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Peer review report

King's College Hospital and Paediatric Network

15 July 2015

Fighting for a Life Unlimited

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1. Executive summary

Overview of the service

King's College Hospital (KCH) has a well-established cystic fibrosis (CF) service, caring for approximately 200 children with CF, around 50 of whom solely attend KCH. The KCH/South East network of hospitals provides both inpatient and outpatient care for the remaining children and includes University Hospital Lewisham, Royal Alexandra Children's Hospital Brighton, Medway Maritime Hospital, Maidstone & Tunbridge Wells Hospitals, Eastbourne District General Hospital & Conquest Hospital Hastings, William Harvey Hospital, Ashford and Kent and Canterbury & QEQM (Margate) Hospitals. The larger units at Lewisham and Brighton undertake more complete care, including annual reviews; the others function as a managed clinical network. The network covers a large geographical area and with difficulties in transport this undoubtedly impacts on how shared care functions. The patient survey feedback is largely positive and reflects the level of commitment of the CF team but does highlight some areas for consideration, particularly around infection control and the transition process.

Good practice examples:

- The KCH team is a well-established and cohesive team that demonstrates high levels of commitment to clinical care, which is welcomed and recognised by its patients.
- The shared care network clinics report that the KCH team is accessible and supportive, providing prompt clinical advice of high quality.
- The annual KCH CF education day is of a high standard; this was consistently praised by all members of the multidisciplinary team (MDT) across the clinical network. This provides relevant continued professional development for many members of the shared care network, ensuring their CF education is maintained and updated.

Key recommendations:

- Review three key points in the patient/family pathway (newborn screening (NBS), annual review, and transition) to ensure a more integrated, equitable and consistent model throughout the network that reflects the CF Standards of Care 2011 document.
- Review infection control procedures to minimise the opportunities for patient contact and cross infection at KCH, including the location of pulmonary function testing and en suite facilities for inpatients.
- Review admission procedures at KCH, including introducing a streamlined bed management protocol and considering the allocation of dedicated beds for CF admissions. This is essential to reduce the delay of admissions for ill CF children.

Areas for further consideration:

- The network would benefit from the opportunity to meet as a group of professionals to develop shared goals and standards. Within the network there is a huge wealth of experience and there are many examples of good practice which should be shared. The panel felt strongly that a regular network 'business' meeting would help unify and drive the network forward.
- There is a paucity of community support for shared care and KCH patients by all members of the MDT. There is an urgent need to benchmark the roles undertaken by the MDT against CF Trust standards, as some of the roles being undertaken may be delegated to administrative staff, allowing clinical roles to be developed. While lines of communication between the CF centre and the outreach teams are excellent, an increase in face-to-face shared working would benefit patient care and ensure a more equitable service. In addition, more investment into psychology, social work, physiotherapy and nursing will support the network service.

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

Models of care

Summary

The KCH CF team are very dedicated and have well-established lines of communication for both families and network clinics. The CF centre sees patients at Lewisham and Brighton less frequently and has minimal input into their annual reviews compared with the other clinics. As a minimum, all other network patients are seen at least twice a year, inclusive of the annual review at King's, and an ill child may have full care at King's regardless of where they live in the region. There is variable early involvement with newly diagnosed patients by the CF centre MDT at some network hospitals. There is evidence that the physiotherapy and dietetic input at many of the shared care clinics fails to meet the inpatient standards of care. The professional development of ward nurses in terms of their level of CF knowledge and training is unclear. The engagement of Lewisham and the developing relationships are a very positive step, and this is an asset to the network. The Royal Alexandra Hospital, Brighton has some examples of good practice and their re-integration into the network would benefit their patients and the South East network, The current uncertainty about their future is detrimental to the ongoing stability of the whole network.

Areas requiring urgent consideration:

- Review of outreach clinic delivery to ensure all network patients are reviewed at least twice yearly by the specialist CF centre MDT.
- Review of the annual review process for network patients to ensure greater involvement of the specialist CF centre for those not undertaken at King's.
- Involvement of the specialist CF MDT in the early management of every newly diagnosed patient to ensure that care is equitable and their expertise is appropriately utilised where the diagnostic visit is not at King's.

Multidisciplinary care

Summary

The KCH team are experienced and demonstrate a good ethos of team working and commitment. The nurses are an invaluable source of information about their patients.

The team recognise that there are areas where development is required, particularly around providing home care for patients receiving home intravenous (IV) antibiotic therapy and input into schools/nurseries. The non-clinical tasks undertaken by the clinical nurse specialists (CNSs), in particular, impacts on their clinical capacity and requires review with improved utilisation of, and investment into, administrative support.

The annual education day is a valuable resource and there is an appetite to develop multidisciplinary education for the network teams further. This would be a positive advancement and help to share knowledge and experience and develop cohesion.

The full MDT requires dedicated time slots to have input into both the annual review process and the outpatient clinics. This process should reflect their skills and the value to the patients of the full MDT.

The network would benefit from the joint development of referral pathways and standard operating procedures to delineate the processes that are currently undertaken on an informal basis. The arrangements for CF-related diabetes (CFRD) are ad hoc and, while deemed satisfactory, with more formal arrangements could benefit all patients across the network, as the expertise would be concentrated and developed further in the specialist centre.

The appointment of a research coordinator is a positive strength and reiterates the centre's desire to increase their involvement in research.

Principles of care

Summary

All staff demonstrated good awareness of the importance of infection control. The physical limitations of both the inpatient and outpatient facilities, however, impact on the ability to comply fully with patient segregation standards. This was flagged in the patient survey, with concerns of patients mixing in waiting areas and, on one occasion, sharing the inpatient bathroom facilities at KCH.

Whilst separate Pseudomonas and non-Pseudomonas clinics do not operate, CF staff endeavour to minimise risk of cross-infection by having separate clinics for NBS babies, grouping potentially transmissible organisms together as far as possible and maintaining meticulous staff hand hygiene.

Most children have pulmonary function testing carried out in the clinic room, but those for annual review and some others are tested in the pulmonary function laboratory, where there is (rarely) the potential for mixing, especially in the waiting areas.

The inpatient en suite facilities, where the majority of CF patients are admitted, are at the end of a ward, meaning patients have to walk through the play area and the length of the ward to enter and exit. If these cubicles are unavailable every effort is made to use an alternative cubicle with en suite facilities. The facilities for the annual review pose an opportunity for patients to mix on an open ward which is minimised by a maximum of two children with the same microbiological status being reviewed on the same day. There is coordination of care to endeavour to ensure they are in different areas of the hospital at any one time.

The annual review process is thorough and addresses the screening recommended in the Cystic Fibrosis Trust's 'Standards of Care 2011'. If adequately staffed, an allocated slot for all members of the MDT, such as the psychologist and pharmacist, would ensure that adequate time is available and would add a further level of robustness to the review. There is feedback to the network clinics and families by a written report, but this can be delayed because of variable timescales for the MDT to upload their report. This can mean the information loses its relevance and the process, its importance. This has clearly been an issue for some parents in their survey feedback. The involvement of the specialist centre in the annual review process at Lewisham and Brighton would benefit from formalisation to ensure that the expertise held by the MDT at KCH is used to inform ongoing management plans.

Delivery of care

Summary

The level of care that the patients in the South East network receive is a credit to the dedication and expertise of the teams providing care. It is clear that many of these professionals are working well above and beyond their allocated time in order to deliver this level and standard of care. However, to address the issues highlighted there needs to be a review of the current level of staffing, the roles they are undertaking and a streamlining of processes for admitting patients, which is currently time consuming and detrimental to patient care.

The input of the specialist team into the community care of all patients across the network requires an investment in staff. The physiotherapy team have an agreed plan for expansion, but the nursing team requires additional administrative support, revision of their roles, and investment at 1.0 whole time equivalent (WTE) Band 6. Both social worker and psychology services are currently unable to provide support to the network clinics and require investment at 0.5 WTE, with a clear remit for support of the network patients.

The pathway for NBS is supported by some excellent paperwork, however the referral pathway into the specialist centre is indistinct and variable. Certain network clinics appear, at times, reluctant to utilise the clear expertise of the specialist centre.

There are benefits of the co-housing of the adult CF team and the working relationships between the paediatric teams and their adult counterparts are well-established with examples of good practice and communication through the MDT. However, the patient pathway was flagged as a concern in the patient survey and it is, particularly for network patients, less developed and requires a more transparent and rigorous process. There is a sense of patient transfer, with often only one joint clinic appointment, rather than transition.

Commissioning

Summary

The King's Paediatric CF Service is very experienced with a well-established and widespread network of hospitals in the South East of England.

The network hospitals undertake varying levels of care and so the percentage split of tariff varies accordingly. Similarly the level of input of the King's specialist MDT also varies: outreach clinics are held at most of the network hospitals but there are different arrangements at the two largest network units, Lewisham and Brighton, where they have well-developed and experienced local MDTs.

It is understood that, given the differing levels of staffing and expertise at the network hospitals, the levels of care provided at each site will be different. However it appears that the care received by patients across the network may be inequitable. The service is subject to a derogation against the requirement that all patients are seen by the specialised MDT twice a year. Currently patients at Lewisham are seen by the specialised MDT once a year and by the local MDT every 2–3 months. However, patients at Brighton may not see the King's MDT at all; input from the King's MDT is therefore 'light touch'. There appears to be a number of reasons for this, including the size and experience of the Brighton team and a lack of capacity in the King's team. While it is accepted that patients appreciate the services they receive closer to home, the King's team has overall responsibility for the governance of the network and the clinical care of all the patients within it. They therefore need to be as fully involved as possible and practical in all aspects of care for their patients no matter where it is delivered.

While communication generally appears to be good and the regional study day was certainly valued, there was not a feeling that the network was a cohesive whole. From the patient feedback it was clear that some do not understand the concept of network care or in some cases even see any value of the specialist MDT at King's. The team at King's needs to work in conjunction with all their network partners to develop a network identity so that patients understand how and where all aspects of their care will be delivered. A step towards this may be to set up a regular network business or management meeting that could look at standardising pathways and documentation to reduce this inequity.

The KCH management team at divisional and service level are very supportive of and work closely with the CF team. They undertake the development and negotiation of service level agreements (SLAs) with the network hospitals, enabling a separation of clinical and contracting functions, which the clinical staff find helpful. SLAs including the percentage tariff split were agreed with all hospitals for 2014/15 and are either in place or being progressed for 2015/16. Generally the service is lacking in administrative support, with some tasks undertaken by clinical staff and others (such as sending clinic and discharge letters) not able to be completed in a timely fashion because of this.

Transition is largely to the adult service at King's and there is a process with joint clinics and home visits for adolescents. However, this appears to be less the case at the shared care clinics and parent and patient feedback showed clear concern around the process. Some patients are still attending local children's services at 17, 18 or even 19 years of age. Greater involvement of the King's team with families from diagnosis and developing the relationship throughout childhood should mitigate this by building familiarity with the King's site.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	130

			Male	Female
FEV_1	Number and % of patients with FEV_1 <85% by age range and sex	0–3 years	0	0
		4–7 years	2 (14%)	0
		8–11 years	4 (29%)	4 (20%)
		12–15 years	5 (35%)	12 (60%)
		16+ years	3 (21%)	4 (20%)

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	(n=14); 10 (71%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	21 (16%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	20 (95%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	9 (45%)
	Number and % of patients on chronic macrolide without chronic PA infection	31 29%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

CF care is shared between five consultants (three part-time). Four share responsibility for CF inpatients and giving advice to the region on a 1:4 service rota. The outreach clinics are shared between two consultants. The bulk of the outpatient work at King's, including annual reviews, are undertaken between three consultants. The staffing levels are felt to be adequate by the KCH team, however with the level of input required to ensure the requisite number of reviews for network patients to be met, this may require review. The enthusiasm and energy of the KCH respiratory consultants could ideally be harnessed to augment the service provision if given the opportunity, providing more network clinics at University Hospital Lewisham and Brighton.

Good work has been done to integrate the Lewisham service and these relationships will prove crucial for the future of this arm of the service. The KCH consultant team have also been supportive of the ambitions of the Brighton team, although KCH and the Brighton team will need support from the commissioners to redefine their role should these not be fulfilled. The network consultants were universally positive about the clinical support they receive from their KCH counterparts and this should provide a great foundation in leading the network forward.

Specialist nursing

King's College Hospital has two CF CNSs (one Band 8a, 0.8 WTE and one Band 7, 0.6 WTE). They care for 200 patients across the King's network. Current CF CNS staffing levels fall below CF Trust Standards of Care (2011) with only 1.3 WTE CF CNS employed within the core specialist team compared with a recommended 4 WTE. Two network clinics employ Band 7 CF CNSs (Brighton 1.3 WTE and Lewisham 0.5 WTE), therefore staffing recommendation recalculates as 2.6 WTE. This continues to highlight suboptimal nursing levels with a shortfall of 1.3 WTE.

The King's CF CNSs have not regularly attended national and international CF conferences, due to work and family commitments. However, one attended the European Cystic Fibrosis Society (ECFS) conference this year. Both are members of the CF Nurse Specialist group and, when possible, one attends the regional meeting as well as the annual Royal Society of Medicine (RSM) CF meeting held in London.

A CFCNS attends the weekly CF MDT meeting, ward rounds and CF clinics, only missing these due to annual leave cover. The CNSs cross-cover each other's annual leave. However, as both work part time, this occasionally leaves inadequate cover. Other Trust responsibilities exacerbate this with the Band 7 also 0.5 WTE respiratory CNS and Band 8a having Trust managerial responsibilities.

King's has an extensive local network (approx. 150 patients). The CFCNS is central to the excellent communication amongst the network CF nurses as well as providing telephone/email advice and support whenever required. The CFCNS attends joint MDT clinics for most local networks, but is unable to provide any extra outreach support to the network clinics due to staffing shortfall. The CFCNS coordinates NBS referrals through King's to the network clinics with differing diagnosis processes depending on local service provision. The CFCNSs are involved in the transition process for the majority of the patients under their care with some networks coordinating their own patients' transition separately from the specialist King's MDT due to historical processes already being in place.

The full care patients at King's (approximately. 50) have limited/non-existent community nursing support due to changes in community nursing provision. This results in an increased workload for the CFCNSs as they coordinate and provide all nursing input for this patient group, including home IVs, NBS educational and supportive follow up. Patients have to travel to King's as current CNS staffing does not allow for a CFCNS outreach nursing service.

The CFCNSs have a large organisational and coordination role within the team for NBS diagnosis, annual review, transition, CF clinics and joint network clinics. This reduces the time available to provide specific nursing input for patients. No dedicated CF beds on the medical ward results in time spent coordinating CF admissions either at King's or network clinics to ensure patients are admitted in a timely manner according to their health needs. Inpatient facilities are not ideal, however with potential for dedicated CF beds in a new hospital unit this may improve; the CNS will be essential in the planning process for these inpatient facilities.

Area of excellence/good practice:

- CFCNSs provide excellent support/advice and communication between the network clinics.
- They are dedicated and knowledgeable about their patients and are an invaluable source of information for team members, patients and families.

Areas for improvement:

- Equitable availability of CF CNSs for both full and network care patients through development of an outreach service.
- Introduction of universal pathways for NBS diagnosis and transition with King's specialist CF team central to the process.
- Dedicated CNS time allocated to the annual review day and CF clinic.

Recommendations:

- Explore funding to increase CNS staffing to develop CFCNS' outreach service to both full care and network care patients, especially during significant life events such as diagnosis, transition, end of life and transplant.
- Introduce dedicated CF beds at King's with improved patient facilities.
- Increase administrative support to relieve the CNS administrative/coordination workload.

Physiotherapy

King's College Hospital (KCH)

1.8 WTE dedicated to CF patients (0.8 WTE Band 8a, 0.5 WTE Band 7, and 0.5 WTE Band 5). All CF inpatients have access to twice daily physiotherapy during the weekdays and weekend. All patients are seen by a specialist physiotherapist at least 2–4 times a year.

Areas of excellence/good practice:

- The physiotherapy team are valued and respected members of the MDT, with a high profile both locally and nationally. All members of the team have current continuous professional development (CPD), regularly attending national and international conferences. They are active and enthusiastic members of the Associate Chartered Physiotherapists in Cystic Fibrosis (ACPCF). They have excellent specialist skills with a good skill mix of specialist areas within CF (eg NIV, inhalation therapy, incontinence etc).
- Good specialist physiotherapy cover at outpatient clinics both locally at KCH and at network centres.
- Communication between KCH and network centres is good. Through an annual regional study day, sharing of documentation (discharge reports, annual review reports) and availability for advice over the phone, network centres do feel supported.

Areas for improvement:

- Community/outreach physiotherapy is complex and hugely variable across the whole network. There is currently no outreach physiotherapy service for CF patients local to KCH (plus other network centres). Therefore there is no support for nursery/school and home visits.
- There are no dedicated exercise facilities for paediatric CF patients. There is a small paediatric physiotherapy gym but this is not suitable for older children. Therefore inpatients often have to rely on the park or adult gym. The adult gym is very busy and used by adult CF patients. Exercise testing is also hindered by this lack of space.
- The organisation and provision of nebuliser and airway clearance equipment at KCH and across the network centres is variable. Although KCH do receive money from the Child Health budget for equipment, the annual budget for this remains unknown. This seems to have an impact on the organisation and replacement of equipment.

Recommendations:

- An additional outreach physiotherapy post to provide community physiotherapy input for all local paediatric CF patients. This post would particularly help to support patients requiring specialist input, such as NBS patients and their families post-diagnosis. This post would also help support physiotherapists in network centres through specialist teaching and coordination of standardised physiotherapy provision across a complex and currently fragmented network.
- A dedicated physiotherapy gym with appropriate cardiovascular (CV) equipment to be made a priority in the new build. In the meantime to look at accessing a larger space in the hospital or a local gym to help support maximally exercising CF inpatients and motivating them to get active.
- The additional support from a physiotherapy assistant to take on responsibility of creating a database for nebuliser/airway clearance equipment. Finding out the annual budget for equipment provision and creating a better system for the replacement and tracking of equipment.

Dietetics

Staffing: King's: inadequate staffing of 1.1 WTE, experienced Band 8a x 0.5 WTE and Band 6 x 0.6 WTE. Two staff enables 'juggling' to cover clinical commitments and leave cover. They are 'running to stand still' and have no time to audit or develop the service.

Network clinics: Meet standards at Lewisham but no cover for leave; exceeds standards at Brighton. Inadequate staffing/no dedicated CF time at Eastbourne, Medway Maritime, Kent & Canterbury or William Harvey. For example, one dietitian covers both the latter, a large commitment of 26 clinics per year with no dedicated time for CF or cover for leave.

Experience and CPD: The dietitians were without exception enthusiastic and seemed dedicated to the service. King's: both members of the UK dietitians CF interest group (UKCFDIG) and attend national CF dietitians meetings once a year each and alternate attendance at the yearly ECFS conference.

Network clinics: Not all dietitians are members of UKCFDIG. Most have had access to CPD in the form of the King's College study day, which is valued. Variable access to study leave, from attendance at ECFS conference for some, to no CF-related study leave for others.

