped two years ago. The physio resumed visits two months ago. BUPA provides a home delivery service for DNase and Colomycin nebulised antibiotics; a service which mother felt was "fantastic" for three years, until six months ago, in which she is now experiencing "a lot of problems, having to go through various departments, making two different calls, deliveries at different times and medications short-shipped".

Good practice:

- "CNS Kath Lambert is excellent – she holds the team together."
- "The whole CF team is committed and caring."

Area for improvement:

- "I'd prefer to see consultants than registrars covering clinics."

Parent F

Parent F's child receives full CF care at Royal London Hospital. At outpatient clinic they never come into contact with other children with CF, apart from on arrival at reception occasionally. On arrival, they are immediately allocated an individual consultancy room. They felt that the clinic is clean and use of hand gels good, adding that 'it is cleaner than the previous facilities'.

Parent F felt that CF team decisions on her child's treatment were made jointly with her, adding "I'm a strong willed mother; they go with what I'm saying". They see the full MDT at most clinic appointments. Sometimes they see a registrar rather than a consultant and sometimes the physiotherapist is not available. Mother is not concerned about the occasional lack of physiotherapist at outpatient clinic, unless she has to see her and added "If the physio is not there, we can call them or they can call us." Mother added that she is aware of psychosocial support in the CF service, but hasn't required it. Prescriptions issued at clinic meanwhile are faxed to her child's GP and she picks these up from the local pharmacy.

Inpatient care (ward)

Parent F's child has had two admissions in the last 12 months. Both admissions took place on the same day as referral or latest on the next day. She could not comment on the staff nurses' knowledge of CF since she administers treatments herself on the ward, adding "they (the staff nurses) do the jobs." She felt the physiotherapy coverage on the ward has vastly improved. She explained that physiotherapy is provided three times a day – morning, afternoon and evening during the week, and as far as she was aware, likewise at weekends. Parent F added, "This gives me a break." Physiotherapy involves use of the incentive spirometer in the morning, exercise in the outdoor space/roof garden in the afternoon and use of the 'Alice in Wonderland' themed space, plus use of the gym.

Annual review

Parent F's child is offered annual review each year, the last review being within the last 12 months. They used to have shared care with Harlow Hospital, but described the CF care there as "awful". At annual review, they see the whole MDT and outcomes are reported back in post clinic letter or parent rings the team for any other information. Communication generally was considered "pretty good" by parent F. She communicates with CF nurses mainly via email, receiving a same day response, or when telephoning them, receives a response within half an hour.

Home care

Parent F's child receives home deliveries of IV antibiotics and DNase from BUPA. She felt the service has improved and been fine for the last few months. BUPA send a text message to notify mother of estimated delivery time. Parent F lives approximately 50 minutes from the CF specialist centre at Royal London Hospital and felt that the only downfall is that they do not receive a home visit as they are too far away from the CF centre. She has mentioned this to the CF team. However, she was pleased that the CNS visits her child's school each year to explain her child's CF and requirements to new teachers.

Good practice:

- "Communication – really good and very happy with this."
- "Knowledge and friendliness of the CF team."

Areas for improvement:

- "Lack of home visits. A wish for home visits, where necessary."
- "Poor parking facilities and it's hard to find a space. Wish for improved parking facilities."
- "Duration of clinics perhaps – too lengthy at the moment."

Children's Hospital at Royal London parent interviews peer review day.

Parent A

Parent A is father to a boy of 21 months, who was diagnosed with having cystic fibrosis at three weeks using the sweat test. When traveling to the hospital from their home in Stoke Newington the family usually travel by taxi which cost approximately £15 per day.

Parent A's child is very well and has never been admitted to hospital, used nebulisers or had intravenous antibiotic treatment.

Parent A praised the team at the hospital and felt that the home visits (approximately 10 since diagnosis) have been particularly beneficial. There was no known family history of cystic fibrosis so their son's diagnosis came as a shock to his parents. The team have been very supportive to the family over the past 21 months.

The family visit the hospital once every six weeks at an outpatient appointment clinic – parent A feels that the system used for the outpatient clinic is very slick and great attention is given to ensuring any possible cross-infection risks are minimised.

Areas of excellence:

- The family feel confident in the standard of care that their son receives.
- Parent A follows developments in research of CF care and treatments very closely and the MDT is always happy to discuss these with the family.
- The team are happy to assist the family with any form filling they may need assistance with.

Areas of improvement:

- Although the standard of care has not been affected, parent A feels that there has been a lot of change within the consultant team. He understands that this is due to sick leave and maternity leave but feels that some consistency within the team will be valuable.
- There are only two lifts which are able to reach the floors where outpatients and CF care is given and parent A is concerned that this maybe a cross-infection risk – could negative pressure help with this?

