

In partnership with

Cystic
Fibrosis why
we're here



British
Thoracic
Society



Peer review report

Royal Brompton Hospital and network clinics
19 February 2015

1. Executive summary

Overview of the service	page 4
Good practice examples	page 4
Key recommendations	page 4
Areas for further consideration	page 5

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

Models of care	page 6
Multidisciplinary care	page 6
Principles of care	page 6
Delivery of care	page 6
Commissioning	page 7

3. UK CF Registry data

page 8

4. Delivery against professional standards/guidelines not already assessed

Consultants	page 9
Specialist nursing	page 16
Physiotherapy	page 20
Dietetics	page 21
Pharmacy	page 23
Psychology	page 25
Social work	page 27

5. User feedback

page 28

6. Appendices

Appendix 1 Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'	page 29
Appendix 2 Staffing levels (paediatric)	page 37
Appendix 3 UK CF Registry data	page 38
Appendix 4 Patient/parent survey	page 42
Appendix 5 Patient/parent interviews	page 47
Appendix 6 Environmental walkthrough: outpatients department	page 58

7. Barnet and Chase Farm Hospitals	page 62
8. Crawley and East Surrey Hospitals	page 77
9. Epsom General Hospital	page 95
10. Frimley Park Hospital	page 108
11. Hillingdon Hospital	page 123
12. Queen Elizabeth II and Lister Hospitals	page 137
13. Queen Mary's (St Helier) Hospital	page 145
14. Southend Hospital	page 160
15. St Peter's Hospital	page 165
16. St Richard's and Worthing Hospitals	page 180
17. Watford General Hospital	page 201
18. Whipps Cross Hospital	page 217
19. Panel members	page 230

1. Executive summary

Overview of the service

Royal Brompton Hospital (RBH) has a large paediatric network, caring for 339 children and young people in 2014, with a well-staffed and experienced multidisciplinary team (MDT). 113 of these patients receive full care and 200 are cared for across the network (shared care). There are 14 network hospitals supported by joint clinics with an MDT from the centre. There are 26 patients at 10 associated hospitals (range 1–7 patients), an historic arrangement, and the numbers are reducing. Additionally, the centre cares for five patients from Malta. Due to their reputation for cystic fibrosis (CF) care, a number of complex patients from across the EU have migrated to the centre. CF Registry data shows that, compared with national data, their outcomes for lung function, body mass index and chronic pseudomonas infection are mid-range. They are often used as a second opinion from other tertiary units within the UK. Their published guidelines are used extensively. Research activity is world class.

Good practice examples

1. A world-leading paediatric academic and research track record. This is augmented by the co-location with the adult CF service.
2. Despite a large number of patients, it offers both excellent clinical care with a holistic and MDT-centred approach to the patients and their families. The accessibility of centre staff to the shared care teams and ongoing professional development (including annual study day and published guidelines) is highly valued.
3. Other examples of good practice across the disciplines include:
 1. Co-location with adult CF service.
 2. Hospital school/family support for inpatients: well integrated.
 3. Physiotherapy: equipment budgets for physiotherapy equipment.
 4. Psychology: Skype appointments and development of pre-admission plans.
 5. CF nurse specialists: active bed management.
 6. Active support of families administering home intravenous (IV) antibiotics.
 7. Dietetics: development of risk matrix for malnutrition.
 8. Pharmacy: self-administration of oral medication for inpatients, encouraging adherence and education.

Key recommendations

1. Inpatient access:
 - a. Access to inpatient beds in a timely fashion – this was highlighted in the last peer review and was again highlighted by the network clinics. These pressures are likely to worsen in 2016, as some of the network clinics struggle to achieve recommended standards for inpatient care.
 - b. Improved facilities to meet infection control requirements, particularly in inpatient accommodation (cubicles with en suite bathrooms). Currently derogated, there need to be clear and detailed plans to urgently increase the number of available cubicles and a memorandum of understanding to detail longer term plans.
2. Shared care arrangements/service level agreements need urgent review:
 - a. There are too many shared care clinics to ensure sustainability of the current network model. It is likely that the rationalisation of clinics will place greater pressures on the inpatient provision at RBH.