Inpatients and inpatient food provision: Most inpatients were reviewed twice weekly. No cover for inpatients at Medway Maritime. Good provision of high-energy food and snacks at all sites. Recent withdrawal of restaurant meal vouchers for CF inpatients at King's a concern.

Annual Review: In most cases carried out by the centre team at a King's dedicated clinic. Brighton and Lewisham do their own annual reviews with local dietetic involvement.

Transition: happens via King's, so no involvement from shared care clinic dietitians, apart from Lewisham, which transitions its own patients with active dietetic lead and audit process.

MDT meeting and ward round: King's dietetic team able to attend ward rounds and MDT meetings; variable dietetic attendance in network clinics.

Audit and research: King's: limited participation in past five years due to increased clinical workload. Network: all are willing, however audit has only taken place for dietetics at Lewisham and Brighton. Active research and publication at Brighton.

Areas of good practice:

- Good communication and rapport across the network and enthusiastic, dedicated dietitians despite inadequate funding and small clinic numbers in some areas.
- Active dietetic involvement at key life stages/increased nutritional needs such as new diagnosis, tube feeding, CFRD and transition at King's and Lewisham via joint clinic with adult CF teams. King's provide other specialist services pertinent to CF care such as surgery for meconium ileus, gastrostomy insertion and liver transplants.
- King's annual study day is valued.

Areas for Improvement:

- Inadequate staffing – King's: 0.2 shortfall and Band 7 desirable. Network: single dietitian in most clinics with low levels or no cover for absence and no training of peers to support the service. No cover for inpatients at Medway Maritime. Difficult to ringfence dietetic funding and time for CF in small clinics.
- Improve CF CPD for all: difficult to get time in small clinics where CF is a small part of an individual's role. Not all dietitians are members of UKCFDIG.
- Shared resources and guidelines.

Recommendations:

- Dedicated dietetic staffing and cover should be provided in all clinics, with suitably trained back up for absence. Consider use of Dietetic Assistants to release qualified dietetic time within the whole service to facilitate meeting standards for CF dietetic care.
- Consideration to network wide nutrition audit/research and resources.
- Reinstate restaurant meal vouchers for CF inpatients at King's to meet nutrition needs.

Pharmacy

CF Centre	Number of Patients	Pharmacy WTE
Royal Alexandra Hospital for Sick Children	35	All pharmacists cover CF patients as part of their normal duties; unable to allocate WTE's.
University Hospital, Lewisham	27	
Maidstone and Tunbridge Wells Hospital	23	
Medway Maritime Hospital	16	
Eastbourne network clinic	20	
William Harvey Hospital	22	
Kent and Canterbury Hospital	14	
Kings College Hospital	49	0.5

Shortfall

Pembury, Eastbourne, Lewisham, William Harvey, Medway and Maidstone do not have a medicines management technician. King's have administrative support for finance and Brighton have ward-based support from a technician. However, at Brighton this support is limited and impacts on the pharmacist's time for clinical work.

Brighton bank pharmacist is a member of CF pharmacist group, others at smaller centres are not, but wish to join.

Inpatient services

- King's have 1 WTE assigned for CF, however time spent on CF services varies (between 0.5 WTE up to 0.75 WTE) with some CF time and the rest is spent on general paediatrics.
- Pharmacist at King's is now a qualified non-medical prescriber in all aspects of CF care, which will aid prescribing of nebulised therapies and medicines reconciliation on the ward.
- All inpatient charts are reviewed daily. Some centres do not have a medicines management technician and pharmacists provide medicines reconciliation, which has an impact on clinical time.
- Cover at smaller centres not provided by pharmacist with CF experience.
- The pharmacist at Brighton is currently on secondment and the post is currently covered by bank staff until a replacement is found.
- All centres have a home IV antibiotic service. William Harvey outsource community IV antibiotic services (CIVAS) for antibiotics on a named-patient basis. No other centres have an aseptic service for inpatient antibiotics.
- All centres have an on-call pharmacy service; the King's guidelines are used in most places. Brighton use their own guidelines, however King's have shared their guidelines with them.

- At the smaller centres, the pharmacist doesn't attend the MDT or ward round. At Brighton, the pharmacist attends the MDT/ward round weekly. At King's the pharmacist attends the ward rounds on a daily basis with a larger MDT round on a weekly basis.
- A pharmacist is always available for advice at all centres, albeit by phone in some.
- Cover for absences and leave is usually provided by pharmacists inexperienced in the area. All queries are therefore left until the 'regular' pharmacist is available.
- High-cost drugs (HCDs) – the smaller centres provide directly from the hospital. Patients at Pembury get their HCDs provided via King's due to issues with NHS South England. King's will transition patients over to home delivery for nebulised therapies beginning in December 2015.
- Home IV services – King's provide a home IV service via 'Baxter at Home' and manage the invoice processes for all the other centres.

Outpatient services

- King's – there is currently no active role in clinics or in newborn screened patients, but pharmacist is available when required. There is no allocated pharmacist slot in the afternoon clinics for annual reviews, however the pharmacist will see all patients over five years old for annual review in the morning prior to their investigations. This service is not provided to patients under five years of age.
- Lewisham have weekly outpatient clinics, however pharmacist only attends once a month, which is not consistently maintained.
- Most network centres pharmacist don't attend MDT or annual reviews.
- Transition to adult care – no handovers to the adult teams, except at King's where one-to-one meetings between the paediatric and adult pharmacy team take place.

Areas of good practice:

- King's – Development of guidance for shared care centres and the provision of home IV antibiotic service.
- Regional study day available for all centre staff to attend for the development of CF knowledge.
- There is good inpatient service provision at all centres and access to information out of hours

Areas for Improvement:

- Smaller centres need better communication within their own MDTs and with the team at King's.

Recommendations:

- All pharmacists should be members of the UK CF pharmacists group.
- All pharmacists should be able to attend network meetings and have adequate communication with King's.
- Pharmacist to have allocated sessions for all newborn screened patients and for all annual reviews.
- To utilise the non-medical prescriber for inpatient/outpatient care at King's.

Psychology

Background

Since last Peer Review, the CF Centre at King's has secured substantive funding for dedicated clinical psychology input. The psychologist was appointed in March 2013, being employed by South London and Maudsley NHS Foundation Trust (SLAM) as part of their wider psychosocial team. She took maternity leave during 2014, during which time a locum clinical psychologist was appointed. She then returned in March 2015, at which point the locum sessions ended. There was a short period of overlap between the permanent psychologist returning and the maternity cover finishing (three months). Her current provision equates to 0.4 WTE dedicated to the CF team, with 0.2 WTE for other respiratory duties.

Current working pattern

- Mon (am) – Psychosocial meeting and 'difficult' asthma but do see CF people
- Tues (am) – CF baby clinic and seeing new referrals
- Wed (am) – CF team meeting and then monthly psychology meeting for the MDT
- Wed (pm) – CF main clinic

Key areas of good practice:

- Broadly meets Standards of Care specifications (with focus on new diagnoses, baby clinics, and early intervention when required), on very limited WTE.
- Strengths and opportunities of being employed by SLAM (case discussion, supervision, access to support with mental health teams working in other areas, clinical governance and professional identity).
- Majority of referrals are either seen within one week (inpatient) or responded to within two weeks (outpatient).

Areas for improvement:

- Annual reviews take place on Thursday or Friday when there is no clinical psychology cover. However, this is mitigated by the development of a comprehensive questionnaire-based review/screen that is under evaluation, with immediate follow-up available if required. Since April 2015, this has been rolled out across the network apart from Brighton and Lewisham, which conduct their own annual reviews.
- Psychology referral pathways tend to come from the King's centre either via King's team or inpatient admissions, although referrals are accepted from any network constituent; these tend to be telephone contacts.
- Frustration that WTE results in focus on providing a basic clinical service. The post-holder and team are disappointed that they cannot secure further funding to provide further preventative, prophylactic psychological work. Leave creates gaps in service.
- Complex bureaucracy of being positioned within two NHS Trusts with their own governance and operational procedures. This can be practical (eg where to store clinical records) as well as inefficient (eg dual policies to adhere to).

Recommendations:

- Work with clinical leads and managers; this to increase clinical psychology resource by 0.5 WTE could be at an 'early career' or even non-qualified grading assuming that there was a substantive senior clinical psychologist (with supervision experience/qualification) to oversee/supervise their work (early career Clinical Psychologist Agenda for Change (AfC) Band 7 and Assistant Psychologist AfC Band 4/5). Although this gap could be met by utilising training placements, such provision is not secure enough to form substantive change.

- In the short term, align clinical priorities with the team's, inputting into screening and transition programmes and establishing parent-groups.
- Develop group-based approaches for parents and consolidate telephone consultations to further maximise capacity.

Summary

The clinical psychologist in the team is to be commended for providing a service creatively that gives the illusion of a far greater WTE provision. This has been achieved by working flexibly, but more often, by working unpaid overtime. Provision at the specialist centre broadly meets psychological standards of care, but contact with the regional clinics is limited, resulting in an inequitable clinical psychology service across the network. The post-holder continues to work creatively as evidenced by recent developments in accessing further services from SLAM Trust and formalising requests for training placements from local Department of Clinical Psychology programmes. However, limited capacity is thwarting substantive development and delivery of the full standards of care.

Social work

King's has a Band 7 social worker (SW) employed 0.5 WTE, which is below the minimum standards of care recommended by the Cystic Fibrosis Trust. Due to the demands on this service the SW provides an additional 0.1 WTE unpaid cover. The post will be increased to 0.6 WTE in July 2015 and a bid has been submitted to the Trust to increase this to 1.0 WTE, which would meet the required standards. The SW is well integrated in to the team and the role is supported by the MDT.

There is good communication between the SW and the MDT at the shared care centres, which report feeling well supported. There is no formal cover arranged for absences so members of the team will liaise with Local Authority SW's if an emergency arises.

The SW is a member of the UK Psychosocial Professionals in CF group (UKPPCF) and has attended several study opportunities including the UKPPCF psychosocial study day in 2015, the national CF Social Work meeting in 2015, the European CF Conference in 2014 and a Transition Study Day in December 2014. The SW presented case studies exploring Chronic Neglect and Adherence to treatment at both the King's CF regional meeting and the UKPPCF psychosocial study day in 2015.

The SW attends weekly MDT meetings and monthly psychosocial meetings. The SW responds to all referrals, but due to time limitations must prioritise patients who have more complex needs such as safeguarding and vulnerability issues and situations relating to difficult family functioning. The social worker currently works with 50/210 King's patients. Due to part time working and associated time constraints the SW does not always have a presence at outpatient clinics. Annual review and transition work is not carried out as routine and visits to network clinics and home visits have to be limited.

Shared Care clinics

All shared care clinics had a good knowledge of the role of a SW and had structures in place to meet child protection issues within their hospital and local authorities. Many other social work roles are being met by the shared care teams especially the nurses. Therefore shared care patients are not able to have a proactive social work service unless they are in a crisis.

Areas of good practice:

- Dedicated experienced SW with a vast amount of knowledge and experience who is able to identify improvements and has enthusiasm to develop the service further. Excellent communication channels and working relationships between the SW and the wider MDT.

Improvements:

- Due to part-time hours the SW is unable to provide a comprehensive and equitable service to all patients, especially a service to shared care patients and ability to contribute to service development is limited.

Recommendations:

- The CF Service would benefit from a dedicated 1.0 WTE social worker in order to deliver a more comprehensive social work service to those attending King's and its shared care centres. However, due to the geographical area it may benefit the service to have another SW to cover shared care patients and develop support locally. This would enable further service development in areas such as new diagnosis, transition, adherence, annual review and outreach community support.

5. User feedback

Kings College Hospital

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	11	5	6	4
Female	10	3	12	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	35	6	1	0
From the ward staff	11	16	4	0
From the hospital	11	22	4	0

Areas of excellence:

1 Accessibility

2 Availability of team members

3 Outpatient – cross-infection/segregation

Areas for improvement:

1 Car parking

2 Food

3 Inpatient ward – en suite facilities need upgrading and improved cross-infection segregation

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

Kings College 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	Amber	Patients in the Brighton and Lewisham network clinics have variable models for feedback.
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	No	No	Safe. MDT work over contracted hours, however would be more effective if adequately staffed.
	% 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	Amber	There are some pathways in place but these need development.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Amber	The standard operating procedures (SOPs) need clarifying for the key points of contact.
	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	Amber	There are relatively small numbers (<10) in CFRD clinics and therefore King's state segregating patients with different organisms is not possible. There is an ad hoc arrangement with no formal clinic.

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%	Single room; en suite when possible.	Amber	Majority of patients in single, en suite rooms.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Amber	Patients are not seen in separate, cohorted clinics but are segregated within clinic.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	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%	Green	Green	

4 Delivery of care

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

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Amber	Amber. Available for clinic if needed.	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red. Refer if needed.	Red. Refer if needed.	SW sets aside time ahead of clinic if she knows there are specific patients to see.
	% availability of a social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Red. Available on call for clinic.	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	1	1	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0		
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green	Amber	There are a number of clinics who describe ongoing negotiations.

Appendix 2

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Kings College Hospital 50 centre and 150 network care patients
Consultant 1	0.5	1	1	0.6
Consultant 2	0.3	0.5	1	1
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	0.4
Specialist registrar	0.3	0.5	1	0.2
Specialist nurse	2	3	4	1.4
Physiotherapist	2	3	4	1.8
Dietitian	0.5	1	1.5	1.1
Clinical psychologist	0.5	1	1.5	0.4
Social worker	0.5	1	1	0.6
Pharmacist	0.5	1	1	0.5
Secretary	0.5	1	2	0.2
Database coordinator	0.4	0.8	1	1
Data Clerk				0.1

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 – Kings College Hospital	
Number of active patients registered (active being patients within the last two years)	Network 190 (Kings 130+ Brighton 33+ Lewisham 25) = 188
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	130
Median age in years of active patients	9.5
Number of deaths in reporting year	0
Median age at death in reporting year	N/A

Age distribution (ref: 1.6 'Annual Data Report 2013')		
Number and % in age categories	0–3 years	26 (20%)
	4–7 years	32 (25%)
	8–11 years	23 (18%)
	12–15 years	34 (26%)
	16+ years	15 (11%)

Genetics	
Number of patients and % of unknown genetics	4 (3%)

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2013')	
Patients with a BMI percentile <10th centile on supplementary feeding	(n=14); 10 (71%)

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%)	0
	8–11 years	3 (17%)	4 (20%)
	12–15 years	8 (44%)	12 (60%)
	16+ years	6 (33%)	4 (20%)

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	26
	4–7 years	32
	8–11 years	23
	12–15 years	34
	16+ years	15
Number of patients with chronic PA by age group	0–3 years	2
	4–7 years	2
	8–11 years	2
	12–15 years	10
	16+ years	6

***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	4 (3%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	16 (12%)

Complication (ref: 1.16 'Annual Data Report 2013')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	4 (3%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	7 (5%)
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 0 without PH

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

IV therapy (ref: 1.21 'Annual Data Report 2013')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	49
	4–7 years	180
	8–11 years	142
	12–15 years	538
	16+ years	210
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	96
	8–11 years	115
	12–15 years	205
	16+ years	131
Total number of IV days split by age group	0–3 years	49
	4–7 years	276
	8–11 years	257
	12–15 years	743
	16+ years	341

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=77) 49 (64%)
If not on DNase, % on hypertonic saline	2 (3%)

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2013')	
Number and % of patients with chronic PA infection	21 (16%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	20 (95%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	9 (45%) with chronic PA 31 (29%) without chronic PA

Appendix 4

Patient survey

King's College Hospital

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	11	5	6	4
Female	10	3	12	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	31	11	1	0
Communication	21	17	4	0
Out-of-hours access	8	14	5	5
Homecare/community support	8	13	3	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	22	21	0	0
Waiting times	16	18	7	1
Cross-infection/segregation	21	16	4	1
Cleanliness	16	20	5	0
Annual review process	15	18	4	1
Transition	3	4	2	4

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	8	12	7	1
Cleanliness	8	12	8	0
Cross-infection/segregation	11	7	5	1
Food	4	8	7	8
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	13	11	1	1
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	5	5	10	4

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	13	6	1	0
Availability of equipment	13	14	4	1
Car parking	2	1	5	23

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	35	6	1	0
Of the ward staff	11	16	4	0
Of the hospital	11	22	4	0

Comments about CF team/hospital

"Very happy with support."

"Very pleased with the care of our son, diagnosed at four weeks and now five months old. As our son is at the stage of introducing solids, I've felt the dietitian at our local hospital is not fully aware/up to date with baby-led weaning (BLW). We will be doing BLW as opposed to purees. The dietitians at King's seem to know more/are encouraging of BLW."

"I personally have struggled with my son's diagnosis. I feel that although the care for my son is very good, the impact on our family has been more than we ever imagined. I don't think that enough help is there for parents who just really can't come to terms with their child's diagnosis."

"Parking is very expensive at King's which makes it financially hard if you have to spend a whole day there."

"The CF team have always been supportive, efficient and proactive."

"Transition to adults is very poor as we have had no contact from them."

"It is very early days still for us but the CF team at King's have been very supportive and caring as it has clearly been a very difficult time for us. My only issue is failure to receive letters after the monthly visit as we haven't received any for two months, but we've had our hand written notes to follow instructions."

"King's has provided our baby daughter with excellent care so far. Initially this was on their neonatal unit and now this is followed by regular checks in their CF clinic. Due to our length of stay at King's when our daughter was born, we have built excellent relationships with the staff."

"King's are a great team. They have been there for us for five years with both my kids. Clinic is great. They need a bigger CF clinic. Nice kids' paintings on walls. The CF team are always there at the end of the phone for anything. Things need to be made easier on them as they all do so much. It's a bit of a way to come for us for King's, but we would rather go there than a hospital near us."

"The team at King's are excellent. I can always get advice when needed and they always go the extra mile to ensure the girls have what they need. I see the team as an extension of our family."

"I think that they work extremely hard, but certainly could do with more resources."

"At this moment in time the support I receive is great. Any problems I have and they (the CF team) are at the end of the phone."

"We have waited in lung function next to another (coughing) CF patient. During every inpatient stay we have had our own cubicle with bed (but no en suite toilet or washing facilities). We have had to wait for toilets/shower and waited outside a toilet until another CF patient had finished inside. Cross-infection policy is frightening and doesn't comply with the CF service specification. I have brought this up with the team who seem uninterested. Other CF parents I speak to are shocked that we don't have en suite facilities at King's. Apparently, the adults department is being improved at some point! We are currently deciding where to go for adult services and whether to change for paeds. I like the staff at the unit, but they don't have the staff numbers, facilities or money for a decent service. It adds to the stress. The diabetes team on the other hand have an outreach nurse that rings, emails, pops round - fantastic!"

"Helpful and informative."

"King's paediatric CF team are awesome. I just wish they worked at weekends – so totally different in every respect come 5pm on a Friday evening until 9am Monday morning."