Parent B

Parent B is the mother of two girls with cystic fibrosis. Her girls are aged 8 and 14 years. The family live in Ilford and travel to the hospital by train as there is no hospital car parking.

Parent B's younger daughter was diagnosed at birth but her older daughter wasn't diagnosed until she was 6 months old following ongoing poor health (at a different hospital).

It is over 18 months since her 14 year old was admitted and over two and a half years since her 8 year old was admitted, both requiring a course of intravenous antibiotics following the growth of pseudomonas.

Areas of excellence:

- Parent B spoke very highly both of the CF MDT and the care her daughters receive. They originally received their care at the Royal Brompton Hospital but transferred to the Children's Hospital at Royal London due to the amount of travel time.
- Parent B feels that the home visits the family receive from the nursing team and physiotherapists are particularly beneficial.
- The full MDT are always easily accessible.

Areas of improvement:

- Parent B is not aware of any access to the internet; having Wi-Fi access would be very helpful especially when her girls need to carry on with their education whilst in hospital.
- Parent B feels that the quality of inpatient food is poor and that the availability of high fat food is limited.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Children's Hospital at Royal London
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Height and weight done in a height and weight room. This is thoroughly cleaned between patients.
Where are the 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?		Play specialist available. Wipeable toys available for young children.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		16 patients have CFRD. These patients are seen in same area.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?		Cystic Fibrosis Trust leaflets given out at clinic as required.

Environmental walkthrough: ward

Ward name: 7E Respiratory

Microbiology status:

		Hospital name	Children's Hospital at Royal London
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Not dedicated CF ward	Suitable for CF Care
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		8	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		No	Medication is looked after by the nursing team.
Can you use mobiles?		Yes	Poor signal.
If there is a television, is the service free?		Yes	Televisions available.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull-out beds available.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Opening visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Both available in the parents' kitchen and most rooms have fridges.
What facilities are provided for teenagers?			Games consoles, XBox, DVDs, can bring in own laptops/iPad, school room and adolescents evenings.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapists take patients to the gym.
What facilities are there to help with school and further studies?		Teachers available in a well-equipped school. Outstanding play/learning area.
Is there a relatives' room?	Yes	
What internet access is there?	None available to patients on ward	Available in school room but investment needed to provide full internet access.
What facilities are there to enable students to continue to work and study?		Teachers available in a well-equipped school five days a week.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Specific cleaning bowls provided.
What facilities are provided for those with MRSA?		Barrier nursed on a different ward.
What facilities are provided for those with *B. cepacia*?		Barrier nursed on a different ward.
What facilities are provided for those with other complex microbiology?		Barrier nursed on a different ward.
Are patient information leaflets readily available on ward?		Cystic Fibrosis Trust leaflets given out at clinics where required.
Transition patients – can they get a tour of ward facilities?		Patients are given the option to tour facilities.

Additional comments

- A strict cross infection policy is in operation.

Environmental walkthrough: Other

	Hospital name	Children's Hospital at Royal London
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	No hospital parking.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Not a dedicated CF ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	The service are looking at using a wristband system where CF patients can be easily identified to prevent them sharing the same lift, for example.
Do patients have to wait at pharmacy for prescriptions?	No	Hospital pharmacy is run by Lloyd's – it is a very open area. Medication would usually be collected by a relative
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Parent feedback/questionnaire system in operation.

Colchester Hospital

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

Colchester Hospital

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N		Y?	Consultant desires local consultant cover due to no. of patients and other commitments.
	% of MDT who receive an annual appraisal	100%	Green	Not assessed	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Red	Not assessed	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Red	Amber	Many of the local MDT have attended local CF meetings. Other commitments limit time spent on CF education.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	RLH guidelines.