- b. Tariff split and service level agreements need transparency for a clear understanding of the service delivery expectations.
 - c. There is a need for a strategic review of the geographical catchment areas and overlap with other paediatric CF centres in London to ensure that there are clear network structures and equity of provision and access for children with CF.
 - d. There is a need to build on the annual study day to include a forum for two-way communication across the network between the centre and the clinics.
 - e. Services for inpatients are excellent, but provision for those not admitted to RBH is variable and often absent, eg psychology, social work (see below).
3. Options for providing CF services on other sites, such as at Chelsea and Westminster Hospital NHS Foundation Trust, should be explored to free up capacity for CF care on the Brompton site. Where CF patients need to be seen on other sites (for the treatment of related or unrelated co-morbidities), appropriate processes and facilities must be in place to prevent cross-infection.

Areas for further consideration

1. New diagnoses via newborn screening: shared care hospitals need to be involved at an earlier stage to engender a better rapport with the local team.
2. Transition: involve the local teams to improve the process.
3. Allied Health Professional (AHP) prescribing.
4. A dedicated CF social worker to work with those not admitted as inpatients would release other staff to carry out their own roles. Currently two of the nurses have responsibility for safeguarding.
5. Psychology: to provide support to outpatients at shared care clinics.
6. Pharmacy: an increase in capacity to deal with the high-cost drugs (HCDs) and, given the complexity of many of the patients, to participate in annual review.
7. CF Registry: to be split by shared care clinics to enable review of outcomes in more detail.

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

Models of care

Summary

This large paediatric network has many features of an excellent shared care network, with patients being seen twice a year by the centre team and once a year for annual review. There is, however, a large variation in the set-up of the shared care clinics, with some looking after a small number of patients, some also sharing care with other CF centres. There is variation in the service provision, cross-cover arrangements, and members of the multidisciplinary team available.

The service level agreements and service delivery expectations need further work to ensure transparency and mutual understanding of expectations.

Multidisciplinary care

Summary

The CF centre is relatively well staffed, with staffing improving significantly since the last peer review. Some patients do not see a consultant in 50% of their clinic visits. However, there are some disciplines which require further resources. These include availability of a pharmacist in clinic, social work support for patients who are not inpatients, and psychology provision to shared care patients. Succession planning appears to be in place and there is good access to ongoing professional development.

Principles of care

Summary

The principles of care are of a very high standard. The major issue is the availability of beds, particularly single rooms with en suite, and this limits the proportion of patients admitted within acceptable time limits.

Delivery of care

Summary

Most aspects of the delivery of care meet the criteria set in the risk matrix. There is lack of availability of pharmacy in outpatient clinics and of social work support for outpatients. Optimal delivery of care for inpatients is affected by the lack of rapid access to wards.

Commissioning

Summary

The RBH has a very experienced CF team, which demonstrates that it provides excellent clinical care, including a well-established home care programme, alongside a strong academic/research programme. The service is clearly valued by the patients and parents who use it.

The two areas that require highlighting remain the same as those which were raised in the 2010 peer review and these are:

- Inpatient facilities.
- The number of shared care hospitals.

Although bed management processes have been strengthened, waiting times for inpatient admissions remain a concern and not all patients are able to be admitted to single en suite cubicles. The service is very aware of the challenges facing them and the trust is mitigating this in the short term by making another cubicle available. However, with long-term development plans currently on hold, the Hospital Trust needs to investigate alternative options such as smaller building projects or further exploring the potential for working with Chelsea and Westminster Hospital as per the Memorandum of Understanding which is in place.

The service is large and complex with an unusually large number of shared care hospitals, plus additional associate hospitals. The shared care hospitals are geographically dispersed across Sussex, Surrey, South West London, North London and Essex, and the number of patients at each varies widely. Shared care hospitals undertake differing levels of care depending on the numbers and experience/expertise of staff (for example, some accept CF patients as inpatients, ie for IV antibiotics, but some do not), but the preference appears to be for overall central control.