"We are always impressed and very thankful for the care and support given."

"The CF team are very good and supportive, but a lot more new members have been added and it takes time to get to know them. They give good care, but the inpatient facilities on Toni & Guy ward for CF patients are getting worse in terms of getting a bed and CF's rarely get a room with a bathroom and having to share facilities with others. Also, you rarely see a CF physio for sessions as an inpatient; usually a general physio most days. The CF team prolong the stays in hospital for CF's too much and do not seem keen in doing home IVs, even when the patient and family are keen to."

Appendix 5

Parent/patient interviews

King's College Hospital & network peer review – Parent telephone interviews (April 2015)

Parent A

Parent A's child attends the Royal Alexandra Hospital (Brighton) for CF care, with the specialist centre team from Kings College Hospital (KCH) joining clinic at Brighton for annual review.

Outpatient clinic

Mother felt that segregation at Brighton is excellent, being directed to a consultancy room shortly after arrival. She felt that the outpatient clinic staff all make good use of hand gel and always replace mouth pieces on spirometry equipment safely. She felt that the CF team is very good at involving her in decisions made about her son's treatment. They see the physio, dietitian, clinical nurse specialist and doctor at each clinic appointment, but she wished they had had psychotherapist support before her son became more challenging at teenage stage. She felt that the CF team don't tackle non-compliance toughly enough.

Inpatient care

Parent A felt that it was easy to be admitted the next day on last occasion in last 12 months. Her son has pre-planned inpatient IVs every three months, so not in an emergency situation. She is IV competent to administer IVs herself for her son at home, but due to child's non-compliance the CF team does not provide home IVs for her son.

On the ward, mother described the physiotherapy support as inadequate at the weekend or during holidays; her son seen just once a day. At weekends physio coverage is better. Mother added that she does a lot of driving to and from the hospital to see and pick up her son who is more compliant with physiotherapy whilst in hospital, adding that "He'll do his physio perfectly if the physiotherapist is available."

Mother described the ward food as "poor/rubbish", adding that "we're thankful for Subway fast food chain, instead of artificial 'mash' and 'half cooked vegetables'. Her son is offered cereal and toast and if he asks if he can receive a cooked breakfast from the staff canteen, but mother felt that the quality is not so good, suspecting it to be reheated a few times. Mother stocks up her son's fridge in his cubicle.

Annual review

Parent A's son is offered annual review each year, just after his birthday, with the Brighton team. This includes x-ray and bloods and lung function with feedback at next clinic. The results of test are available at Royal Alexandra clinic a month prior to annual review appointment and the clinical nurse specialist goes through the patient annual review questionnaire with her son during a home visit.

Home care

Parent A's son has a home visit from the clinical nurse specialist, if needed. He has deliveries of some nebulised antibiotics from BUPA, from whom they've received a good service. BUPA deliver on the days specified and text in advance.

Good practice:

- "The CF teams have been supportive and kind right from the beginning. There is continuity in the team."
- "The clinical nurse specialist goes above and beyond for us."
- "The consultant treats my son as if he were his own."

Areas for improvement:

- "Inpatient physiotherapy coverage at the weekend or during holiday periods."
- "Earlier introduction of psychotherapist support, before adolescence."
- "Better quality food preparation on the ward – not undercooking veg, not reheating breakfasts."

Parent B

Parent B's child attends King's College Hospital for full care.

Outpatient clinic

On arrival at clinic her daughter is weighed and measured at main reception, then directed to a consultancy side room. Mother felt the clinic team are vigilant with hand hygiene. She raised concern that at lung function, which takes place on floor 2 at the end of the hospital, her daughter can be waiting with other patients, not knowing if they have CF.

They have an afternoon appointment where they see the full multi-disciplinary team and if there are absentees in the team mother is not concerned as she says, "They know my daughter's history, so we don't have to see them always." Mother explained they can access psychosocial support if needed, but the replacement for the psychologist on maternity leave is leaving in June 2015. Mother commented that the social worker "is never there or arrives late in the day."

Inpatient care

Parent B felt it was getting harder to be admitted to the ward. She felt that the clinical nurse specialist did her best to get people with CF admitted onto the only ward, but mother felt that CF is a lower priority on the ward, citing an example where her daughter was asked to move room twice in one admission without explanation. Mother felt that staff retention on the ward was not good and felt that 'people were forgetting paediatrics'. Parent B felt that the care from the nurses on the ward was very good.

Mother explained that she felt that the catering team did not understand her daughter's additional diet-related issues on top of the CF diet, adding that she felt that oncology patients and A&E get priority, but she brings in food for her daughter which involves additional journeys to hospital. The dietitian has helped her by providing gluten free biscuits for her daughter.

Parent B described once daily physiotherapy on the ward, but explained that a physiotherapist does not attend to her daughter in the afternoon. Sometimes they are advised that a second session is not possible. She mentioned that during the last two inpatient admissions her daughter has seen the CF specialist physiotherapist once during each admission. Mother mentioned that her daughter rarely gets to the gym whilst in hospital. She prefers however to see her daughter having traditional physiotherapy rather than Wi fit exercises. Parent B's daughter has a blue badge but finds these parking spaces often occupied on arrival and so they are unable to park near the CF unit.

Annual review

Parent B's child is offered annual review each year at King's College Hospital where they see consultant, nurse specialist, dietitian and physiotherapist, with the contact numbers to be able to contact the clinical psychologist and social worker if necessary. Mother currently asks the clinical nurse specialist to help fill in welfare benefit forms.

Feedback on annual review outcomes take place at next outpatient clinic and by letter to GP, copied to parent.

Home care

Parent B's home community team flush her daughter's portacath each month. Abbott provide a good service for her daughter's PEG gastrostomy feed, mother carries out PEG button replacements herself and she's been lead to believe that nebulised antibiotics (Promixin) and DNase may become part of the home delivery service too soon. Her daughter has home IVs delivered when finishing a course that has begun on the ward.

Transition

Parent B's daughter wanted to see the adult service. She has requested a visit with the clinical psychologist and has spoken to the adult nurse about this.

Good practice:

- "The consultants and CF team do really care."

Area for improvement:

- "I'd like inpatient admissions reduced to half an IV course, so the rest can be done at home."
- "Would like to see more CF specialist physiotherapists on the ward – it would be reassuring to see one. The physios are nice, but seem rushed, stressed and tired. Even when unwell, my daughter doesn't get a full physio session."

Parent C

Outpatient clinic

Parent C's child attends University Hospital Lewisham for their CF care. The King's College Hospital team visit Lewisham annually. On arrival at outpatient clinic her child is first weighed and measured and then led straight to a consultancy room. Good hand hygiene is practised throughout clinic and generally they she and her child see all of the multi-disciplinary team, occasionally not the clinical psychologist though as mother felt this was not always necessary. Mother believed that the clinical psychologist had recently left the service and as far as she knew there was no social worker dedicated to the service. The previous clinical nurse specialist undertook some of the roles of a social worker, for example advice and form filling, according to mother; her replacement is an asthma nurse, also covering CF. Mother and child have no problems associated with pharmacy waits at the hospital as the prescriptions are sent to the GP for processing locally.

Inpatient care

Not applicable for this child.

Annual review

Parent C's child is offered annual review each year with the Lewisham team and all assessments take place at Lewisham Hospital. The outcome of the review is reported back at next outpatient appointment and via letter to GP, copied to parent and which outlines everyone's recommendations, giving an overview of her child's health status and details of x-ray and bloods tests. They do not see the consultant at annual review.

Home care

Mother and child have no routine home visits. Her child no longer has a portacath, but used to have it flushed at home by the clinical nurse specialist. They have home deliveries of Tobi via BUPA, a service which mother described as "excellent", adding, "They phone ahead and are good at phoning and texting me the day before. They leave the medications, on agreement, with a neighbour I trust if I'm out."

Good practice:

- "People in the CF team get back to us very quickly to answer queries/concerns."
- "We are able to get clinic appointments at short notice in an emergency."
- "The CF team are extremely friendly. It's like 'home from home' and my daughter feels comfortable in their presence."

Areas for improvement:

- "A need for increased parking spaces and reducing cost of parking. We have to park 10 minutes' walk from the hospital, off site. The parking is very expensive."
- "The CF service needs a social worker at Lewisham."

Parent D

Outpatient clinic

Parent D's child has shared care between Tunbridge Wells Hospital (Pembury) and King's College Hospital CF specialist centre. They are 45-minutes journey from their local hospital and 75 minutes from King's College Hospital. They moved their CF care from Maidstone to Tunbridge Wells and are impressed with the continuity in the paediatric team and felt that their consultant at Tunbridge Wells is very good, alongside an excellent CF team who educate mother and daughter well and practise safe segregation measures. They are pleased to have more regular physiotherapy support at Pembury, compared with Maidstone, but from April 2015 understand that the physio support will be hospital based and mother felt she might have to turn to King's College Hospital for physio support.

Inpatient care

At Pembury, mother explained that she has direct access to a consultant on duty if it is an urgent case. She felt that the ward nursing staff have good experience of CF, dealing with various other admissions. Mother mentioned that physiotherapy support on the ward is provided only once a day at Pembury; at the weekends the physiotherapists are community based, so there's no guarantee of being seen at the weekend – it's on a priority basis. There is no access to the ward gym at the weekend. At King's College Hospital, during the week her child is seen twice daily by the physiotherapist on the ward and at weekends the physio tries to see her child once a day, although it's not always certain when the physio may come to the room.

Mother commented, "There's a new, model hospital with individual bathrooms at Pembury, compared with only two en suite cubicles on the ward at King's College Hospital. Why can't two weeks IV courses be given at Pembury, then transfer to King's College Hospital if things don't improve for my child?"

Annual review

Annual review is offered every year to Parent D's child, with all assessments at King's College Hospital where they see the whole multi-disciplinary team. Mother understood that the social worker was in position for a year then went on maternity leave. The clinical psychologist saw her daughter about 18 months ago. Mother believed she's a more recent appointment to the team. The outcome of the annual review is provided at the outpatient clinic appointment and through a letter to GP, copied to parent. Mother felt that bloods could be taken locally to shorten the annual review appointment.

Home care

Her child's Tobramycin levels are checked before she leaves King's College Hospital if on home IVs. Mother questioned why they couldn't have the two week course of IVs at Pembury, then transfer to King's College Hospital if her child's health doesn't improve.

Although her child does not have home deliveries of any treatments as yet, she has heard that this situation may change – ie she thought that King's College Hospital pharmacy is liaising with the local pharmacist on this matter.

Good practice:

- "Expert knowledge in the CF team. I have confidence in the King's College Hospital team and my local team."
- "Segregation measures are good at both King's and Pembury. At King's they always tell me what other CF patients are on the ward."
- "Pembury's play room. Also, they have Wi-fi now. In the previous three years my child missed a lot of school."
- "King's College Hospital – It's got a good school room and it's a change of scenery, with safe segregation."

Area for improvement:

- "Admission times."
- "More widely available physiotherapy support locally."
- "A community team to support home IVs."

Parent E

Parent E's child has shared care between William Harvey Hospital (Ashford) and King's College Hospital specialist centre.

Outpatient clinic and annual review

They see the specialist centre team twice a year at the outreach clinics in Ashford and at annual review up at King's College Hospital.

On her first visit, parent felt frustrated making the trip to King's College Hospital and waiting one and half hours for an x-ray in an open waiting room, not knowing if others had CF. She and her child had a further wait at clinic and felt that she did not gain more from the King's College team than from the outreach team, adding, "All I got was an x-ray and bloods which I could have got from William Harvey Hospital." Parent explained that she had no telephone confirmation of the outcome of the x-ray and waited eight weeks for the written outcome of the annual review blood tests on which changes to vitamin E were made. She felt this was too long a wait without changes to such a treatment, adding that, "routine clinic reports take longer to come through."

Parent E felt that, although aware of the expertise of the specialist centre team, their input would be more beneficial when her child is older.

Parent E felt the CF team at King's are excellent, their verbal communication too. However, she felt their written communication is poor. She felt segregation measures are more robust at William Harvey Hospital – at King's College Hospital she explained that her daughter has to wait in an open clinic area initially; at William Harvey Hospital it is straight into a consultancy room. She felt that cleanliness is good at King's College Hospital; excellent at William Harvey Hospital and that both teams' availability is excellent.

Inpatient care

Parent E's child has inpatient treatment at William Harvey Hospital. She described admission waiting times, cleanliness of the cubicle and bathroom, the cross infection/segregation measures all as "excellent", describing the ward food in a similar vein. Her child had an inpatient episode at two months where her child had her own room and staff were attentive. Her daughter has since had Pseudomonas aeruginosa and has been treated at home. She is very grateful for the dietetic and physiotherapy support, adding "Without the team's support I'd have suffered and I've telephoned the outreach team many times with my concerns – they are lovely and friendly."

Good practice:

- "Very open, transparent and compassionate team. They called me in the evening about the diagnosis even."
- "I cannot fault the William Harvey Hospital team – they always come back to me quickly."
- "I receive quick responses/feedback on (sputum) samples from William Harvey Hospital."

Area for improvement:

- "Quicker response from King's College Hospital following appointments and when providing annual review feedback."
- "Transfer more care to local hospital in early years as long as they have the expertise and equipment."

Parent F

Parent F's child has shared care between University Hospital Lewisham and King's College Hospital. The King's College team come to Lewisham where all annual review assessments take place.

Outpatient clinic

At Lewisham this parent and child see the full multi-disciplinary team, although they believed the clinical psychologist is leaving and they did not know whether there was a social worker attached to the team. Mother felt that there was no discernible difference between routine outpatient appointments and annual review appointment – they have x-ray, blood tests and feedback on the annual review appointment, as with routine appointments is via letter to GP, copied to her. They also receive a telephone call from the Lewisham team if more urgent matters arise before the letter is likely to go out.

Transition

Mother was pleased that the transition process has not been rushed and is at her son's pace, when he is ready for it. He hasn't yet been to any adult CF centres to assess services, but met with Lewisham team at the last two outpatient transition clinics. She explained that both the paediatric clinical nurse specialist and dietitian work in both paediatric and adult CF service.

Inpatient care

Parent F felt that admission waiting times, cleanliness and hygiene and segregation measures at Lewisham on the ward were excellent. She also felt the home IV service was too, and the physiotherapy coverage on the ward during the whole week. Her son has twice daily physio on the ward seven days a week and can exercise in the gym. He has also been able to purchase a 'home gym' with a grant from the Cystic Fibrosis Trust.

Parent F's son receives a lunch box on the ward each day, has access to the hospital restaurant where he can use the 'top up' voucher for the duration of his inpatient stay. His mother saw this as important as she described the hospital menu portions as "small for a teenager and served cold". Mother added that the dietitian has been doing her best to improve meal portion size.

Home care

Parent F's son has no routine home visits, although she felt that it would be easy to arrange one if needed. She mentioned that the clinical nurse specialist used to make home visits and would still do if necessary.

IV courses are started and last a week on the ward at Lewisham, then completed at home the following week. BUPA deliver the IVs and ancillaries, a service which is delivered on time, on schedule and BUPA agree with Parent F what is needed during stock checks.

Good practice:

- "Availability of team, out of hours too."
- "We don't have to wait for outpatient appointments."
- "The continuity of nice, accommodating staff over 13 years."

Area for improvement:

- "The standard of the food for older children on the ward."
- "Some harsh realities need addressing by the CF team occasionally for my son."

Parent G

Parent G's child has all their care at King's College Hospital.

Outpatient clinic

They attend monthly clinic appointments due to a few viruses of late. Parent G felt that availability of the CF multi-disciplinary team, waiting times and cross infection/segregation measures at clinic are all excellent and that the standard of hygiene and cleanliness is good. She felt the CF team definitely listen to her and take into account her views when making decisions on changes to treatments, adding that the team tell her as much as she needs to know and are quite sensitive in their approach to covering the various aspects of CF. Parent G felt the CF team explain things well to her which was important to her as she is still at the development of understanding stage.

Parent G felt the CF team are "super busy", but that the clinical nurse specialist is amazing at emailing in response and providing day to day contact – eg regarding x-ray results. She felt that the doctor doesn't use electronic communications so much so that reports from January and February have been received in March which parent G felt makes it difficult to obtain new treatments/ dosages in a timely manner from the GP on repeat prescription.

Annual Review

This patient has yet to undergo annual review at such a young age.

Home care

Cough swabs are taken locally, at the Phoenix Centre. There has been one instance of contradictory information given to parent from community nurse and clinical nurse specialist, although the community nurse apologised for the error of judgement on that occasion.

Parent G has no home visits, but has found her local pharmacy brilliant and collects medications from this pharmacy. She felt the wait at hospital pharmacy was "ridiculous, around 90 minutes" and it concerned mother regarding the potential risk of cross-infection to her child whilst waiting.

Good practice:

- "Amazing clinical nurse specialist – kind, honest and just there and if not there has suitable cover."
- "A brilliant physiotherapist."

Area for improvement:

- "To reduce the length of wait for admission to the ward – waited over a week with the antibiotics not working."

Parent H

Parent H's child has shared care with Eastbourne and Hastings (Conquest Hospital) and the CF specialist centre King's College Hospital CF service, attending outpatient clinics at Eastbourne, receiving inpatient care on the ward at Hastings Conquest Hospital and sometimes inpatient IV treatment at King's College Hospital.

Outpatient clinic

The outpatient experience at both Eastbourne/Hastings and King's College Hospital was deemed good to excellent by parent H; good availability of MDT members, and acceptable waiting times, along with excellent segregation and cross-infection minimisation measures, an excellent degree of cleanliness and an excellent annual review process.

Parent H felt that the doctor was very approachable, involves her in decision making on her child's changes to treatments, and sees her child at short notice and so parent H has every faith in Dr Gopal's care. The doctor sends out appointments for the whole year in January, which parent H finds helpful. Dr Gopal comes to Hastings every other session. At Hastings clinic she always sees Dr Gopal and for two-thirds of clinic appointments both dietitian and physiotherapist. Parent H felt that the expertise of the dietitian from King's College Hospital was particularly useful. The physiotherapist at Hastings left and so they missed some physio sessions at clinic, but now Hastings has appointed a replacement. Parent H explained that the King's College team come to Eastbourne 3–4 times a year, which she described as a massive help to her in saving a three-hour return trip to London.

Inpatient care

Parent H's child has not had inpatient ward care in the last two years. Their last experience started on the ward at King's College Hospital then continued at Hastings for three nights. They preferred having her child treated on the ward at Hastings, which she described as a "good experience and it surprising how much the ward staff understood about CF and my child's needs." Her child had their own room, but had to share bathroom. She was pleased the ward staff made her aware of other CF patients on the ward, to help them with segregation.

Annual review

Annual review is offered to parent H's child each year at King's College Hospital where they see the doctor, clinical nurse specialist, physiotherapist and dietitian. Parent H explained she had only ever had two written annual review reports back and still awaits one for the October 2014 annual review. In 2013 she had to chase up the annual review report, adding "It would be useful to have the results explained at the following clinic appointment." She mentioned in passing that they'd also not had the results of clinical trials from GOSH that her child was involved in.