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red	Red	CFRD is managed well and segregation difficulties in a joint CF-diabetes clinic avoided by having CF consultant attend diabetes clinic or vice versa.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red Usually within 36 hrs	Red	Samples need to be couriered to RLH and delay must be urgently addressed.
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	NA RLH	See RLH Risk Matrix	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	Access to CNS at RLH.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Amber	May be issue at weekend.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	Heavy dependence on dietetic support from RLH.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Green	Managing only because relatively few patients admitted to Colchester.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red If needed RLH	Red	Support at RLH only.
	% availability of a clinical psychologist for inpatients	100%	Red If needed RLH	Red	Support at RLH only.
	% availability of a social worker at clinic	100%	Red	Red	Needs addressing.
	% availability of a social worker for inpatients	100%	Red	Red	Needs addressing.
	% availability of pharmacist at clinic	100%	Green	Green	Based at RLH.
	% availability of a pharmacist for inpatients	100%	Green	Green	Based at RLH.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Red	See RLH risk matrix	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	See RLH risk matrix	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Red In negotiations	Green	Apparently SLA now in place with Colchester receiving 40% of tariff.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Colchester Hospital 30 patients
Consultant 1	0.5	1	1	0.75 PAs
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.4 WTE
Physiotherapist	2	3	4	0.2 WTE
Dietitian	0.5	1	1.5	0.2 WTE
Clinical psychologist	0.5	1	1.5	0 no dedicated staff
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0 no dedicated staff
Secretary	0.5	1	2	0.1 WTE
Admin assistant	0.4	0.8	1	0
CF unit manager				0

Patient survey

Colchester Hospital

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	2		1	
Female	2			

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	2	2	1	0
Communication	1	3	1	0
Out-of-hours access	2	2	0	1
Homecare/community support	4	1	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	1	1	2	1
Waiting times	1	1	1	1
Cross-infection/segregation	0	3	1	1
Cleanliness	1	3	1	0
Annual review process	1	1	0	0
Transition	0	0	0	0

How would you rate your inpatient care (ward)?

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

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	0	0	0	0
Availability of equipment	2	2	0	0
Car parking	2	0	1	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	3	1	1	0
Of the ward staff	1	1	1	1
Of the hospital	1	0	3	0

Comments about CF team/hospital

"The CF team is based in Royal London. They are lovely, helpful and communicate well. The children's community nurses are lovely (Colchester) helpful and available when needed. Colchester hospital waiting times need improvement and staff numbers."

"Royal London team are excellent, always there by phone or email."

"My CF team at the Royal London Hospital are my life line I can't imagine raising my son without the help and support they provide us."

"Very friendly, understanding and accommodating. They work very well together and put the whole family at ease every time we see them."

"Because Colchester Hospital do not deal with CF hospital ward staff don't know enough information and makes the stay stressful for both parent and patient."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Colchester
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Height and weight is done in the nursing rooms.
Where are the lung function tests done for each visit?		Done in individual clinic rooms.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		Patients bring in their own computing equipment and games.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Patients are seen at the Royal London diabetic clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Packs are usually given at diagnosis.

Environmental walkthrough: ward

Ward name: Paediatric ward

Microbiology status: All

		Hospital name	Colchester
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	General paediatric ward, suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		10	Patients with CF are given priority to side rooms.
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	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service from 7am–9pm.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Zed beds in rooms.
Visiting hours – are there allowances for CF patients/families out of normal hours?			Open visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?			There is a fridge and a microwave in the parents' kitchen.
What facilities are provided for teenagers?			Adolescents' room – TV, games, snacks.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		Gym in physiotherapy department.
What facilities are there to help with school and further studies?		Teachers and school room.
Is there a relatives' room?		Parents room – refreshments available.
What internet access is there?		No internet available as unable to monitor usage. Parents can make a special request for access.
What facilities are there to enable students to continue to work and study?		As above – laptops, teachers.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		CF nurses clean nebuliser parts.
What facilities are provided for those with MRSA?		No occurrences of MRSA in the last three years. Would be barrier nursed.
What facilities are provided for those with *B. cepacia*?		No patients with *B. Cepacia* – would be barrier nursed.
What facilities are provided for those with other complex microbiology?		Barrier nursed.
Are patient information leaflets readily available on ward?	No	Patients given information packs at diagnosis/ annual review.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	Colchester
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	5 day permit - £10 7 day permit - £12
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Not a dedicated CF ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	Adequate space in all areas.
Do patients have to wait at pharmacy for prescriptions?	No	Nursing staff collect medication from the pharmacy.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Feedback boxes on the ward.

Queen's Hospital

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

Queen's Hospital

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Not assessed	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Not assessed	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Red	Amber	Many of the local MDT have attended local CF meetings. Other commitments limit time spent on CF education.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red	Green	RLH guidelines.

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	RLH guidelines.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green		However, CFRD is managed well & segregation difficulties in a joint CF-diabetes clinic avoided by having CF consultant attend diabetes clinic or vice versa.