The number of shared care hospitals should be streamlined (depending on the age of the patients, it may be possible to link this in with transition to minimise the impact on families). Some of the centres feel they have the skills and capacity to take on more work and have identified the lack of new patients and falling numbers as a threat. Through both the tariff and the existing good relationships, the service should consider supporting these services to develop. Strengthening these relationships should benefit both sides by relieving the pressure on the RBH inpatient service and both improving and ensuring the sustainability of local services.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	312
-------------------	--	-----

			Male	Female
FEV ₁	Number of patients and % with FEV ₁ <85% by age group and sex	0–3 years	0	0
		4–7 years	4 (8%)	1 (2%)
		8–11 years	10 (21%)	12 (27%)
		12–15 years	22 (46%)	23 (52%)
		16+ years	12 (25%)	8 (18%)

Body mass index (BMI)	Patients with a BMI percentile <10 centile on supplementary feeding	n = 24; 10 (42%)
------------------------------	---	------------------

<i>Pseudomonas aeruginosa</i> (PA) Chronic PA is 3+ isolates between two annual data sets	Number and % of patients with chronic PA infection	23 (7%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	20 (87%); live registry data 2015 – 100%

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	12 (52%)
	Number and % of patients on chronic macrolide without chronic PA infection	68 (24%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

The paediatric CF service is co-located with a large adult CF centre. It provides almost comprehensive CF care, although some allied services are provided by Chelsea and Westminster Hospital and Great Ormond Street Hospital (GOSH). Patients are cared for here from diagnosis until transition to adult services. Shared care is initiated with local hospitals either if the patient was seen at a local centre at diagnosis or if they live a distance away from the centre and are willing to be seen locally.

Outpatient clinics are run twice a week with alternate monthly MRSA and cepacia clinics. Two consultants and two registrars are present at each clinic, and four shared care consultants attend the clinic at the centre on a fortnightly basis. There are nine outpatient rooms with two waves of patients. Owing to the number of patients, some patients attend for their annual reviews at the outpatient clinic, whilst others attend a stand-alone annual assessment clinic. Specialist clinics include monthly cystic fibrosis related diabetes (CFRD) clinics.

Inpatients are admitted mainly to the paediatric ward, although babies recently diagnosed with CF are admitted to a separate ward area. This is solely for the education day or two that is held a week after diagnosis with the family; other than that, all admissions are to the single respiratory ward. There are nine cubicles, some with en suite facilities. Some patients are cared for in a bay area, although this is limited to one CF or non-CF bronchiectasis patient at a time. There is a hospital school with excellent arrangements to avoid cross-infection (glass partitions). There are no specific adolescent facilities. There is sometimes a delay in patients being admitted while waiting for an appropriate bed to become available.

The RBH is well staffed by experienced and well-qualified consultants, although only three cover inpatients. They are supported by specialist registrars and fellows.

Strengths include extensive clinical experience; clinical innovation; the development and regular updating of guidelines, which are used across the network and beyond; links with the adult service; academic activity and the training of paediatricians who go on to work in other parts of the UK and beyond.

Weaknesses in the service include insufficient inpatient facilities; insufficient pharmacy capacity; lack of a social worker; and variable shared care arrangements and busy outpatient clinics, which can affect continuity of care.

Opportunities include planned developments at RBH, which may help inpatient waits, and use of tariff to fund developments.

Threats include trust developments; financial pressures on NHS England; and increased pressures on the already insufficient inpatient facilities.

Network

1. East Surrey and Crawley

Number of patients cared for = 18 (10+8).

One clinician, who reports insufficient job plan sessions, but manages to find the time to cover the work. They receive excellent support from the Brompton team and find the RBH clinical guidelines very useful.

Service provision

Better since specialised commissioning (funding is transparent) and appointment of one whole time equivalent (WTE) CF clinical nurse specialist (CNS) over both sites.

Outpatient care

Joint clinics with the RBH MDT. Recent change in clinic structure to individual rooms.

Inpatient care

Planned admissions, so clinician is around when patients are in. Some cross-cover from Epsom/St Helier.

Ongoing professional development

Ongoing CPD by attending clinic twice a month at RBH, regular attendance at national/regional meetings.