Home care

The community team based at Conquest Hospital supply iNeb parts and help and advice on treatment methods. The community nurse went with mum to school to talk to the teachers. Parent H finds the community nursing team very helpful and always available to contact.

Good practice:

- "Community nurses are supportive and know my child. If the GP surgery questions a request for change to a prescription item, community nurse will step in and explain/support me. They understand CF better than the GP."
- "The local CF doctor at Hastings is very good."
- "It's a superb care package, simply amazing. I keep my CF contact with my local team as they seem to know my child's history better. I don't always know who to contact so muddle through."

Area for improvement:

- None suggested

Parent I

Parent I's child receives all their CF care at King's College Hospital.

Outpatient clinic

Parent I felt that all aspects of the outpatient clinic experience are excellent – availability of the CF MDT, length of waiting time, segregation measures, cleanliness of the consultancy room and the annual review clinic arrangement. She had the same high opinion of the ward staff and hospital service as a whole. Parent I felt that the CF team definitely involve her in their decision making on treatment changes, adding that she is forthright in her views anyway. She asked the consultant to start her child on DNase, which they've agreed to.

Inpatient care

Admission waiting time, physiotherapy coverage and segregation measures were all deemed "excellent". However, parent I brings in her own bleach and antibacterial wipes and commented that the toilets on the ward, although cleaned by staff, are not looked after properly by some patients and their families.

Parent I described the food on the ward for inpatients as "awful", adding that they used to bring the trolley on the hot burner which kept meals warm, but then had microwaved the same meals so that they seemed double cooked. Consequently, she brings in pre-cooked ready meals for her daughter. She felt her complaint regarding the catering is shared by other parents and mentioned that Prof Price had also made a formal complaint when he was still in the CF service. Parent I added that there is a snack bar of crisps, biscuits and chocolate and she brings in other snacks for her child.

Parent I explained that exercise depends on gym availability or the family take a walk in the park or to a supermarket for exercise. Their child was an inpatient just over one year ago. Each admission they've had is a planned admission and they'd accessed A&E twice with distal intestinal obstruction syndrome (DIOS) and dehydration symptoms and on both occasions were admitted straight away. For inpatient IVs they spend the first three days in on the ward (to have antibiotic levels checked) and then complete these at home.

Annual review

Annual review is offered each year. It takes most of the day for her children and includes bloods, chest x-ray, lung function and liver ultrasound – the wait for lung function being 30-40 minutes – then afternoon clinic. Parent I thinks there is still a clinical psychologist in the service but last saw her a number of years ago and knows she'd receive advice and support if necessary. She has never seen the social worker, but knows there is one.

They receive the annual review results and feedback forms same day, apart from bloods, results from which are in the letter sent to GP and copied to parent, four weeks later, or advised earlier by phone if there is a pressing issue.

Home care

They have Tobramycin and Ceftazidime delivered, pre-mixed and their PEG parenteral feeds delivered by courier company. They preferred it when there previous supplier provided the feeds as the pump was quieter and service better. The new company require family to reuse feed syringes for three days. The deliveries with the courier have become fragmented, with some items missing from first delivery.

Good practice:

- "Easy to contact the CF team and they get back to me same day."
- "Can always speak to a specialist consultant and can email too."

Area for improvement:

- "Car parking – it's tiny and we have to queue for 45 minutes. It costs us £8–10 each time for clinic appointments. Two spaces have recently gone too due to building works. They need to build a multi-storey car park."
- "Food on the ward needs improving."
- "Shared toilets on the ward need to be better looked after by patients and their families."

Parent J

Parent J's child has all their CF care from King's College Hospital specialist centre.

Outpatient clinic

Parent J felt that availability of the CF MDT at outpatient clinic is good, as are the waiting times and the annual review process. Cleanliness did not score so highly, nor did the services cross infection and segregation measures which parent J felt are "poor". At annual review clinic or on return visit to the CF service after home IVs and sometimes at routine outpatient clinics they wait in a public area with the potential risk of cross infection. Their wait at lung function lasts 40 minutes with others coughing around her child. At outpatient clinic they are usually sent to a side room as soon as possible on arrival at clinic. Parent J feels that the clinical nurse specialist is quite stretched and that the service could do with two more nurses, adding that they have no support in the community from nurse or physio and son has grown MRSA.

At outpatient clinic they see the CF dietitian and CF physiotherapist and when the CF team make decisions about changes to treatments, parent J feels involved to a point, but added that she also feels that clinic appointments seem rushed so that there is not enough time for comments and decisions to sink in, so feels pushed into accepting what is said.

Annual review

Parent J's child sees the full CF MDT at annual review clinic, including clinical psychologist. They used to see a social worker whom they haven't seen in a long time and believe the clinical nurse specialist deals with the social worker tasks. They completed the clinical psychologist review form at annual review. It is a recent introduction to annual review which mother felt was long overdue and is good.

Annual review outcome is reported back at next clinic appointment, along with results of bloods. The findings from the x-ray and liver scan are fed back same day on annual review day. They do not receive a letter reporting outcomes of annual review unless asking for one.

Inpatient care

The most recent admission in last 12 months was a planned admission following haemoptysis. Following subsequent outpatient appointment referral for admission was made same day. Parent J felt that experienced ward nurses have pretty good knowledge of CF and her child's requirements in terms of medications and timing of these, but she felt the nutritional understanding on the ward was "awful". She felt reassured that the ward staff know her child well.

Her son received physiotherapy on the ward twice daily during the week and once a day at the weekends, adding that at the weekend the level of expertise amongst the physios is not so good and simply ask her child if he's able to do his own PEP and not follow this up. "There is no CF team at the weekend", mother added. She also mentioned her son's frustration that the adult gym is double booked at times, meaning he cannot use it on arrival with the physiotherapist.

Home care

Mother administers pre-mixed, home IV antibiotic treatment. Lambeth and Southwark community nurses used to come out to do port flushes, but that support is no longer available, so mother and son return to King's College Hospital to get port flushed and antibiotic levels checked.

Their home IVs are delivered by a new supplier, this service she described as "o.k., but not as good as the previous supplier, so I have to chivvy them along and they are not as flexible." Her son's DNase and Promixin are not delivered so mother collects from the local chemist.

Good practice:

- "Easy to contact the clinical nurse specialist – they need more of her."
- "The CF specialist team are good and know their stuff."

Area for improvement:

- "Need to reduce the waiting time at lung function in an open area, to reduce potential for cross infection."
- "Lack of en suite cubicles on the paediatric CF ward, raising cross infection risk."
- "A need to improve communication between adult and paediatric physiotherapists so that the adult gym is not double-booked."

Parent K

Parent K's children attend Medway and Maritime Hospital and King's College Hospital for their shared care. They attend Medway & Maritime every two months for routine outpatient appointments and in the past also accessed Medway for inpatient care. More recently, their son has been treated as an inpatient at King's College Hospital which they have particularly valued for its inpatient physiotherapy support and expertise. The King's College Hospital team come to Medway in February and July to hold joint clinics.

Outpatient clinic

Parent K felt that segregation is very good at Medway's outpatient clinics where it's usually pointed out to mother if there are other children with CF in attendance at the same time. They are led into a consultancy room on arrival and remain there for the duration of clinic. Parent K felt that the consultant is very good, adding that he understands their situation and is easy to talk to and that she and he bounce ideas off each other with regard to decisions relating to her children's treatments. Mother added that she always asks questions which the team are happy to answer.

Parent K always sees the physiotherapist, clinical nurse specialist and doctor at clinic, but rarely the dietitian. She thought she only worked at certain clinics. She added that the social worker came at the right time, to coincide with the departure of the respiratory sister whom the parent relied upon. She considers the social worker to be very good and happy to investigate any queries mother has.

Her son saw the clinical psychologist at King's College Hospital as an inpatient recently. They were referred to a clinical psychologist initially a few years ago.

Inpatient care

Their daughter has had just one inpatient episode at Medway, whilst their son now has inpatient care at King's College Hospital where they find the physiotherapy support better.

The food on the ward at Medway they felt was poor, but better at King's College Hospital. Mother explained that the dietitian had helped enable increased access to the whole menu at King's College Hospital as her son has additional dietary needs not associated with CF.

Opportunity for exercise involves going to the park near to King's College Hospital with family, but apart from that mother felt it involved mainly breathing exercises. At Medway mother takes their son to the nearby park, if an inpatient there.

Her son's last admission to King's College Hospital was onto a pre/post-surgical ward rather than a CF ward, but she questioned why her son could not be on the CF ward. On the non-CF ward she had to battle to get a dedicated toilet for her son's needs which she felt the ward team did not understand. She felt concerned about the difficulty in getting access to CF nurse specialists at this time and lack of ward staff knowledge of her son's medication timings, an example she gave being their keenness to give him his treatments earlier than usual on his day of discharge when correct timing were more important than this.

Mother felt that at Medway the CF service is "ok", but added that "the communication amongst the community team isn't great". Two nurses work part time and mother questioned whether information is effectively shared.

Annual review

Parent K's children have annual review at King's College Hospital. She explained how frustrated she was by what she felt was 'disorganisation' at the annual review, including a lot of waiting around due, she felt, to lack of communication between administrative staff and nurses.

At annual review they discuss changes to treatments with the CF team. Parent K could not remember receiving a written report of her son's review last year, receiving the annual review report only near to the next review appointment. She felt annual review reports in writing take a long time to arrive with her, adding that her GP surgery will not make changes to treatments until they have written confirmation from the CF team.

Homecare

Parent K's children have routine home visits for cough swabs and monthly port flushes for her son in the home, but they have to visit Medway & Maritime Hospital for IV bloods.

Mother collects the children's medications from the local pharmacy/GP surgery with talk of changing over to home care service not having progressed. Her son has a gastrostomy, but it is not currently in use.

Good practice:

- "The consultants at both King's College Hospital and Medway & Maritime Hospital are very good, approachable and speak on our level."
- "Physiotherapists at King's College Hospital are very good. At Medway it almost feels like it's a chore for the physiotherapists."

Areas for improvement:

- "Improve communication between the community nurses. I would like to meet and get to know the Respiratory Manager so that she gets to know us better too."
- "Improve the food on the ward at Medway – e.g. more variety on the menu and a menu that is more suited to children. Even with voucher supplied the food is not always what a 10 year old wants."
- "Improve organisation at annual review clinic at King's College Hospital. There's too little time to see a nurse to make them aware of communication issue between administrative staff and nurses and don't want to bother a consultant over this sort of point."

Parent Interviews - King's College Paediatric Service - Face to face

Parent A, the mother of an 11 month old son, diagnosed by heel prick test.

She felt that her views were taken into consideration and usually saw the same consultant, which was helpful. She sees all of the MDT that she feels she needs to. She was reassured by the team at the time of diagnosis.

Inpatient care (ward): Parent A explained that the ward appeared clean. Her baby ate all the food he was given on the ward. They were in a cubicle without toilet or shower and this was fine, as her son is a baby.

She described the physiotherapists as being very helpful however, at weekends physiotherapy was not so readily available.

She was happy with the communication from her CF team.

Areas of good practice:

- Friendly staff who know you as an individual.
- Supportive and responsive staff who communicate well.

Areas for improvement:

- Improvement in waiting times for a bed for admission, increase beds available to CF patients.
- Improved timely feedback after clinics and visits which may require extra administrative staff to process letters.

Parent B the mother of a daughter is 13 years old and was a later diagnosis. This had been difficult via her GP and local hospital. Things improved after their transfer to King's. Parent B sees all the MDT she needs to see, however it would be good to be able to access psychosocial support from more than one part-time professional.

Inpatient care (ward): Parent B felt it was difficult to get admitted to the ward. She explained that she thought the physiotherapists were very good and knowledgeable, however it was difficult, particularly at weekends, to access physiotherapy. She described the ward food as 'not good', adding that cereals and yoghurts had been taken away. Her daughter would like extra snacks more readily available as she doesn't like the food at all. Vouchers are no longer available for the restaurant or shop where a roll or baguette used to be available free of charge. Also, it would be good to have chips back on the menu. The ward is not always clean. Sinks, showers and ventilation ducts are often dirty and unhygienic and require a good clean. She has brought this to the staff's attention.

Areas of good practice:

- "Very friendly team"
- "Good communication"

Area for improvement:

- Better food choices
- Better entertainment, particularly for those particularly in isolation
- More school tuition time
- More physiotherapy over weekends, staff are very busy even during the week
- Increased cleaning of ward
- Repaint and revitalise outpatients department
- More rooms with en suite facilities to be made available

Appendix 6

Environmental walkthrough: Outpatients/CF clinic

	Hospital Name	King's College Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	No	Three separate waiting areas in children's outpatients. Two separate doors/entrances and lifts to access clinic. The area is cramped, however the HCAs work hard to get the patients straight into clinic rooms.
Do patients spend any time in waiting room?	Yes	Minimal time, as receptionists will phone CF CNS as soon as first child arrives. Clinic HCAs will weigh and height the child and then direct into allocated clinic room. Clinic room allocation discussed with CF CNS at start of day to enable separation of children.
Is there easy access to toilets?	Yes	Toilets in main waiting room but additional toilet on outpatients corridor.
Where do height and weight measurements take place? Is this appropriate?		There are two separate height and weight rooms in clinic, but requires patients to walk through the narrow clinic corridor.
Where are the lung function tests done for each visit?		Either in the child's clinic room or in the chest unit (respiratory physiology labs), there may be adult CF patients in the area with clear policy to ensure segregation.
Are clinic rooms appropriately sized?	Variable	Size varies from large to cramped, some reconfiguration has occurred but further changes constrained by the fabric of the building. Some rooms have no blinds on the windows or no examination couch – these issues are being addressed via the paediatric clinic user's group/forum.
For annual review patients, are any distractions provided?	Yes	CF team have activity packs that are given to children and can be taken home. Parents are advised to also bring toys.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		General paediatric diabetes clinics occur in the same clinic area, so usually the diabetes team come into the child's clinic room.
Transition patients – can they get tour of outpatients' facilities?	Yes	Adult CF team will contact the young person before the transition clinic to arrange visits.
Transition/new patients – do they get information pack?	Yes	

Environmental walkthrough: ward

Ward name: King's College Hospital

Microbiology status: All

		Hospital name	King's College Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		The ward is not dedicated to CF, however it is suitable for CF care	Paediatric medical ward for acute paediatrics, oncology and sickle cell patients. Winter does impose bed pressures that necessitates close working with the paediatric nurse practitioners (senior nurses for bed management). An emergency department (ED) short-stay unit was opened last year, which had a positive impact for inpatient bed availability last winter.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Overflow onto Princess Elizabeth Ward.
Number of side rooms?		Ten	Three of which are en suite. None dedicated to CF.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Yes	Very rarely patients may use the general bathroom as flagged in patient survey.
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	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Fold down beds in cubicle; parent accommodation also available in "Ronald McDonald House".
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Parents have free access to ward.

	Yes/no number N/A	Notes/comments
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?	Yes	
What facilities are provided for teenagers?		Adolescent room sited off the ward. With a dedicated adolescent worker that will provide activities and support in the teenager's/young person's room.
Is there access to a gym or exercise equipment in the rooms?	Yes	Small physio gym near the ward. Lovely park next to the hospital and used by physios for exercise/games with patients.
What facilities are there to help with school and further studies?		School room with full-time school teachers, open during term time. School teachers will also go to the ward.
Is there a relatives' room?	No	There is a small parent's room near the day case ward.
What internet access is there?		Free Wi-Fi access via a voucher system.
What facilities are there to enable students to continue to work and study?		Access to school room. The school has several laptops that they loan out. Wi-Fi access via free vouchers.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sterilisers available for use in rooms.
What facilities are provided for those with MRSA?		Isolation room on Toni & Guy (T&G) ward.
What facilities are provided for those with *B. cepacia*?		Princess Elizabeth (PE) ward is used, rather than T&G ward. No other patients with CF will be admitted onto PE ward at the same time. PE ward will have similar facilities to T&G ward.
What facilities are provided for those with other complex microbiology?		Isolation room on T&G ward.
Are patient information leaflets readily available on ward?	No	Parents are encouraged to access CF specific information from the Cystic Fibrosis Trust website. Generic information about King's and T&G ward are available on the ward.
Transition patients – can they get a tour of ward facilities?	Yes	

	Hospital name	King's College Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	King's is very close to Denmark Hill rail and overground station, which is fully 'accessible'. Good local area bus links.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	There is a separate lift from the main hospital corridor on the ground floor (has a picture of one of the patients on it). The only public accessible floor from this lift is the paediatric floor. Further lift into outpatients from an entrance at the front of the hospital that is signed 'Variety Children's Hospital'.
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?	No	Radiology – yes. Pharmacy – limited. Chest unit (lung function) – has problems with waiting space. Moving towards dedicated, timed slots for paediatric patients or the physiologists come to clinic.
Do patients have to wait at pharmacy for prescriptions?	Yes	Try to pre-empt the need for prescriptions or scripts sent to pharmacy by a member of staff so that parents can collect medication en route out of hospital without the present waiting time.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	On each ward.

Royal Alexandra Children's Hospital

Consultant

The Royal Alexandra Children's Hospital (RACH) in Brighton is the original and largest of the network clinics caring for approximately 36 children and young people with cystic fibrosis. It benefits from dedicated facilities within a new hospital build, experienced staff with access to paediatric surgery, bronchoscopy and ENT.

Outpatient care: Full local MDT in segregated clinics with appropriate infection control procedures. Network clinics do not have the capacity to see all patients twice a year.

Inpatient care: Appropriate facilities and MDT input into admitted patients. No problems with access to beds.

New born screening: Results communicated by KCH and parents informed by local team conforming to CF Care Standards for sweat test and results on the day of the initial consultation.

Annual Review: All done locally with appropriate investigations. No input from KCH.

Transition: Mostly to adult service at KCH but pathway being developed for transition to Southampton for patients for whom it may be more appropriate.

Positives:

- Very experienced MDT
- High staffing levels
- Research active
- Excellent facilities

Areas for development/concern:

- The main concern is the position of Brighton within the KCH network and the effect that becoming an independent centre would have on the network and on the neighbouring network. This needs to be resolved as soon as possible so that all concerned – staff and patients/parents alike – can work with the outcome to give best care to the children with cystic fibrosis.
- Development would include improving access to social work and cleansing of data on the CF Registry.

Specialist Nurse

Royal Alexandra Hospital, Brighton, cares for approximately 36 patients under the King's Hospital network and employ two Band 7 CFCNSs with hours totalling 1.3 WTE. This is above the recommended staffing levels in the Cystic Fibrosis Trust's 'Standards of Care (2011)'; however, there is potential that patient numbers may increase over the next few years if Brighton succeeds in their bid to become a regional CF specialist centre.

Both CFCNSs attend national and international conferences and are members of the CFNA group, attending both regional and national meetings. They actively participate in the team's research and audits and do wish to pursue nurse-led audits in the near future.