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	See RLH risk matrix	CF patients not admitted to Queen's.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	Admissions to RLH.
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	See RLH risk matrix	Admissions to RLH.
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	RLH	See RLH risk matrix	Screened at RLH.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	RLH	See RLH risk matrix	Screened at RLH.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	RLH	See RLH risk matrix	
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%	RLH	See RLH Risk Matrix	

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	See RLH risk matrix	Admissions to RLH.
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	See RLH risk matrix	Admissions to RLH.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	See RLH risk matrix	Admissions to RLH.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Red	Green	Full MDT attends network CF clinic.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	See RLH risk matrix	Admissions to RLH.
	% availability of a CF specialist dietitian at clinic	100%	Red	Green	Full MDT attends network CF clinic.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	See RLH risk matrix	Admissions to RLH.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red	Red	
	% availability of a clinical psychologist for inpatients	100%	Green	Red	Support at RLH only.
	% availability of a social worker at clinic	100%	Red	Red	Appointing a SW dedicated to CF is a key recommendation.
	% availability of a social worker for inpatients	100%	Red	Red	Appointing a SW dedicated to CF is a key recommendation.
	% availability of pharmacist at clinic	100%	Red	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	RLH	See RLH risk matrix	IV antibiotics instigated at RLH.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	0	Green	Has not been required but palliative advice is available at RLH.

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	RLH	Amber	No user survey of CF patients at Queens specifically.
5.4	Service level agreements in place for all	100%	RLH	Amber	SLA being drafted & will need to be signed.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Queen's Hospital 13 patients
Consultant 1	0.5	1	1	No dedicated PAs for CF work
Consultant 2	0.3	0.5	1	0
Consultant 3			0.5	0
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	No dedicated PAs for CF work
Physiotherapist	2	3	4	0
Dietitian	0.5	1	1.5	0
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	0
Database coordinator	0.4	0.8	1	0

Patient survey

Queen's Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"The team are always available regardless of the query would be lost without them!"

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Queen's
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In a separate room away from non CF children.
Where are the lung function tests done for each visit?		In the clinic/consultation room
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		Annual reviews not done in Queen's.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	
Transition patients – can they get tour of outpatients' facilities?		No adult CF service in the trust hence no transition patients.
Transition/new patients – do they get information pack?		No adult CF service in the trust hence no transition patients.

Environmental walkthrough: ward

Ward name: Tropical Lagoon

Microbiology status: All

		Hospital name	Queen's Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No/Yes	Not a CF dedicated ward.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		6	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	Only with the carer/parents.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)			
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		No	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	
Visiting hours – are there allowances for CF patients/families out of normal hours?		No	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	There is a parent's side room with a kitchen.
What facilities are provided for teenagers?			School, TV.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	
What facilities are there to help with school and further studies?		There is dedicated teacher who helps with the curriculum.
Is there a relatives' room?	Yes	
What internet access is there?	Yes	
What facilities are there to enable students to continue to work and study?		Their school is contacted for their homework, they need to do. The teacher in the ward supervises the home work and other studies.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?		We have a set protocol for isolation and containment of MRSA infection.
What facilities are provided for those with *B. cepacia*?		Isolation in overflow rooms.
What facilities are provided for those with other complex microbiology?		We discuss with the consultant microbiologist for advice.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	No	There is no adult CF service in the Trust.

	Hospital name	Queen's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	There is no dedicated CF ward or unit.
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	
Do patients have to wait at pharmacy for prescriptions?	Yes	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

Princess Alexandra Hospital

When peer reviewed the hospital no longer did CF care due to long term sickness. Patient survey had already been sent out and results below.

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"The staff are fantastic but the parking at the Royal London is very, very poor."

"Our team at the Royal London are wonderful – I just wish they weren't so far away from our house!"

"The Princess Alexandra Hospital we did visit this hospital in previous years, but have not used it recently as we use the Royal London whenever possible our last appointment there was probably about a year ago and this was a shared clinic with the Royal London. In recent times getting an appointment here hasn't been very easy as the shared clinics are not very frequent I believe and there are only a few slots."

Panel members

Gary Ruiz*	**Consultant**	**Kings College Hospital**
Helen Haley	**Pharmacist**	**North Staffordshire Hospital**
Claire Browne	**CF Specialist Psychologist**	**Royal Manchester Children's Hospital**
Anita Betts	**CF Clinical Nurse Specialist**	**Northampton General Hospital**
Sue Wolfe	**CF Specialist Dietitian**	**Leeds Hospital**
Julie Simpson	**CF Specialist Physiotherapist**	**Birmingham Children's Hospital**
Claire Oliver	**Social Worker**	**Southampton General Hospital**
Carrie Gardner	**Commissioning**	**NHS England (London Region)**
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	**Quality Assurance and Control Manager**	**Cystic Fibrosis Trust**
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for Peer Review

Bold: attended on the day of peer review

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