Good practice points

Developing a local team with local guidelines.

Main issues

- a. Lack of play facilities/school for inpatients.
- b. Supply of HCDs (from centre).

Areas for development

Keen to develop shared SOP with the centre.

2. Chichester and Worthing

Number of patients cared for = 22 (11+11).

Service provision

One clinician (one PA), but cross-cover with second clinician at other site (0.5 PAs).

One nurse across the two sites, who is leaving.

Outpatient care

Joint clinics with RBH team; very positive about the clinician who visits from RBH.

Inpatient care

Admissions are planned as much as possible.

No formal cross-cover arrangements exist, but there is nurse cover or else escalation to RBH (using the RBH guidelines).

Ongoing professional development

Gets CPD, including annual Brompton meeting and Royal Society of Medicine (RSM), but difficult to fit in with other clinical areas, which also need to be kept up to date.

Good practice points

Investigations are done locally and sent to RBH; a new innovation summary letter, which has been adopted.

Main issues

- a. Lack of transparency/engagement regarding commissioning/SLA.
- b. Annual review process at RBH.
- c. Access to RBH.
- d. Some patients moving to other local clinics (geography).

Areas for development

More robust cross-cover arrangements; increase the MDT workforce across both sites (commensurate with combined patient numbers).

Equity in job plans across both sites.

3. Barnet and Chase Farm

Number of patients cared for = 10.

Problems with engagement with this clinic; clinician not contacted – see risk matrix.

4. Southend

Number of patients cared for = 25.

Service provision

One clinician (one PA), recently taken over from someone who was there for many years.

No risk matrix submitted as “no admin support”.

Good MDT support; use of the RBH guidelines.

Outpatient care

MDT outpatient clinics once a month.

Inpatient care

Inpatients are not seen regularly by CF clinician, who may have 1–2 at a time.

Ongoing professional development

New clinician recognises the need for training in CF and is in the process of receiving this.

Good practice points

Asks RBH for queries.

Main issues

- a. SLA/understanding of funding including CPD budget.
- b. Lack of CF experience.

Areas for development

Better cover for inpatients; professional development of new consultant with appropriate job planning; consideration of geographical distance from the centre (London-wide review).

5. Whipps Cross, Maria O'Callaghan (written feedback)

Number of patients cared for =10.

Service provision

One clinician (no dedicated CF PAs).

Lack of MDT.

Outpatient care

Joint MDT clinics.

Inpatient care

Good cover by non-CF colleagues and from RBH.

Ongoing professional development

Not possible as study leave not allowed.

Good practice points

Good inpatient care with school.

Patients not aware of threat to local service.

Main issues

- a. Uncertainty about the affiliations with tertiary centres across London.
- b. Lack of MDT.

Areas for development

Succession planning.

The Royal London does not do outreach clinics.

6. East and North Hertfordshire NHS Trust, Dr Kavita Chawla

Number of patients cared for = 12–13 (8+2+2).

Eight patients cared for by RBH, two by GOSH and two by Cambridge; as only RBH visits, all patients seen by RBH, but then some attend GOSH or Cambridge for their annual assessment.

Service provision

One clinician with no dedicated time and no cross-cover.

Community nurse for CF, who supports IV antibiotics. There is physiotherapy for inpatients, but there is no outpatient physiotherapy or dietetic support.

Outpatient care

Joint clinics with RBH team at Queen Elizabeth II (QEII) Hospital in Welwyn Garden City (insufficient clinic rooms at Lister Hospital). Very positive about the team that visits from RBH.

Inpatient care

Admissions to Lister Hospital. Physiotherapist for inpatients Monday–Friday, on-call service only at weekends, so is rarely done. There is a general paediatric dietitian for inpatient care.

Ongoing professional development

Gets CPD (including annual Brompton meeting and RSM), but difficult for non-dedicated MDT to do so.

Good practice points

Good support for home IV antibiotics.

Main issues

- a. Split sites for RBH joint outpatient clinics and inpatient services.
- b. Clinician has no formal time at present and needs more protected CF time.
- c. There is no community physiotherapy or dietetic support.
- d. There is no administrative support.
- e. There is inequity of care dependent on which is the lead centre for individual patients.