The CFCNSs cross-cover each other's annual leave and ensure they never take leave at the same time. They are able to attend the weekly MDT meeting as well as ward rounds and CF clinics.

Brighton follows their own established NBS diagnosis pathway, independent of King's CF MDT, and ensures all patients are reviewed and have a sweat test within the current recommended guidelines. Newly diagnosed patients/families will meet the King's MDT at the following joint CF clinic held every six months in Brighton. As a King's CFCNS is temporarily unavailable to attend this clinic, patients/families potentially would not meet them in person for a long period of time, however the local CNS and King's CNS are in regular communication about patient care/health status.

Brighton have an established transition process with the adult CF service at King's Hospital so coordinate and organise their own patients' transitions, independent from King's CF MDT. The adult team attend clinics in Brighton four times a year and adolescent CF patients are invited to meet with them at this clinic as coordinated by the Brighton CFCNS. Brighton is in the early stages of setting up a transition relationship with Southampton adult CF service for patients who geographically would benefit from going there.

Inpatients are seen regularly by the CFCNSs and home IV's are offered and supported if appropriate. There are no reported issues with bed availability and facilities meet recommended standards. The CFCNSs are able to provide an outreach service to their patients and are involved in gathering information for the annual review at home to reduce the amount of time the family has to spend in hospital as well as home IV support and NBS follow up.

Areas of excellence/Good practice:

- Above recommended CNS staffing allows for excellent nursing support to all patients/families with quick response times and outreach availability.
- CNSs are able to meet the psychosocial needs of the families especially as there is no social work support available at the hospital and a newly appointed psychologist.
- Good communications links with King's specialist team.

Areas for Improvement:

- Nursing audit/research.

Recommendations:

- If to remain part of the King's network, to invite CFCNS to attend some of the joint clinics so patients have access/meet the whole specialist MDT.
- Seek funding to employ CF social worker.

Physiotherapy

Royal Alexandra Children's Hospital Brighton

Currently 36 patients, although there are hopes to move towards centre status.

Full-time Band 7, in post since December. ACPCF member. Cover provided by Band 7 for clinics and Band 6 for the wards. Staffing is currently stretched as having to help cover maternity leave.

King's do clinics twice a year; all annual reviews done by Brighton.

Areas of excellence/good practice:

- Weekend and on-call provided by paediatric physios.
- Good gym and exercise facilities.
- Good strong communication with King's.
- Those on home IVs seen once a week either at home or in clinic.

Areas of improvement:

- Last new diagnosis was an inpatient, looking to develop community support.
- No control over budget for equipment.

Recommendations:

- Annual budget for CF equipment.

Dietetics, Pharmacy and Social Work please see main KCH report (page 13). No response given for Psychology.

Royal Alexandra Children's Hospital (RACH)

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

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	Red	Annual review done locally.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	Concerns about some of the quality of the data. See below.
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	Green for discussion with the local team. Red for discussion with KCH team.

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	Red	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	Excellent staffing levels.
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care 2011'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	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%	Red. New 2015 policy in place to achieve this.	Red	Improving with new policy.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber. 2x daily on week days, 1x daily at weekends.	Amber	Due to maternity leave.
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red. Referral basis.	Red	Business case in place for increased psychology.
	% availability of a clinical psychologist for inpatients	100%	Greed	Red?	Referral basis.
	% availability of a social worker at clinic	100%	Red. Referral basis.	Red	
	% availability of a social worker for inpatients	100%	Red. Referral basis.	Red	
	% availability of pharmacist at clinic	100%	Green	Green	Bank staff covering a secondment.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	1	1	
5.2	Number of clinical incidents reported within the past 12 months	<1%	2	2	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green	Green	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	RACH 36 patients
Consultant 1	0.5	1	1	0.5
Consultant 2	0.3	0.5	1	0.5
Consultant 3			0.5	0.2
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	1.3
Physiotherapist	2	3	4	1.33
Dietitian	0.5	1	1.5	0.33
Clinical psychologist	0.5	1	1.5	0.33
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.33
Secretary	0.5	1	2	0
Database coordinator	0.4	0.8	1	0.2

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 Alexandra Children's Hospital	
Number of active patients registered (active being patients within the last two years)	Network 190 (130+33+25) = 188
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	33
Median age in years of active patients	11
Number of deaths in reporting year	0
Median age at death in reporting year	N/A

Age distribution (ref: 1.6 'Annual Data Report 2013')		
Number and % in age categories	0–3 years	6 (18%)
	4–7 years	7 (21%)
	8–11 years	5 (16%)
	12–15 years	9 (27%)
	16+ years	6 (18%)

Genetics	
Number of patients and % of unknown genetics	8 (24%)

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

FEV_1 (ref: 1.14 'Annual Data Report 2013')			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	5 (23%)
	4–7 years	1 (6%)	4 (18%)
	8–11 years	3 (17%)	4 (18%)
	12–15 years	8 (44%)	7 (32%)
	16+ years	6 (33%)	2 (9%)

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	6
	4–7 years	7
	8–11 years	5
	12–15 years	9
	16+ years	6
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	1
	16+ years	2

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	0
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	4 (12%)

Complication (ref: 1.16 'Annual Data Report 2013')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	6 (18%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	4 (12%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH 1 (3%) without PH

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

IV therapy (ref: 1.21 'Annual Data Report 2013')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	68
	4–7 years	49
	8–11 years	42
	12–15 years	132
	16+ years	265
Number of days of home IV therapy in reporting year split by age group	0–3 years	4
	4–7 years	79
	8–11 years	131
	12–15 years	64
	16+ years	99
Total number of IV days split by age group	0–3 years	72
	4–7 years	128
	8–11 years	173
	12–15 years	196
	16+ years	364

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=18); 10 (56%)
If not on DNase, % on hypertonic saline	1 (10%)

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2013')	
Number and % of patients with chronic PA infection	4 (12%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	3 (75%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	3 (75%) with chronic PA 9 (31%) without

Patient survey

Royal Alexandra Children's Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Never visit King's College Hospital, but team from King's visit and see my son once a year. Shame no CF psychologist on team to help prevent needle phobia and provide support and advice (including CF-related diabetes diagnosis), which we had at a previous centre, although I understand this is being looked into now. Annual review – lots of appointments for different tests and not all done on one day as had been done at previous centre; means a lot more time to do. Not sure how well cross-infection policies for CF are known by all. Food on the ward not of good quality; always take/buy own food. Excellent caring and dedicated consultant and CF nurse, although sometimes feel another consultant doesn't always have time for you and to explain and listen to concerns. Excellent CFRD care under endocrinology/diabetic team and excellent surgical team/care when a portacath was required."

"Since the arrival of a dedicated physio, physio has vastly improved. We've not been there at a weekend to see how good weekend physio is. The CF team at Brighton have given excellent care for my daughter who not only has CF but lupus too."

"We don't go to King's College Hospital, just see their team when they visit Brighton annually. I would never have made it through the past 14 years (11 of them as a single mum) without the dedicated CF team at our hospital. I believe it is about to move status upwards to a CF specialist centre. I hope things will only get better. I wish the psychotherapist had been a standard part of care as my son was growing up, before he became a resistant teenager! I am very scared of transition to adult care in a few years because the current team are so amazing and know us so well."

"Overall I am very impressed with the service we receive, how well the transitions from King's to our local hospital was handled and how we were supported with starting school etc."

"The staff at the Royal Alexandra Children's Hospital, specifically the CF team, have cared for my son for the past 18 years. Members of that team have gone out of their way on many occasions to help in many different ways. I have chosen to not have any King's Hospital involvement for my son."

"They are a brilliant team. We have complete trust in them. They are thorough and it will only become better now that they are a centre and CF hours have increased." (Royal Alexandra Hospital Brighton).

	Hospital Name	RACH Brighton
	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	Patients are escorted into a clinic room as soon as they have booked in.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	In weighing room Yes	Two weighing rooms available. Patients spend brief time in weighing room and do not mix.
Where are the lung function tests done for each visit?	In Respiratory care, one patient at a time	Charitable funds have been identified to purchase mobile lung function equipment: from summer 2015 PFTs will be done in clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Books and toys. Annual review investigations are done at a separate visit prior to annual review clinic visit.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Seen in CF clinic by diabetes team.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	N/A	

Additional comments

Patients with known MRSA, *B. cepacia* or *M. abscessus* are seen at the end of clinic, with at least one empty patient time slot (30 minutes) before them.

Environmental walkthrough: ward

Ward name: Level 9 Medical Ward, Royal Alexandra Children's Hospital, Brighton

Microbiology status: All

		Hospital name	Royal Alexandra Children's Hospital, Brighton
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		12	Take this to mean single 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	
If no, are there any concessions for CF patients?			
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?		Visiting 24/7	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Stocked fridge in room (supplied by Rocking Horse charity specifically for CF patients). Microwave in parents' kitchen.
What facilities are provided for teenagers?		Internet access	

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Exercise bike brought to room.
What facilities are there to help with school and further studies?	Yes	School room with teacher Mon – Fri. If more than one CF patient on ward, teacher comes to room.
Is there a relatives' room?	Yes	
What internet access is there?	Wi-Fi	
What facilities are there to enable students to continue to work and study?	See above	Teacher support plus internet access as above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?	Yes	All CF patients, regardless of known culture of potentially resistant organisms, are admitted to a single room with facilities as described above. Patients with known MRSA, *B. cepacia* or *M. abscessus* receive physiotherapy (including supervised exercise) in their own room.
What facilities are provided for those with *B. cepacia*?	Yes	
What facilities are provided for those with other complex microbiology?	Yes	
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	N/A	

	Hospital name	RACH - Brighton
	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	
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?	No	Prescriptions sent from clinic to pharmacy by air pod beforehand.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

University Hospital, Lewisham

Summary: Second largest hospital in the network providing care for approximately 29 patients with CF. Until recently a CF centre in their own right who had been peer reviewed against the previous care standards. Relationships with KCH developing.

Outpatient: Segregated clinics with full MDT input and discussions. Transition clinic well established with adult service. Infection control appropriate.

Inpatient: Cubicles with en suite on a general paediatric ward. Compliant with hospital standards for children as well as CF standards. May take patients from KCH when they have capacity issues.

NBS: Local team currently as experienced in NBS and concerns about the capacity of KCH.

Annual Assessment: Local assessment with DEXA done at KCH. Issues with typing of reports

Transition: Well-established process with local adult service.

Strengths:

- Very experienced MDT.
- Excellent local guidelines and procedures.
- Transition process.
- Good inpatient facilities.

Areas for development/concern:

- Issues with secretarial system, which is outsourced, means that clinical staff are doing admin work in clinical time.
- More psychology required to meet the needs of the patients. SLA negotiations and funding should reflect the amount of work done in the local hospital.
- Competency training for home IVs.

Specialist Nurse

Lewisham University Hospital employs a 0.5 WTE band 7 CFCNS and cares for approximately 29 CF patients. This is appropriate for the size of the clinic and as part of the King's network there is telephone/email access to the CFCNS there if required.

The CFCNS is a member of the CFNA and attends the regional meeting as well as the RSM CF meeting in London, however due to work and family commitments, as well as lack of funding, is unable to attend the national CFNA meetings as well as national and international conferences.

They are able to attend ward rounds, CF MDT meetings and CF clinic except when on annual leave where there is no established cover. However, the adult CFCNS at Lewisham is available for onsite advice and support and the King's CFCNS via telephone/email.

Lewisham follows their own established NBS diagnosis pathway, independent of King's CF MDT, and ensures all patients are reviewed and have a sweat test within the current recommended guidelines. Newly diagnosed patients/families will meet the King's MDT at the following joint CF clinic held every three months in Lewisham unless there is a clinical need to see the specialist team sooner, at which point an appointment is made at King's. The local CNS and King's CNS are in regular communication about patient care/health status.

Lewisham have an established transition process with the adult CF service at Lewisham so coordinate and organise their own patients' transitions from the age of 12 years, independent of King's CF MDT. Adolescent CF patients are invited to meet with the adult team in the local clinic as coordinated by the paediatric and adult CFCNSs. If patients are admitted during their transition period the adult CFCNS will also meet with them while on the ward.

There are three joint Lewisham/King's CF clinics per year held at Lewisham and they are coordinated so each patient will see the King's MDT at least twice a year.

The CFCNS is able to provide an outreach service that includes home IV support and NBS follow up. They have an excellent relationship with the patients and families and know them very well. They have access to inpatients' en suite facilities on the paediatric ward and do not report bed availability issues.

Communication between King's CFCNS and Lewisham CFCNS is good with advice and support available when required.

Areas of excellence/Good practice:

- Excellent knowledge of families so adaptable to their needs.
- Good communications links with King's specialist team.
- Excellent transition pathway for the Lewisham patients.

Areas for Improvement:

- Introduction of parents evening and development of parent support and information leaflets.
- Nursing audit/research.

Recommendations:

- Psychology input for the CF team would free up CFCNS time to be able to carry out above improvements.

Physiotherapy

University Hospital Lewisham

Currently 28 CF patients with approx. 0.5 WTE dedicated to CF. A skill mix of one Band 8 and Rotational Band 5/6's. Band 8 will cover the majority of CF inpatients and outpatients are shared between the team.

Areas of excellence/good practice:

- Lead physiotherapist is supported and regularly attends CF conferences, study days etc.
- CF patients have access to physiotherapy twice a day at weekends with appropriate training for weekend physiotherapists.
- Good communication with KCH.

Areas of improvement:

- No community physiotherapy input for CF patients locally.
- Only a small budget for CF equipment.
- Limited space for exercise testing.

Recommendations:

- A dedicated annual budget for CF equipment.
- In collaboration with KCH (see recommendations for KCH) an outreach position to support patients in the community.

Psychology

Lewisham and Greenwich NHS Trust Network Centre

No clinical psychologist (CP)

Areas of good practice:

- 0.2 WTE psychological provision from local Child and Adolescent Mental Health Services (CAMHS) team.
- Attempts to attend all clinics and see all patients at annual review for psychosocial assessment and screening and meets all new families as soon after diagnosis as possible.
- Have further local access for patients whose issues are less directly related to cystic fibrosis.

Areas for improvement:

- Further scope for work on feeding behaviour problems.

Recommendations:

- Foster hub and spoke arrangement with centre psychosocial team.
- Develop telephone support/consultation.

CP staffing compared with recommendations: Not meeting recommendations

Dietetics, Pharmacy and Social Work please see main KCH report (page 13)

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

University Hospital, Lewisham

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%	N/A	N/A	
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%	N/A KCH	Red	Insufficient capacity in the network clinics.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care 2011'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
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%	Amber	Green	No reported issues with bed capacity reported.
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red	Red	
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%	N/A	Red	Not reported.
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. Patients now all go to KCH.	Red	Will improve with new arrangement with KCH.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Amber	Red	Issues with outsourcing of secretarial work.
	% of dictated discharge summaries completed within 10 days of discharge	100%	N/A	Green	Immediate discharge summaries.
	% 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	There is cover for annual leave, however not the same grade.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	There is cover for annual leave, however not the same grade.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	Cover provided by Band 8a.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Green	Cover provided by Band 7.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Amber	Red	Limited cover.
	% availability of a clinical psychologist for inpatients	100%	Amber	Red	No cover described.
	% availability of a social worker at clinic	100%	Red. No dedicated social worker input via Common Assessment Framework (CAF).	Red	Locality based model.
	% availability of a social worker for inpatients	100%	Red. No dedicated social worker input via CAF.	Red	Locality based model.
	% availability of pharmacist at clinic	100%	Green	Red	Once a month.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Red	Red	Needs to be sorted.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	1	1	
5.2	Number of clinical incidents reported within the past 12 months	<1%	2	2	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Red. Clarification needed from KCH.	Red	There are concerns around funding through the SLA.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	University Hospital, Lewisham 28 patients
Consultant 1	0.5	1	1	3 PAs (0.3 WTE)
Consultant 2	0.3	0.5	1	2 PAs (0.2 WTE)
Consultant 3			0.5	0
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	Inpatient cover
Specialist nurse	2	3	4	0.5 WTE
Physiotherapist	2	3	4	2.7 WTE (0.5 for CF)
Dietitian	0.5	1	1.5	0.2 WTE
Clinical psychologist	0.5	1	1.5	0.2 CAMHS psychologist
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	Telephone contact
Secretary	0.5	1	2	0.1
Database coordinator	0.4	0.8	1	0

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 – University Hospital, Lewisham	
Number of active patients registered (active being patients within the last two years)	Network 190 (130+33+25) = 188
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	25
Median age in years of active patients	9
Number of deaths in reporting year	0
Median age at death in reporting year	N/A

Age distribution (ref: 1.6 'Annual Data Report 2013')		
Number and % in age categories	0–3 years	3 (12%)
	4–7 years	7 (28%)
	8–11 years	6 (24%)
	12–15 years	6 (24%)
	16+ years	3 (12%)

Genetics	
Number of patients and % of unknown genetics	4 (16%)

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2013')	
Patients with a BMI percentile <10th centile on supplementary feeding	(n=2); 1 (50%)

FEV_1 (ref: 1.14 'Annual Data Report 2013')			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	0	1 (8%)
	8–11 years	2 (17%)	2 (15%)
	12–15 years	2 (17%)	0
	16+ years	1 (8%)	0

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	3
	4–7 years	7
	8–11 years	6
	12–15 years	6
	16+ years	3
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	2
	8–11 years	0
	12–15 years	1
	16+ years	1

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

Complication (ref: 1.16 'Annual Data Report 2013')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (4%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	5 (20%)
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 0 without PH

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

IV therapy (ref: 1.21 'Annual Data Report 2013')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	46
	4–7 years	58
	8–11 years	70
	12–15 years	33
	16+ years	14
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	14
	8–11 years	70
	12–15 years	14
	16+ years	0
Total number of IV days split by age group	0–3 years	46
	4–7 years	72
	8–11 years	140
	12–15 years	47
	16+ years	14

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=18); 5 (28%)
If not on DNase, % on hypertonic saline	6 (33%)

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2013')	
Number and % of patients with chronic PA infection	4 (16%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	4 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	2 (50%) with chronic PA 2 (19%) without chronic PA

Patient survey

University Hospital Lewisham

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	3	0	0	0
Of the ward staff	2	1	0	0
Of the hospital	3	0	0	0

Comments about CF team/hospital

"Always very friendly, available to answer questions when required. Luckily my daughter his generally very well so not needed inpatient/IV care since 2009, but when it has been needed the care and support has been excellent. Very happy with the care Lewisham provides. There is now no social worker in the team, which there used to be; maybe something that could be addressed."

"My son has received an excellent service from the CF team based at Lewisham Hospital for a number of years (14)."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic: Kingfisher Children's Outpatient Department

	Hospital Name	University Hospital Lewisham
	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	The waiting room has toys/activity tables. Very occasionally if there is one child of suitable age, clinic staff are aware of the need to show the children to their allocated room as soon as possible.
Is there easy access to toilets?	Yes	There are two toilets available in different areas.
Where do height and weight measurements take place? Is this appropriate?	Yes	There are two weighing rooms and additional scales which can be moved into a room. The staff have a clinic list which indicates what weigh room to use for each child.
Where are the lung function tests done for each visit?		These are done in the child's allocated clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Tablets purchased for the children to use. Every room also has toys and colouring equipment.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	They are seen in the CF clinic or as inpatients.
Transition patients – can they get tour of outpatients' facilities?	Yes	This is offered on a number of occasions and is undertaken with the Adult CF CNS.
Transition/new patients – do they get information pack?	Yes	Newly-diagnosed receive CF booklet. Young people in transition: we have started to use the 'Ready Steady Go' documentation with them.

Environmental walkthrough: ward

Ward name: Children's Ward

Microbiology status:

		Hospital name	University Hospital Lewisham
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Does not have a dedicated ward but have a regular flow of CF patients and provide the necessary environment for them.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Five	There are also two other areas that can be used as isolation rooms with designated toilet and bathroom.
Do the en suites have:	**Toilets?**	Yes	Only two of the side rooms have en suite.
	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	
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?		Yes	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	There is a fridge and microwave for use by CF patients in their side rooms. Another set of appliances are being purchased. There is also a parents' lounge where there is a fridge and microwave along with other facilities.
What facilities are provided for teenagers?		Yes	There is a teenage lounge area.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is exercise equipment that can be used and left in patients' rooms and there are two gym areas available in the physiotherapy department. ***see additional comments.**
What facilities are there to help with school and further studies?	Yes	There is a school room next to the ward, which they can attend. The school teachers will also do work with them on the ward when required and they have access to laptops to use for school work. The school teachers also liaise with their community schools to obtain work for them and so they are providing the right work and materials appropriate to age and development.
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?	Yes	There is a schoolroom and laptops that can be used on the ward.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	There is a microwave that is available for them to have in their room. There is access to the parents' room where there is a sink, kettle and microwave.
What facilities are provided for those with MRSA?		They would be nursed in a side room following the infection control policies. CF patients are always nursed separately from each other and do not mix on the ward. Physiotherapy always takes place in their cubicles or away from the ward area, eg a park or gym.
What facilities are provided for those with *B. cepacia*?		As above.
What facilities are provided for those with other complex microbiology?		As above.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

Physiotherapy gym areas: The main inpatient gym area is used at times by both paediatric/adult CF patients. This area has a strict booking system on use of the area, with close attention paid to local/cystic fibrosis standards of care in relation to cross-infection. Priority would be given to the adult patients as paediatrics have access to more facilities eg the outpatient gym area and the local park.

	Hospital name	University Hospital Lewisham
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	As inpatients, reduced daily rate.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To inpatient ward and outpatients.
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	This can depend how busy the department is. On annual review clinic-different time slots are used.
Do patients have to wait at pharmacy for prescriptions?	No	Prescriptions are ordered mainly through GP. Other prescriptions are sent to pharmacy and family collects at time of choice reducing wait.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Leaflets, posters in corridors.
Are there patient comment/ feedback boxes?	Yes	In outpatients and on ward – Matron Mouse and friends/family test.

Maidstone and Tunbridge Wells Hospitals

Consultant

Maidstone and Tunbridge Wells (MTW), Pembury

Summary

Amalgamation of two sites, with a separate experienced consultant previously at each location. With the retirement of the consultant at Maidstone 2014 the two clinics have been amalgamated under the care of Dr Blyth who has been doing CF clinic at MTW since 2006.

Outpatient – Full local MDT usually available at approximately monthly clinics.

Inpatient care – There is no specific cover for consultant absence (consultant on ward [COW] covers), supported by discussion with KCH team. Inpatient physio provided by adult physios and limited dietetic cover from two part-time dietitians. This is due to change with implementation of new business case (see below).

All inpatient paediatric beds are in single, en suite cubicles. Patients prefer inpatient to home IV therapy indicating they value the service provided.

Annual review – paperwork from KCH often delayed and becomes a less useful exercise, the process for feedback to patients once the results are available is not defined and patchy.

Newborn screening – all seen by KCH and initial care at KCH.

Positives/good practice:

- Staff feel that the education day provided by KCH maintains their CPD and CF education.
- Well supported by KCH by phone/email, feels the team provide a cohesive service with good working relationships.
- The inpatient facilities meet a high standard.
- MTW Trust has recently approved a business case to appoint extra physiotherapy, dietetic and specialist nurse to meet CF standards of care.

Areas for improvement:

- The inpatient care does not meet the Cystic Fibrosis Trust 'Standards of Care 2011' as there is no specific cover for consultant absence. Inpatient physio should be provided by paediatric physiotherapist and dietetic cover is limited.
- Written protocols for standardisation of care from KCH eg portacaths.
- Psychology support.
- Improving the process for AR feedback.

Specialist Nurse

Maidstone and Tunbridge Wells (Pembury)

Pembury has 1 WTE Band 7 Network CFN with special interest in respiratory; this includes 0.6 WTE hours specifically for CF. There are 27 patients; 24 shared with King's. Joint clinics will decrease from six to four/year. CNS highlighted that she had been formulating clinics but CNS at King's now involved again/good working relationship.

MDT meetings held post clinic. No pre-clinic MDT. CNS reports a good and supportive working relationship with CNS at King's. Inpatients are seen daily by CF nurse but not specifically during ward round.

When on leave, no equivalent CF nurse cover. Five Children's Community Nurses (CCNs) in the local team do provide cover but do not perform lung function tests. A business case has recently been accepted for a second Band 7 nurse who will also cover respiratory including CF, but at this point it was not clear how much allocated CF time this would include.

She is a CFNA member, but not had opportunity to attend European/international CF conferences. Attends study days at King's, and undertook Royal Brompton CF Course three years ago. Had involvement with peer review audit of ward, home IV antibiotics and outpatient services; service improvement initiatives include centralising annual review data.

Since joining this team, CNS said she had nil involvement as yet with NBS process at time of call. King's contact health visitor (or midwife) to visit family and deliver a letter advising sweat test planned for following day; if aforementioned unavailable the CF nurse would go instead. No specific NBS 'pack' held locally as King's provide leaflet. Post diagnosis, CF nurse is able to provide weekly visits according to need and sees in clinic monthly; it was not clear when they would next be seen by King's CNS, however this is adapted for each infant and the CF nurse felt liaison at this time with King's was good. Transition is led by King's who coordinate a joint transition clinic appointment but the network CF nurse has no involvement at this joint visit. There is no formal documentation used locally, nor do they have any transition themed leaflets. The CF nurse stated that there is no formal pathway to follow so transition processes occur within her discipline 'naturally' rather than it being an equitable, structured process. End-of-life care has not been required for any CF patients to date.

Areas of excellence/good practice: The network CF nurse has good input with patients at local level. Having reviewed current facilities and mindful of infection control within the outpatient department, innovatively designed individual toy boxes for CF patients under 10 years.

Area for improvement: CF nurse would like to enhance linkage with King's in respect of following same procedures/policies/guidance. Introduce a psychology service – currently CF nurse provides support.

Recommendations: implement business plan asap; includes homecare physio support.

Physiotherapy

Maidstone and Tunbridge Wells (Pembury Hospital)

As of 1 April this year the acute trust took over CF care, which had been run by community that offered in-reach care when patients were admitted. A senior respiratory therapist had been covering the service as an interim whilst waiting for staff to be put into post. They now, as of today, have a Band 8a CF and respiratory paediatric physio three days a week, who will lead the CF service. They will have a second Band 8 along with a Band 7 that will cover the days that the CF physio is not in. They plan to have an outreach service to see patients at home and at school and have had confirmation of further 0.47, not sure what band to help develop the community support.

At the time of the Peer Review, staffing had improved to the extent that twice daily physiotherapy was provided seven days per week.

They have not had any new diagnoses since care has moved to the acute trust but with their planned community service do not envisage there being any issues with seeing new diagnoses at home. There has also not been any transition into adult care. They report excellent communication with King's.

Recommendations:

- Develop physiotherapy service in line with CF national standards.

Dietetics, Pharmacy and Social Work please see main KCH report (page 13). No response given in regard to Psychology.

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

Maidstone and Tunbridge Wells 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	Data provided in audit.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	KCH	KCH	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	KCH	Amber	There is a variable process for feedback due to delay receiving reports from KCH.

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	Data was provided in audit.
	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%	KCH	Amber	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	No written policies or guidelines.	Red	
	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	Green	Only one patient with CFRD. Very close liaison with both teams.

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?	Outpatients are seen in single rooms but not in separate clinics. Children are carefully cohorted within the clinics and capacity to not reuse clinic rooms if needed.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
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%	No data	Amber	No data but flagged in patient survey KCH states 'It is extremely unusual for children not to be admitted in this timeframe'.
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red. Need to focus on.	Red	
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%	Data provided in audit.	Red	KCH states this is done routinely as part of the annual review process and communicated in report.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green/Amber	No cross-cover for consultant leave, however seen by Consultant of the week, who liaises with KCH as needed. Clear plan left by Dr Blyth. MTW Trust paediatricians work across two sites on complicated rota therefore impractical for only one person to cross-cover. Will be seen by CF CNS and/ or CF physio, who will flag up concerns to CoW and/or KCH as needed.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Red	Red	No data provided but concerns raised.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Red	Red	No data provided but concerns raised.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	Discussions stated CNS not always available. Business case to expand support.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	Discussions stated CNS not always available. Business case to expand support.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	Reported but no supporting data.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Reported in Dr Blyth's audit.
	% availability of a CF specialist dietitian at clinic	100%	Green	Amber	No cross-cover for clinics.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Amber	Amber	Dr Blyth's audit identifies some documented consultations.
	% availability of a clinical psychologist at clinic	100%	Red. Psychologist at KCH.	Red	
	% availability of a clinical psychologist for inpatients	100%	Red. Psychologist at KCH.	Red	
	% availability of a social worker at clinic	100%	Red. SW at KCH.	Red	
	% availability of a social worker for inpatients	100%	Red. SW at KCH.	Red	
	% availability of pharmacist at clinic	100%	Red. Not in clinic but advises.	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Red. KCH now producing assessment.	Red	Lack of clear guidelines to support.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A		

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	1	1	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	No data		

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Maidstone and Tunbridge Wells Hospitals 26 patients (23 SC with KCH)
Consultant 1	0.5	1	1	2 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	0.6 WTE
Physiotherapist	2	3	4	Under development
Dietitian	0.5	1	1.5	2 full-time dietitians cover CF ward & clinics
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	Full-time pharmacist covers ward and advises at clinics
Secretary	0.5	1	2	0.6 (CF only part of this)
Database coordinator	0.4	0.8	1	

Patient survey

Maidstone and Tunbridge Wells Tunbridge

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	6	2	0	0
Communication	6	2	0	0
Out-of-hours access	2	3	2	0
Homecare/community support	6	2	0	0

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	3	0	1	0
Availability of equipment	2	3	1	0
Car parking	2	4	0	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	7	1	0	0
Of the ward staff	1	4	0	0
Of the hospital	2	3	1	0

Comments about CF team/hospital

"The Tunbridge Wells team are only let down by the physio's disinterest, but the physio team is changing, so I hope to see improvement."

"To improve annual review appointments it would be helpful to have the x-ray and bloods done prior to the review, so that these can be discussed during the appointment and any adjustments to medications can be explained. Tony & Guy ward at King's needs updating as it's not really fit for purpose of treating CF patients that require segregation. Shared bathrooms is not good. Pembury children's wards seem to be very understaffed at the moment, although I expect this is the case right across the NHS; it is still worrying though. A home physio would be a welcome addition, but expensive I know."

"Overall, both CF teams are exemplary. I find parts of the King's team do not always consider our son on individual merit, as his CF is 'non-classic', and err on the negative, whereas the team at Pembury are more supportive and can see how well he is doing."

"So far we have had excellent care by our CF team. Admission times could improve and physio services locally could be more widely available. Home IVs have not been supported by a community team which is in other areas and improvements can be made. Biggest worry is transition to adult care. Children's CF service seems excellent. I have only heard alarming, negative reports from adult care services."

"Very happy with support"

	Hospital Name	Tunbridge Wells Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	It is our aim that all children go directly into single clinic rooms after weight/height and saturations are measured. No children are asked to wait in waiting area. Occasionally children may be given an alternative single room until their allocated clinic room is ready.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	Two public toilets are available on either side of the clinic corridor.
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight take place in one of three individual assessment rooms prior to going into allocated rooms. A portable measuring stick is available if needed.
Where are the lung function tests done for each visit?		Lung function tests are measured within the child's allocated room.
Are clinic rooms appropriately sized?	Yes	There are six good sized rooms with external windows which are generally allocated for use during CF clinics. Two extra smaller clinic rooms are also occasionally used.
For annual review patients, are any distractions provided?	Yes	Annual reviews generally take place at King's, however during CF clinics at Tunbridge Wells all CF children under 10 years old have their own individual named toy box.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Diabetes services are accessible across both our hospital sites and are held in single clinical rooms.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No	There is no information pack available.

Environmental walkthrough: ward

Ward name: Hedgehog ward

Microbiology status: All

		Hospital name	Tunbridge Wells Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	A general paediatric ward suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Completely single rooms only.
Number of side rooms?		23	All rooms on ward are single, en suite.
Do the en suites have:	**Toilets?**	Yes	Every room has all these facilities.
	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	The regular medications that children take while inpatient can sometimes be kept in the rooms. They are not kept locked.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	There is a wall-mounted, fold-down bed in every room for parental use. A parent's room with free tea/coffee is on the ward. Access to the canteen is encouraged for meals and snacks are also available in ward-based vending machines.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open visiting policy.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In the parents' room.
What facilities are provided for teenagers?		Yes	There is a ward-based 'den' for secondary-age children, with a pool table and age-appropriate toys.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	See comment	There is a physiotherapy room in children's outpatients, a level below the ward. Due to the reconfiguration of physio services, new gym equipment is being ordered for this.
What facilities are there to help with school and further studies?	Yes	A school teacher attends the ward on a weekly basis. Further studying can take place in the child's individual room or the 'den' during school hours.
Is there a relatives' room?	Yes	Ward-based parents' room.
What internet access is there?	Yes	Free Wi-Fi.
What facilities are there to enable students to continue to work and study?	Yes	Free Wi-Fi. Single rooms or the 'den' as quiet areas.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	See comment	Parents/children are able to wash/dry their nebulisers within the single rooms but are required to take them home on a weekly basis to sterilise parts.
What facilities are provided for those with MRSA?	See comment	Isolation in single rooms, with 'standard isolation' notice displayed. Facilities for hand cleaning, gloves and aprons provided to be worn for patient contact. Screening in accordance with Maidstone and Tunbridge Wells (MTW) policy and procedure MRSA care pathway. Intervention and risk monitoring and management in accordance with previous policy. MRSA decolonisation and prescribing protocol. Environmental cleaning and guidance in accordance with previous policy. Factsheet on MRSA 'information for patients and visitors'. Telephone support and advice from microbiology and infection control teams.
What facilities are provided for those with *B. cepacia*?	See comment	Isolation, hand washing and standard procedures and support as above but no specific written policy. All rooms with windows for ventilation.
What facilities are provided for those with other complex microbiology?	Yes	All of above and in accordance with MTW control and management of multi-resistant organism's policy. Lung function tests take place within individual rooms.
Are patient information leaflets readily available on ward?	Yes	Laminated guidance in rooms re facilities and car parking information.
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

Free car parking after 10 days of admission.

	Hospital name	Tunbridge Wells Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free parking for inpatients after 10 days admission. Assistance with travel cost for those on certain benefits.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Hospital in coloured zones. Green for paediatrics close to entrance of hospital.
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	If staff, parents or patients highlight need for isolation children can be segregated in pre-assessment rooms whilst waiting for x-rays or scans.
Do patients have to wait at pharmacy for prescriptions?	Yes	Need to wait if prescription not organised to be collected during clinic time. There is a separate 'counselling room' where children can be segregated.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Directly located close to reception. Leaflets available in reception stands or PALS office on many issues including complaints.
Are there patient comment/ feedback boxes?	Yes	Comment and Feedback specific form available in reception and PALS office. One of our CF children recently had meeting with catering team and management following her feedback on meals after inpatient stay.

Additional comments

One child who is admitted frequently has written to the chief executive complaining about the quality of the food. At present, children can get vouchers for canteen meals at lunchtime, or if they want to stay in their rooms, there is a trolley that comes round with sandwiches. In the evening there is a trolley that comes round with hot meals, and the children choose what they want. There is a snacks machine for food after hours, but there is no hot food after 7pm. The child wanted to be able to choose meals by selecting from a menu in the morning for the day ahead. Following the letter, she had a meeting with the head of catering, who said it was not possible to change the system. No changes have been made to date.

Medway Maritime Hospital

Consultant

Summary: Care is provided by an experienced Trust grade doctor with some minimal cross-cover from colleagues. The staffing levels suggest that there should be some investment in staffing provision.

Outpatient: KCH provide two clinics/year, the regular clinics have an MDT, full dietetic cover in clinic was planned to start in November 2015, inpatient cover is only by general paediatric dietitian, who may liaise with King's.

NBS: Patients are notified by the local respiratory nurse and then reviewed at KCH within a few days, where there is opportunity to meet the full MDT.

Annual Review: Undertaken at KCH with a report emailed out promptly. There is some opportunity for feedback of this information at the next appointment (but as only two clinics/year this may not be timely).

Transition: There is no fixed age (varies between 16–17 years) as this is dependent on a multitude of factors including co-morbidities, maturity etc; however, there is a formal process that has and continues to occur; this is a multi-stage process.

Strengths/Good practice:

- The physio provision has been addressed well with an enthusiastic member of staff and adequate cover.
- The inpatient facilities are good.
- There is a good working relationship with KCH.

Areas for development:

- The medical lead is not a consultant, which therefore does not adhere to the Cystic Fibrosis Trust 'standards of care 2011'; however, there is good evidence of clinical commitment.
- There is inadequate dietetic provision, improvement is to be made in November 2015.

Specialist Nurse

Medway Maritime Hospital (East Kent Region) employs four respiratory nurses (two full time and two part time) who each provide care for the 16 CF patients in their area within their respiratory role. A total of 1 WTE hour between them is allocated for CF and they provide cross-cover amongst themselves for annual leave.

All nurses have attended the annual CF Study Day at King's, but have not, as yet, attended any other national or international CF conferences/meetings/study days. They are not members of the CFNA group.

At least one nurse is able to attend the CF MDT meeting and where possible all attend. Inpatients have access to the CF nurses with one visiting on a daily basis. There are no reported bed availability issues with four en suite cubicles available to CF patients if they require IV antibiotics. More complex admissions are referred to King's Specialist CF team. There is well established communication links between Medway nurses and King's CFCNSs so inpatient advice and support is available when required and King's are aware of local admissions. The CF nurses are able to provide an outreach service which includes home IV support. A CF nurse attends the monthly CF clinic as well as joint clinics with the King's specialist MDT which occur every six months. All patients are reviewed two monthly in the local clinic with annual reviews undertaken at King's College Hospital.