Areas for development

Increase the MDT workforce and concentrate shared care with a single centre.

7. St Peter's Hospital, Chertsey, Dr Diab Haddad

Number of patients cared for = 12.

Service provision

One clinician session per month is given over to CF, but the workload is probably half a PA per week. One respiratory nurse (who also covers allergy), one paediatric physiotherapist and one paediatric dietitian, all of whom have one session per month for the CF service.

Outpatient care

Joint clinics with full RBH MDT.

Inpatient care

A mixture of home and hospital IVs is offered, with approximately two-thirds of IVs being performed in hospital. Inpatients receive physiotherapy twice daily Monday–Friday, with varied cover at the weekend. There is a home nursing team for home IVs Monday–Friday, but there is no home nursing at the weekends. There is close supervision of home IVs from the home nursing team at RBH.

Ongoing professional development

CPD is available, including annual Brompton meeting and RSM.

Good practice points

Home nursing support for IV antibiotics.

Main issues

- a. There is no consultant cross-cover.
- b. Increase in respiratory nurse provision is needed.
- c. Psychology provision is needed.
- d. Information sharing with RBH could be improved.
- e. Potential for closer working with the Royal Surrey Hospital in Guildford.

Areas for development

Consultant cross-cover and psychology support.

8. Epsom Hospital, Dr Ruth Charlton

Number of patients cared for = 18.

Service provision

Clinician has two PAs per week for CF care and has an honorary consultant contract at the RBH. Cross-covers with St Helier's service. There is a CF nurse who also cross-covers with St Helier and a physiotherapist who has CF in the job plan. Dietetic cover is generic paediatric dietetics.

Outpatient care

Joint clinics with full RBH MDT.

Inpatient care

IV antibiotics are conducted in hospital as the default. Physiotherapy is offered for three sessions a week Monday–Friday, with one dedicated session at the weekend. There is nursing and dietetic support.

Ongoing professional development

Whole team attends annual Brompton meeting and RSM.

Good practice points

Consultant cross-cover between Epsom and St Helier.

Weekend physiotherapy provision.

Main issues

- Dedicated dietitian time needed for CF.
- Increase in physiotherapy provision needed from once daily to twice daily at the weekends.
- Paucity of psychology input apart from when seen at RBH.

Areas for development

Development of closer MDT links with RBH.

9. Frimley Park Hospital, Dr Clare Betteridge

Number of patients cared for = 19, of whom one has care from another centre and two have full care from RBH.

Service provision

Centre not contacted, but a high-quality comprehensive audit of service is in the risk matrix.

10. St Helier Hospital, Dr Anne-Marie Ebdon

Number of patients cared for = 20 shared care, plus 2 receive full care at RBH.

Service provision

Anne-Marie is a locum covering maternity leave. The post holder has a 0.2 WTE commitment to CF. There is a nurse split between St Helier (0.6 WTE) and Epsom, a 0.4 WTE dietitian during term time only and a 0.4 WTE physiotherapist, and two sessions a week of psychology time for CF. All members of the MDT have CF included in their job plans. There is cross-cover between the St Helier and Epsom consultants. Anne-Marie performs a clinic at the RBH every month.

Outpatient care

Joint clinics with full RBH MDT.

Inpatient care

All IV antibiotics are performed in hospital, with seven-day physiotherapy provision. There are regular consultant and dietetic reviews.

Ongoing professional development

Whole team attends annual RBH meeting and RSM.

Good practice points

Consultant cross-cover between Epsom and St Helier.

Shared care visits work well with a breakfast club for a pre-clinic meeting where all members of the local and RBH MDT discuss all patients.

Main issues

- a. St Helier was previously recognised as a CF centre, and there is still the feeling that this has been taken away.

Areas for development

Development of closer MDT links with RBH.

11. Hillingdon Hospital, Dr Stephen Goldring

Number of patients cared for = 18.

Service provision

The local MDT has only been finalised recently. There is a single-handed clinician with one session per week for CF, with another clinician to cover leave (although they have limited CF experience). There is a 0.5 WTE CF nurse specialist. Dietetic support is always available charged on time, but physiotherapy provision is still being finalised.

Outpatient care

Joint clinics with full RBH MDT: the clinic is an all-day clinic with a mixture of CF and Primary Ciliary Dyskinesia (PCD).

Inpatient care

All IV antibiotics are administered as inpatients. They have regular consultant review, have twice-daily physiotherapy performed seven days a week and will see a dietitian twice a week.

Ongoing professional development

No barriers to the MDT attending meetings.

Good practice points

Good support from RBH MDT.

Main issues

- a. Would like improved communication with RBH with remote access to correspondence.
- b. Very good service from RBH.

Areas for development

Physiotherapy service.

12. Watford General Hospital, Dr Amanda Equi

Number of patients cared for = 33; 28 receive care from the RBH and five from GOSH.

Service provision

Single-handed clinician with a respiratory interest in a 1:10 general on-call; allowed to do as much CF as necessary. There is no one dedicated nurse; there is a combination of link nurses and community nurses. There is a 0.4 WTE Band 7 physiotherapist and 1.0 WTE Band 5 physiotherapist, whose responsibilities are mostly CF. There is a 1.0 WTE dietitian, who sees as much CF as necessary and sees outpatients and inpatients. A CF pharmacist attends the CF MDT meetings and sees all inpatients. There is a CF ward round twice a week and a CF MDT meeting once a week.

Outpatient care

Joint clinics with full RBH MDT. All-day clinics are performed with respiratory in the morning and CF in the afternoon. In total, there are 13 CF clinics per year.

Inpatient care

Approximately 80% of IVs are in hospital with 20% at home, with the IVs being delivered for home IVs from the ward. Inpatients are seen by physiotherapists three times a day, comprising two physiotherapy sessions and an exercise session, and even at weekends there are at least two dedicated physiotherapy sessions per patient. There are strong pathways with community nurses and good communication between the specialist nurses and local team.

Ongoing professional development

Whole team attends annual Brompton meeting.

Good practice points

Weekend physiotherapy provision.

Communication between the RBH specialist nurses and local team.

Main issues

- a. Lack of dedicated nurse specialist for cystic fibrosis.
- b. Single-handed clinician with no cross-cover.
- c. Decrease in tariff from 60% to 55% has adversely affected the service.
- d. Difficulty in admitting patients to RBH.

Areas for development

Cross-cover for single-handed clinician.

Specialist nursing

Overview

- Patient numbers: 339.
- Clinics: Monday and Friday pm, 18 patients per clinic, two nurses in clinic, two ad hoc emergency review slots, annual assessments, two nurse-led AR slots.
- Wards: one paediatric ward with nine cubicles, some of which have a communal bathroom, sometimes in bay.
- Nurses have a direct telephone number, two bleeps and mobiles for patients to contact nursing team.
- MDT meetings pre and post clinic to plan care and admissions. Good planning of Oesophageal Patients Association (OPA), use of templates and pre-clinic summary sheets.

Staffing levels

CF CNSs: 4.5 WTE LOG, all Band 7

- Stable team, very experienced, well educated, keep up to date.
- No nurse prescribers, but would like to do it in the future.
- May 2014 review of nursing services rota: 3/52 home care, 1/52 Brompton clinic and ward.
- Key Worker. Each CF CNS assigned to a shared care clinic.
- Started key nurse for shared care clinics 18 months ago and allocated patients geographically.

Areas of good practice

- Experienced staff/highly motivated.
- Annual shared care study day.
- NBS two-day training programme.
- Transition: own YouTube DVD.
- Parents evening.
- AR good, but recognize need to develop further.
- Webcam to school; glass partitions in school so more than one young person can attend at a time.
- Exercise therapist.
- Family liaison worker.
- Home monitoring/review of those patients awaiting admission.