NBS referrals are coordinated via Kings CFCNS with news of a child's abnormal NBS result, and subsequent diagnostic appointment at King's College Hospital with the specialist CF MDT, given to the family by the local CF nurse and a health visitor at a home visit. Initial diagnosis and education, for new families, is provided by the King's MDT with local nurses providing outreach follow up support.

Transition is coordinated by the King's CFCNS, with patients meeting the King's adult CF MDT in onr clinic before transferring care at age 16.

Areas of excellence/Good practice:

- Excellent outreach service with four nurses providing the service there is flexibility and availability for home visits.
- Well established regular communication between King's CF MDT and local nurses about patients care.

Areas for Improvement:

- Increase CF educational opportunities for the CF nurses.

Recommendations:

- Nurses to become members of the CFNA group.
- Seek local psychology and dietetic input for CF patients.

Physiotherapy

Medway Foundation Trust Hospital

16 patients covered by one paediatric Band 7 physiotherapist. Patients have access to two physiotherapy sessions a day (including one exercise session).

Areas of excellence/good practice:

- Dedicated physiotherapist – locally awarded Excellence in Care Award 2015.
- Good communication with KCH.
- CF physiotherapy input for inpatients on a weekend has recently been introduced.

Areas of improvement:

- Limited community/outreach physiotherapy service.
- Physio cover is by an adult Women's Health Physio when CF physio is on leave.

Recommendations:

- More dedicated CF physiotherapy hours, therefore cover is not limited to Women's Health. Part-time covering and outreach physiotherapy can be introduced.
- Annual budget for CF equipment.

Psychology

Medway Maritime Hospital Network Centre

No clinical psychologist.

Areas of good practice:

- Telephone contact with centre psychologist.
- Local psychosocial support from clinical nurse specialists.
- One patient has been seen by CAMHS, who delivered good patient care.

Areas for improvement:

- No official support from centre psychologist.
- Unclear of annual review and transition processes.

Recommendations:

- Develop telephone support.
- More even coverage of psychology input across centre and network patients.

CP staffing compared with recommendations: Not meeting recommendations.

Dietetics, Pharmacy and Social Work please see main KCH report (page 13).

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

Hospital name

Medway Maritime 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	Specialist centre KCH	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Amber	Amber	

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	KCH Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
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%	N/A	No CFRD patients	

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	Amber	Patients are not seen in separate, cohorted clinics but are segregated within clinic.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	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%	N/A		
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Amber	There are no robust systems for cross-cover for leave. A consultant paediatrician would normally cover annual leave.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Red. Should improve due to secretary taking over all CF-related correspondence	Red	Clinic letters to shared care/ GP – e-mailed initially with plan – this happens within 10 days from King's in all patients'. Discharge letters – electronic document notifications (EDN) completed at discharge with copy to KCH – 100%.
	% 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	Amber	There are up to four CNSs who cross cover 90% of clinics.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	There are no robust systems for cross-cover for leave.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	There is generally cross cover available from a physio pool.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	This is a new development.
	% availability of a CF specialist dietitian at clinic	100%	Amber	Amber	Patchy clinic cover.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	There is no cover.
	% availability of a clinical psychologist at clinic	100%	Red	Red	
	% availability of a clinical psychologist for inpatients	100%	Red	Red	
	% availability of a social worker at clinic	100%	Red	Red	
	% availability of a social worker for inpatients	100%	Red	Red	
	% 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%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A		

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	6%	6%	
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%	Red	Red	
5.4	Service level agreements in place for all	100%	Uncertain	Red	Needs to come from KCH.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Medway Maritime Hospital 16 patients
Consultant 1	0.5	1	1	0.5
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
Physiotherapist	2	3	4	0.05 additional time on IP care
Dietitian	0.5	1	1.5	0.025
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	Available for advice
Secretary	0.5	1	2	0.01
Database coordinator	0.4	0.8	1	
Admin assistant				0.01

Patient survey

Medway Maritime Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	2	3	0	0
Of the ward staff	3	0	2	0
Of the hospital	2	1	2	0

Comments about CF team/hospital

"Very pleased with the care of our son, diagnosed at four weeks and now five months old. As our son is at the stage of introducing solids, I've felt the dietitian at our local hospital is not fully aware/up-to-date with baby-led weaning (BLW). We will be doing BLW as opposed to purees. The dietitians at King's seem to know more/are encouraging of BLW."

"Team at Medway are all lovely people. Cleanliness of ward rooms is extremely poor. I clean my son's room before I allow him to touch anything. Ground in dirt around sinks, pubic hairs on skirting in bathroom – still there after one week of admission."

Environmental walkthrough:

Outpatients/CF clinic

	Hospital Name	Medway Maritime NHS Foundation Trust
	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?	Yes	In a side room specifically for that purpose.
Where are the lung function tests done for each visit?		In their respective clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Age-related toys/games, which are kept separately for each individual child.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	No	
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	New patients. N/A as no transition.

Environmental walkthrough: Ward

Ward name: Dolphin ward

Microbiology status: All

		Hospital name	Medway Maritime NHS Foundation Trust
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		12	
Do the en suites have:	**Toilets?**	Four	
	Wash basins?	Four	
	Bath or shower?	Four	
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)		N/A	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Parents: 24-hour visiting. 1.30–7.30pm normal visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?		Yes	Adolescent room (if no other CF patient present).

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	
What facilities are there to help with school and further studies?	No	
Is there a relatives' room?	Yes	
What internet access is there?	No	
What facilities are there to enable students to continue to work and study?	No	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?		Segregation and appropriate management. Infection control precautions.
What facilities are provided for those with *B. cepacia*?		As above. No mixing with any other vulnerable patient.
What facilities are provided for those with other complex microbiology?		As above.
Are patient information leaflets readily available on ward?		Distributed as needed.
Transition patients – can they get a tour of ward facilities?	N/A	

William Harvey Hospital

Consultant

Overview: William Harvey Hospital (WHH) in Ashford is the larger of the two hospitals in the Kent and Canterbury Trust delivering CF care to approximately 35 children. The service has developed over the last 10 years and relationships between the two MDTs and with KCH are good.

Inpatient: Excellent admission system for IVs with clear background and instructions. Ward is suitable for CF patient care with cubicles that have en suite facilities.

Outpatient: MDT clinics run with appropriate infection control and segregation within the clinic. Excellent handheld record sheet given to patient/parent with record of the consultation.

NBS: Largely done locally with MDT review with sweat test results. Given Cystic Fibrosis Trust information pack.

Annual review: Done at KCH. Report sent to WHH but delays in receiving reports.

Transition: To KCH adult service. Patients and parents apprehensive about transition.

Strengths:

- Dedicated local team providing service above and beyond their time allocation.
- Excellent service for IV access.
- Good relationship with KCH.
- Handheld record from clinic and IV admission pro forma.

Areas for development/concern:

- Lack of clinical admin support.
- Lack of recognition of programmed activity (Pas) for CF in consultant job plan.
- No CFCNS.
- Need better transition service to deal with patient concerns.

Specialist Nurse – see East Kent report (page 131)

Physiotherapy

William Harvey Hospital

Inpatients are seen by the acute physios and any outpatient appointment or community input is provided by the community team who liaise with the inpatient physiotherapists.

Areas of excellence/good practice:

- Excellent access to community physiotherapy including school/nursery visits, home visits, college visits etc.
- Physiotherapists regularly attend CF study days and members of ACPCF.
- Good links with KCH.

Areas of improvement:

- No access to any weekend physiotherapy when an inpatient at William Harvey Hospital.
- Limited communication between acute and community team.
- Access to a gym for inpatients is limited.

Recommendations:

- Develop weekend service to ensure CF patients receive physiotherapy input on a weekend to meet national CF standards.
- Better communication between acute and community team is required. Both teams to arrange regular meetings and communication paperwork.
- Develop dedicated paediatric respiratory/CF physiotherapy role in the acute setting.

Psychology

Psychology services are limited and would benefit from additional resource. They are provided by local CAMHS service and clinical psychologist based at Kent & Canterbury.

Dietetics, Pharmacy and Social Work please see main KCH report (page 13).

Hospital name

William Harvey 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	Y	Lack of secretarial time.
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
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%	Green	N/A	

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	
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%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Amber	No cover for annual leave/ study leave.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Red. No secretary. Consultant types own letters.	Red	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	Immediate discharge summaries.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Red. Community nurse team provide some support.	Amber	The patients are getting some nursing input.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Red. Community nurse team provide some support.	Amber	
	% 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%	Red. Twice daily in week. Weekend on request.	Amber	Only weekend issue.
	% availability of a CF specialist dietitian at clinic	100%	Red. Local dietitian.	Amber	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red. Local dietitian.	Amber	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red. Sourced as outpatient basis.	Red	
	% availability of a clinical psychologist for inpatients	100%	Red. CAMHS if needed.	Red	
	% availability of a social worker at clinic	100%	Red. Social support not available locally.	Red.	They also have direct input from KCH SW including home visits and attending clinics.
	% availability of a social worker for inpatients	100%	Red. Only upon special request.	Amber	They also have direct input from KCH SW including home visits and attending clinics.
	% availability of pharmacist at clinic	100%	Red. Contact name only.	Amber	Generic pharmacy.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0%	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. Some SLA in place. To be updated by KCH.	Red	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	William Harvey Hospital 24 patients
Consultant 1	0.5	1	1	1
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	Community Nurse Team (0)
Physiotherapist	2	3	4	Two Community Paediatric physiotherapists (0.5)
Dietitian	0.5	1	1.5	Dietitian attends all outpatient clinics and inpatient cover (0.5)
Clinical psychologist	0.5	1	1.5	0 (CAMHS service and non CF clinical psychologist based at Kent & Canterbury)
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	0.2
Database coordinator	0.4	0.8	1	0

Patient survey

William Harvey Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	2	1	0	0
Of the ward staff	1	2	0	0
Of the hospital	1	1	1	0

Comments about CF team/hospital

"The local CF consultant is excellent, always willing to fit my daughter in or telephone. The local team work well together and our CF nurse is brilliant for home appointments or advice over the telephone. Our CF nurse at King's is fantastic; makes access to our King's team work far more easily. We would be lost without our CF consultant, team and community nurse. I wish local adult care could be provided in the future to ease the burden for CF adults."

"I think there could be improvement and they seem to be the same issues constantly. We live in Folkestone so it is not viable to go to King's for everything, but at our network clinic it isn't always specialised enough; for instance on one 48-hour admission for IVs my daughter had a reaction to a drug and so all IVs stopped until her consultant was back, hence we ended up being in hospital for a week and when you are admitted every three months that is very frustrating as this our lives. We can often have an issue with 'levels' not being back so this can also mean a longer stay as drugs aren't ordered. We are often admitted over a weekend as I work and to limit my time off and actually sometimes I think it is worth taking the time off to ensure a smoother stay, especially as our consultant isn't someone who can make decisions for us. If my daughter has been well and it is a routine admission over a weekend, we haven't been seen at all by a physio as she hasn't been unwell enough. At least we can get admitted to our local easier than a bed on Toni & Guy ward at King's, so I guess it's swings and roundabouts. This is our lives and it is forever, so it would be nice if someone in government realised that illness doesn't just occur Monday to Friday, between 9am and 5pm. For some it is 24 hours a day, 365 days a year."

"Unlike William Harvey Hospital, at King's you are waiting in the main waiting area rather than taken straight to a consultation room. Only experienced annual review once with a one year old. No toys were provided (luckily, taken own) and were long in comparison with the outreach clinic. Cannot fault the outreach hospital (William Harvey). Their support and community nurses are fantastic. My experience of King's College leaves me frustrated that I have to take my daughter for review. The first year was long (three hours) and I felt that the x-rays and blood test could have been arranged locally and the outreach hospital could have done the review."

Environmental walkthrough:

Outpatients/CF clinic

	Hospital Name	William Harvey Hospital, EKHUFT, Ashford, Kent
	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	All the outpatient clinic rooms are usually taken up by the paediatric CF clinic and the patients go into individual consultation rooms at presentation following measurement of their growth parameters.
Do patients spend any time in waiting room?	No	As above.
Is there easy access to toilets?	Yes	There are two toilets in the outpatient clinic area.
Where do height and weight measurements take place? Is this appropriate?		Growth parameters are measured in the reception area.
Where are the lung function tests done for each visit?		In the consultation room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		Annual reviews are done at the CF tertiary centre, ie King's College Hospital, London.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Diabetic care of CF patients is done at the CF centre, ie King's College Hospital, London.
Transition patients – can they get tour of outpatients' facilities?		Adult care is provided at the CF centre.
Transition/new patients – do they get information pack?		Yes. An information pack is provided to new patients.

Additional comments

Outpatient care is provided to meet the needs of the patients and in keeping with the set standards.

Environmental walkthrough: Ward

Ward name: Padua ward

Microbiology status: All

		Hospital name	William Harvey Hospital, EKHUFT, Ashford, Kent
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Ward is suitable for CF patient care with cubicles that have en suite facilities.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Nine	
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	
If no, are there any concessions for CF patients?			
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?		Yes	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?		Yes	

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	
What facilities are there to help with school and further studies?		Hospital teacher available and so is a play specialist who also assists.
Is there a relatives' room?	Yes	This is a spacious room with good facilities.
What internet access is there?		Free internet access ie Wi-Fi.
What facilities are there to enable students to continue to work and study?		Privacy in cubicle and facilitation by the hospital teacher and play specialist.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?		Infection control relevant facilities.
What facilities are provided for those with *B. cepacia*?		Infection control relevant facilities.
What facilities are provided for those with other complex microbiology?		Infection control relevant facilities.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	In arrangement with tertiary centre (King's) that they are transitioned to.

Additional comments

Padua ward staff are used to caring for paediatric patients with cystic fibrosis and there are standard procedures in place that have been established over years that are followed. A front sheet (which contains the key details required) is always completed by the consultant paediatrician responsible for their CF care for individual paediatric CF patients being admitted and is referred to regularly during the admission by all the members of the team.

	Hospital name	William Harvey Hospital (WHH), EKHUFT, Ashford, Kent
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	No	Ward staff usually pick up prescriptions on discharge. Prescriptions done for community care are sometimes picked up by the CCNT.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

Additional comments

Consideration is ensured for the care of the paediatric CF patients in the hospital. The hospital catering service also provide flexibility and the patients are encouraged to make use of the resource.

Kent and Canterbury Hospital (QEQM)

Canterbury and Margate

Summary

Three sites amalgamated into one Trust. MDT outpatient clinics at Canterbury and Margate, 40-minutes travel time between sites. Canterbury has ambulatory paediatrics only, inpatient care at Margate or Ashford.

CF consultant Dr Newson, separate CF care at Ashford – Dr Smith.

Outpatients: Two-monthly. Physio and dietetic presence. Six-monthly joint clinics at Canterbury with KCH. Clinics segregated, with most infectious coming to end of clinic, and one cubicle/ outpatient department (OPD) visit. Community nursing team provide cover for portacaths, specimens, etc.

Inpatients: Some cross-cover between Dr Smith and Dr Newson but no coordinated leave; KCH will advise when away. Problematic cover for weekend physiotherapy, the general inpatient team provide physio input.

NBS: Seen locally unless Dr Newson not available and then undertaken at KCH.

Annual Review: Done at KCH with report fed back at subsequent clinic visit by KCH.

Positives:

- Good support from KCH with clear lines of communication.
- Home care IVAB service well supported by community nurses.
- Approval has been granted for a CF nurse.

Areas for development/ concerns:

- The inpatient care does not meet the CF Trust standards of care.
- It would be useful to re-instigate MDT across both sites to increase shared working between Dr Smith and Dr Newson.

Specialist Nurse

Kent and Canterbury and (QEQM) Hospital

East Kent has 1 WTE Lead Community Nurse with special interest in CF; the CCNT Team in whole consists of 14 generic CCNs. There is no CF CNS at present, however it has been acknowledged locally that the service would be enhanced with a CF CNS.

Total 35 patients; 12 children placed under Queen Elizabeth Queen Mother Hospital (QEQM); 23 at William Harvey Hospital (WHH). Multidisciplinary team meetings are held post clinic at six-monthly joint clinics with no pre-clinic MDT meetings. The CCN Lead attends CF clinics every month and regularly has post clinic meetings with the local consultant. The CCNT/Lead do not attend ward round routinely.

When the CCN Lead is on leave, the generic team cover, including carrying out spirometry, obtaining specimens and portacath maintenance. All CF patients have a named CCN; the team provides an on-call service and all staff are then made aware of all patients. The CCN Lead is not a member of the CF Nurses Association currently; details were requested and subsequently sent. All study day training is via King's whereby team take it in turns to attend. Not had opportunity to attend European/International CF Conferences. Two CCNs were trained and involved in the Torpedo Study. CF quality audit (new communication tool) has been carried out at local level only.

NBS involvement occurs once the consultant contacts the CCNT who are invited to attend a meeting with them (the consultant), newly diagnosed baby and family locally; CCNT follow-up visits occur as required with ongoing education provided. New diagnosis patients are immediately discussed with King's and a King's review planned, regular telephone communication with King's CNS occurs. Good information sharing was also reported. Transition is led by King's; the age of transition is dependent on the patient and is decided by King's as they provide most if not all of the adult provision, however if there is a need for them to have a local adult Consultant then they have a joint outpatient appointment (OPA) and handover; this could be due to compliance issues and patients not attending OPAs for specialist input from King's so it has been agreed this can be done locally. If there are no issues then King's decide when appropriate to transfer to adult services and they are seen there. End-of-life care has not been required for any CF patients to date but if necessary could be managed by the local team.

Areas of excellence/good practice:

- All round good communication reported. CCNT working hours are 8am–8pm seven days a week. Good home IVs support for CF patients.

Area of improvement:

- Better access to psychology service; very limited at present.

Recommendations:

- A CF CNS would ensure specific CF input for patients and better ownership for managing the CF caseload. At the time of peer review a CF nurse is planned and the team aim to look at formalising MDT meetings.
- Need a paediatric physiotherapist – current input provided by adult team. Would like to receive more regular updates led by King's; good telephone communication but some 1:1 working would be welcomed.

Physiotherapy

Kent and Canterbury

Two members of staff Band 7, one based in Thanet the other in Canterbury covering community. Inpatients go to Margate and Ashford.

Areas of excellence/good practice:

- ACPCF member- attends study days. No local network days.
- Can do home and school visits.
- IVs mainly done at home, offer physio sessions but with little uptake.

Recommendations:

- Better communication with King's with regard to annual reviews.

Margate – Queen Elizabeth Queen Mother

Inpatients:

- No funding for CF paediatric physio, service covered by adult respiratory that also cover ITU, HDU, general respiratory, adult CF and paediatrics. Find it difficult to prioritise those with cystic fibrosis. Recently have had a set of twins in, who they have struggled to find the time to treat.
- Seen daily, unable to offer weekend treatment unless very unwell.
- Band 7, previously worked in London but has not had any recent CF training. Band 6 and 5 trained by Band 7.
- Communicate with King's via the community physio in Kent and Canterbury.

- Limited access to the gym (general adult physio gym) which is used most of the time and not appropriate to take children to.
- No equipment budget.

Recommendations:

- Develop dedicated paediatric respiratory/CF physiotherapy role in the acute setting.

Psychology

Thanet & Canterbury Network Centre (QEQM)

No clinical psychologist.

Nursing team provide psychosocial support however they do not provide the standards of care for psychologists and SWs.

Areas of good practice:

- A University of Kent service offers psychological support to families in area. Families can self-refer and there are not long waiting lists at the moment.
- The bulk of the psychosocial standards of care (SoCs) are currently provided by the nursing team. However, this is neither sustainable nor desirable substantively. In order to meet psychosocial SoCs, provision must be delivered by/overseen by a qualified clinical psychologist.

Areas for improvement:

- University of Kent service only covers half of the geographical area that the network centre covers.
- Uncertainty about patients being seen psychosocially at annual review.
- No official support from centre psychologist.

Recommendations:

- Develop telephone support (as with the rest of the team).

Clinical psychologist staffing compared with recommendations:

- Not meeting recommendations.

Dietetics, Pharmacy and Social Work please see main KCH report (page 13)

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

Hospital name

Kent and Canterbury Hospital (QEQM)

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	Patients are all seen for annual review plus at least once or twice in Canterbury.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	
	% 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	Amber	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Amber	
	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. Patient seen if needed.	Red	

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	Amber	Patients cohorted within clinic, but no separate cohorted clinics.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	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%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Amber	No fixed cross cover arrangements for leave.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Amber	Amber	
	% 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	Amber	There is funding for additional nurse time.
	% 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%	Red. Daily physio (twice if clinically unstable).	Red	Additionally problems with weekend cover.
	% availability of a CF specialist dietitian at clinic	100%	Green	Amber	No fixed cross cover arrangements for leave.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Amber	No fixed cross cover arrangements for leave.
	% availability of a clinical psychologist at clinic	100%	Red. Access to non CF psychologist or CAMHS.	Red	
	% availability of a clinical psychologist for inpatients	100%	Red. Access to non CF psychologist or CAMHS.	Red	
	% availability of a social worker at clinic	100%	Red. Social services involved as appropriate.	Red	
	% availability of a social worker for inpatients	100%	Red. Social services involved as appropriate.	Red	
	% availability of pharmacist at clinic	100%	Red. Paediatric pharmacist available.	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	Good home IV service well established.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Red	Red	

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%	1	1	
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 negotiation with KCH.	Red	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Kent and Canterbury & QEQM 12 patients
Consultant 1	0.5	1	1	1 PA
Consultant 2	0.3	0.5	1	1 PA
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	0; no dedicated CF time; team (Community Nurses provide cover)
Physiotherapist	2	3	4	0; no dedicated CF time (2 community and acute team cover)
Dietitian	0.5	1	1.5	0; no dedicated CF time (2 dietitians cover)
Clinical psychologist	0.5	1	1.5	0 (Psychologist at K&C also CAMHS)
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	1 lead
Secretary	0.5	1	2	2 secretaries
Database coordinator	0.4	0.8	1	

No patient surveys were returned for analysis

Environmental walkthrough:

Outpatients/CF clinic

	Hospital Name	Kent and Canterbury Children's Assessment Unit
	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?		Briefly always separated.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Separate room.
Where are the lung function tests done for each visit?		In the room patient is in.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		King's do annual reviews.
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?		King's adult team arrange this.
Transition/new patients – do they get information pack?		King's team provide.

Additional comments

Kent & Canterbury unit is a new-build, purpose-built children's ambulatory, outpatient and Child Development Centre (CDC) unit. It provides an excellent facility for CF care with eight consulting rooms, three used for CF clinics. The day ward allows CF patients to attend for glucose tolerance tests etc. It is an excellent environment for CF clinics with adequate space to allow good infection control measures. Patients are directed to a free consultation room when they arrive so minimal time is spent in the waiting room, all nurses and receptionist are aware of the need to separate patients. Clinic are segregated into non-pseudomonal, pseudomonal, all MRSA, Mycobacterium abscessus and Cepacia patients are seen separately at end of scheduled clinics. This site is at present where Canterbury based patients are seen two-monthly with all CF patients from Canterbury and Thanet seen here six-monthly, jointly with the King's team.

Environmental walkthrough:

Outpatients/CF clinic

	Hospital Name	Broadstairs Suite, Queen Elizabeth Queen Mother Hospital, Margate
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	Yes	Minimal.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Separate room.
Where are the lung function tests done for each visit?		In consulting room patient is in.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		King's do the annual reviews.
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?		King's provide this.
Transition/new patients – do they get information pack?		King's provide this.

Additional comments

Broadstairs suite is a new purpose-built children's outpatient area at Queen Elizabeth Queen Mother hospital. It has six consulting rooms and we use three for CF clinics. Patients are directed to a free consultation room when they arrive, so minimal time is spent in the waiting room. All nurses and receptionist are aware of the need to separate patients. Clinics are segregated into non-pseudomonal, pseudomonal, all MRSA, Mycobacterium abscessus and Cepacia patients are seen separately at end of scheduled clinics. Local CF clinics are carried out here every two months and the plan in the future is to have a joint clinic here (at present this occurs at Canterbury).

Environmental walkthrough: Ward

Ward name: Rainbow

Microbiology status: All

		Hospital name	Queen Elizabeth Queen Mother Hospital 10 patients
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			Suitable general ward with cubicles for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Nine	
Do the en suites have:	**Toilets?**	Two	
	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.
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?			Anytime.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?		Yes	Separate areas and play equipment.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		Access to gym with physio.
What facilities are there to help with school and further studies?		Liaise with school.
Is there a relatives' room?	Yes	
What internet access is there?		Wi-Fi.
What facilities are there to enable students to continue to work and study?		Access Wi-Fi.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?		Infection control procedures.
What facilities are provided for those with *B. cepacia*?		Infection control procedures.
What facilities are provided for those with other complex microbiology?		Infection control procedures.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?		This occurs with adult service at King's.

Additional comments

Rainbow ward is a 24-bedded recently refurbished general ward with cubicles which are reserved for CF patients. CF patients will be prioritised to have side rooms with en suite facilities.

	Hospital name	Kent and Canterbury Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	No	Try and reduce need for this. Community nurses aid getting prescriptions and will deliver medications if needed.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

	Hospital name	Queen Elizabeth Queen Mother Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?		Try and reduce need for this. Community nurses aid getting prescriptions and will deliver medications if needed.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

Eastbourne/Hasting (East Sussex)

Summary

Two sites covered at Eastbourne and Hastings (Conquest). One consultant provides CF care with no cross-cover.

Outpatient: Usually full MDT, with some ability to undertake community visits and a named CF community nurse. No psychology input (CAMHS). Joint review of all patients usually six-monthly.

Inpatient: Review weekly by consultant (unless away when cover provided by COW, with advice from KCH if required), physio review daily, occasionally twice daily by hospital team who can liaise with the outpatient team, dietetic review is ad hoc.

All in patients have en suite facilities and single rooms.

Eastbourne/Hastings patients do have access to homecare IVs; using homecare service via Baxter.

NBS: Seen locally unless consultant is away then seen at KCH.

Annual Review: Done at KCH and the local team feel that the communication is effective.

Positives:

- Community set up for nursing appears positive.
- Inpatient facilities.
- Education day at KCH.

Areas for development/concerns:

- The uncertainty about the future of Brighton is unsettling as may change the shared care arrangements.
- The inpatient care does not meet the CF Trust standards of care.
- Psychology support.
- Problems getting beds at KCH for transfers.
- Ensuring inpatient staff receive CF education.

Specialist Nurse

East Sussex Hospitals (Eastbourne/Hastings)

East Sussex have a CCNT with 1 WTE CCN with special interest in CF; cover is provided by a CCN who works 1 WTE but with no specified CF hours and another CCN who works 20 hours per week = 0.6 WTE. Currently, the CCN without specific CF hours is on long-term sick leave. 23 shared care CF patients with King's. CCN feels supported both locally and by King's. CF clinics are held at E. Sussex four times per year, and a MDT meeting is held post clinic. They do not have pre MDT clinic meetings. CCN support provided with occasional home IV antibiotics; lung function tests and portacath flushes. CCN does not work on the ward or routinely attend ward rounds but any CF inpatients are reviewed most days as the CCNT are located within the vicinity.

CF Nurses Association member who attended last year. Not had opportunity to attend European/international CF conferences due to funding. Attends study days at King's, spent a day working alongside the CNS at King's and has undertaken the Royal Brompton CF course online. No involvement in CF specific research or audits but has contributed to service improvements including the development of the CF special interest role, which was new to the team. The CCN attends all CF outpatient clinics where previously this was covered by a generic outpatient nurse without specific CF knowledge.

For NBS babies, the CCN may carry out a home visit alone or with a health visitor to advise CF suspected and inform they need to attend King's or locally for a sweat test the following day; the local consultant usually updates the CCN who then follows up at home once diagnosis has been confirmed, visiting as often as is deemed necessary at the time. King's take the lead in respect of providing NBS education initially, if local consultant away, otherwise this is done locally. The CCN takes guidance and advice from King's as required and feels suitably supported. Transition is led by King's with one transition focused clinic usually before moving to adult services. Any end-of-life care would be led locally by the palliative care team.

Areas of excellence/good practice:

- CCN has good rapport with CF families, the local team and King's. CCN attends all CF clinics providing excellent patient continuity.

Area of improvement:

- Improved staffing levels would enable more CF specific time for holistic rather than task-orientated patient care especially as some areas are quite deprived. It would also allow time to carry out CF-related training with ward staff.

Recommendations:

- Consider CF Homecare Physio to work alongside CCNs.
- CCN to arrange some joint visits alongside CNS from King's, ie school teaching sessions.
- Enable CCN opportunity to carry audit re: home IVs, adherence; also 'the ward experience' from a nursing/MDT perspective.

Physiotherapy

Eastbourne (East Sussex)

Covers complex-need children and CF, Band 7, not an ACPCF member but attends King's annual study day.

Currently one physio covering service east and west of the region which geographically is very difficult. Able to attend clinics.

Inpatients seen by different Trust (Hastings).

Patients, when on home IVs, seen once.

Newly diagnosed seen by King's team then followed up locally.

Unaware of how funding has been cascaded down from King's.

Areas of excellence/good practice:

- Good communication with King's.

Areas of improvement:

- Poor communication with hospital physios in Hastings.
- As inpatients covered by a different Trust, physio is unable to accesses hospital system for results.
- Unable to provide community service across the whole district.

Recommendations:

- Develop two posts covering east and west sides with support from Band 7.

Hastings (East Sussex)

All paediatric now inpatient in Hastings, no specialised paediatric physio, adult respiratory/ orthopaedic cover.

Community covered by a different Trust.

Exercise sessions with physios when inpatients; all equipment from King's.

Weekend only once a day.

Areas of excellence/good practice:

- Good communication with King's; feel well supported. Good feedback from King's with care plans and reports.
- On call staff have annual updates.

Areas of improvement:

- No specialist paediatric physios, service covered by adult respiratory/orthopaedic team.
- Patients do an airway clearances programme independently, this can include the Bird (intermittent positive pressure breathing equipment) seen by the physios once a week (the patients are seen once a day, and are supervised.)
- Business plan in place for paediatric physio.

Recommendations:

- Develop dedicated paediatric respiratory/CF physiotherapy role in the acute setting.

Psychology

Eastbourne/Hastings East Sussex Network Centre

No clinical psychologist.

Areas of good practice:

- Psychologist from King's attends some network clinics, supporting patients when they are inpatients.
- Patients completed screening questionnaires for annual review.

Areas for improvement:

- Unclear of annual review process.
- Better developed input around time of diagnosis and transition.

Recommendations:

- More even coverage of psychology input across centre and network patients.

Clinical Psychology staffing compared with recommendations:

Not meeting recommendations.

Dietetics, Pharmacy and Social Work please see main KCH report (page 13).

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

Hospital name

Eastbourne/Hastings (East Sussex)

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	No data provided but frequent clinics.
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	All patients are seen at annual review at King's and usually at least twice in Eastbourne (Four clinics a year in Eastbourne).
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	
	% 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	Amber	There is a lack of formal guidelines.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Amber	There is a lack of formal 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%	Red. Patients seen by local paediatrician with interest in diabetes.	Red	

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	Amber	Not all rooms have en suite facilities, but CF patients prioritised.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Amber	Whist patients are cohorted within clinic there are no separate cohorted clinics.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Red. Done at KCH.	Green	Annual reviews completed at KCH.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red. Done at KCH.	Green	Annual reviews completed at KCH.
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. Not done locally.	Green	Annual reviews completed at KCH.

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	Amber	No cross-cover for leave.
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	Amber	Primarily outpatient service.
	% 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	Cover is ad hoc.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Amber	Amber	Cover is ad hoc.
	% availability of a clinical psychologist at clinic	100%	Red. No Psychologist.	Red	
	% availability of a clinical psychologist for inpatients	100%	Amber. Refer to CAMHS	Amber	
	% availability of a social worker at clinic	100%	Amber	Red	No designated social worker.
	% availability of a social worker for inpatients	100%	Amber	Amber	
	% availability of pharmacist at clinic	100%	Green	Amber	No designated pharmacist.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0%	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Red. Done 5 years ago.	Red	
5.4	Service level agreements in place for all	100%	Green	Green	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	East Sussex Healthcare 23 patients between both sites
Consultant 1	0.5	1	1	1 WTE consultant dedicated for CF
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	1 WTE community nurse dedicated for CF
Physiotherapist	2	3	4	2 community physios WTE (1=Eastbourne 1=Conquest)
Dietitian	0.5	1	1.5	1 WTE paediatric dietitian interest in CF
Clinical psychologist	0.5	1	1.5	0 CAMHS if needed
Social worker	0.5	1	1	0 Safeguarding team in dept.
Pharmacist	0.5	1	1	0 Paediatric pharmacist
Secretary	0.5	1	2	Named person
Database coordinator	0.4	0.8	1	Named person

Patient survey

East Sussex paediatric network service

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	4	0	0	0
Of the ward staff	1	1	1	0
Of the hospital	2	1	1	0

Comments about CF team/hospital

"There is no overnight ward at Eastbourne. King's was excellent in my son's recent inpatient stay. However, Eastbourne has closed their paediatric overnight ward so we don't have a local hospital for anything other than outpatient appointments. Hastings is one hour's drive away. I find this totally unsatisfactory. Also, because Hastings are covering a larger area they often don't have beds. We could have been discharged from King's after one week but there was no cubicle available at Hastings. The down-grading of Eastbourne has knock-on effects, because then we were bed-blocking at King's and more ill children could not have our room."

"Very good team and very helpful, but we have too many appointments in three different hospitals (Conquest, Eastbourne and King's College Hospital) – we can't afford them. It's too expensive for us."

"Our local team – Eastbourne & Conquest are fantastic. The community nurse team are very helpful and always available to contact. King's team are great but a long way away. We are seen straight away locally if we need it and are always able to get support through the community team."

"I personally have struggled with my son's diagnosis. I feel that although the care for my son is very good, the impact on our family has been more than we ever imagined. I don't think that enough help is there for parents who just really can't come to terms with their child's diagnosis."

"Parking is very expensive at King's which makes it financially hard if you have to spend a whole day there."

Environmental walkthrough:

Outpatients/CF clinic

	Hospital Name	East Sussex Health Care
	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	The patients are shown straight to the clinic rooms on arrival and are seen by the team in the same room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	They are weighed and heighted in the weighing room. The patients are brought in separately from the clinic rooms for their weight and height.
Where are the lung function tests done for each visit?		The lung functions are done in the clinic rooms. We have a portable machine which is taken into the rooms.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	N/A	This takes place at King'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?	N/A	This happens at King's, they get a tour of the adolescent/adult services and wards between 16–18.
Transition/new patients – do they get information pack?		Done by King's.

Environmental walkthrough: Ward

Ward name: Kipling ward

Microbiology status: All

		Hospital name	Conquest Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			It is a general paediatric ward with side rooms where CF patients are admitted. Usually there is only one patient admitted at a time.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Yes	Nine
Do the en suites have:	**Toilets?**	In a couple of rooms	There are nine side rooms, and two have bath and toilet attached. All others have a wash basin. We try and admit CF patients to the rooms with attached shower and toilet as much as possible.
	Wash basins?	Yes	
	Bath or shower?	In a couple of rooms	
Do CF patients have to share any bathroom facilities?		Occasionally	Only if admitted to a side room with no toilet attached.
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	In certain areas.
If there is a television, is the service free?		Yes	Free till 7pm.
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?		Yes	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?			There is a Wii and a Playstation that they can use.

	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?	No	Flexible Learning Education Support Services (FLESS) ring weekly or we can contact them to get work for the patients.
Is there a relatives' room?	Yes	
What internet access is there?	No	
What facilities are there to enable students to continue to work and study?	No	FLESS ring weekly or we can contact them to get work for the patients.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?	We do not have any with MRSA	Isolation cubicles with en suite, gowns and gloves. Advice from microbiology/ infection control.
What facilities are provided for those with *B. cepacia*?	No patients	
What facilities are provided for those with other complex microbiology?	Only PA	No complex microbiology, but if there are advice sought from microbiology team and infection control.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	N/A	This happens at King's.

Additional comments

Rainbow ward is a 24-bedded recently refurbished general ward with cubicles which are reserved for CF patients. CF patients will be prioritised to have side rooms with en suite facilities.

	Hospital name	East Sussex Health Care
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	N/A	
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

7. Panel members

Extended panel

Noreen West*	**Consultant**	**Sheffield Children's Hospital**
Mary Barraclough	**Consultant**	**Castle Hill Hospital, Hull**
Robyn Huggins	**CF Specialist Dietitian**	**Nottingham Children's Hospital**
Carolyn Patchell	CF Specialist Dietitian	Birmingham Children's Hospital
Sam Phillips	CF Specialist Clinical Psychologist	Bristol Children's Hospital
Alistair Duff	**CF Specialist Psychologist**	**Leeds General Infirmary**
Khola Khan	**CF Specialist Pharmacist**	**Royal Brompton Hospital**
Elaine Bowman	CF Specialist Pharmacist	Royal Brompton Hospital
Kate Lindsay	CF Specialist Physiotherapist	Bristol Children's Hospital
Louisa Hill	**CF Specialist Physiotherapist**	**Great Ormond Street Hospital**
Karen Henney	Clinical Nurse CF Specialist	Royal Brompton Hospital
Charlie Dawson	**Clinical Nurse CF Specialist**	**Great Ormond Street Hospital**
Carrie Gardner	**Commissioner**	**London**
Claire Oliver	**CF Specialist Social Worker**	**Southampton General Hospital**
Fiona Dowdall	CF Specialist Social Worker	Wythenshawe Hospital Manchester
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

Bold: the core panel who attended on peer review day.

This report has been considered and underwritten by the Peer Review Oversight Board.

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