Areas for improvement/development

- No social worker on team, which impacts on nurses' workload and is not the best service for patients. Appointing a social worker would free up nursing time to enable the nursing team to develop nurse-led services and improve the shared care.
- Facilities and access to beds are the biggest issues for patients. Patients do share bathrooms at times.
- Possible redevelopment of echo room into a cubicle should help this.
- Consider improving and standardising care across shared care network to better utilise beds at other hospitals to reduce pressure on Brompton beds.

Recommendations

- Be innovative in employing a social worker, use of CF tariff.
- Development of nurse prescribing and nurse-led services.
- Develop shared care links, bigger shared care clinics to have a named CF nurse to lead the nursing service in that area, develop shared nursing guidelines.
- More administrative support to free up nursing time.

Other comments specific to shared care themes

- All praised RBH communication and annual study day.
- Resilience required maintaining CF nursing roles at shared care clinics.
- Strategic plan required to develop equitable nursing service across the network.
- Shared nursing guidelines and standards need to be developed across the network.
- When services established NBS babies could then be cared for more locally with confidence at an earlier stage and local beds could be utilised for admissions.

Barnet and Chase Farm

- No respiratory nurse in post (clinics managed by senior staff nurse in outpatient department).
- Clinic nurse is able to attend study days.
- Funding is not an issue.
- Negotiate funding for a paediatric respiratory nurse.
- Organise an MDT feedback meeting.

East Surrey

- Excellent shared care.

Epsom and St Helier

- The paediatric respiratory and endocrine nurse contracted hours are 37.5 per week (1 WTE) and she is employed under Homecare nursing. Out of the 37.5 hours per week, 25.0 are allocated to Respiratory (0.6 WTE) and 12.5 hours are allocated to her endocrine job (0.3 WTE).
- CPD up to date (including spending a week at the RBH).
- Exempt from clinical shifts.
- To be allocated more hours for her respiratory post.
- To be more involved with the Newborn Screening Programme.

Hillingdon

- The paediatric respiratory and allergy nurse contracted hours are 30 hours per week (0.8 WTE).
- CPD up to date (funding for study leave is not an issue).
- Independent nurse prescriber.
- Exempt from clinical shifts.
- Management is aware of the need for succession planning.
- To be more involved with the Newborn Screening Programme and accompany the nurse/physiotherapist from the tertiary centre at home visits following the diagnosis of a new patient.
- Liaise more closely with the GP.

Southend

- A community nurse supports patients' needs to be formalised into a CF nurse role.

St Peter's

- An experienced respiratory nurse.
- Need to build in resilience to maintain this as a CF nurse role.
- Study leave has been difficult and would value social work support.
- Experienced nurse new in post; develop this post further into a CF nurse role.

St Richard's and Worthing

- One WTE Respiratory Nurse Specialist (Band 7).
- One Band 6, who is contracted for 15 hours a week.
- Both members of the cystic fibrosis nurse specialist (CFNS) group and have completed the Management and Care of Children and Adults with CF.
- Objectives met for 2014.
- Funding is not an issue.
- Exempt from clinical shifts.
- Management are aware of the importance of succession planning.
- Parent support meetings have been organised and a newsletter is published three times a year.
- To continue running a progressive dynamic service. To think of ways to ensure operational services run more efficiently.

Watford

- No paediatric respiratory nurse.
- Ward senior staff nurse provides a service for the patients.
- The community nurses have their own caseloads and look after the CF patients in the community.
- Staff can access funding for study leave.
- No succession planning in place.

Frimley Park

- Does not at present have a CFNS, however they do require one.

Physiotherapy

Staffing

- All of the physiotherapists are enthusiastic and dedicated to providing a high level of service. RBH has adequate staffing, although currently has a Band 6 vacancy. RBH has an experienced and dedicated home care team who are flexible and accommodating of home visits. The Band 4 assistant is currently shared with Occupational Therapy (OT).
- Staffing in the shared care centres is variable, with some physiotherapists having to cover CF clinics, general wards and neonatal intensive-care unit (NICU) with insufficient staffing levels. Not all shared care centres have a named physiotherapist.

Inpatients

- All patients have access to twice-daily physiotherapy during the week at the RBH. Weekends and on-call are covered and, with planned changes to working practice, the number of physiotherapy staff working at the weekend in the RBH will improve (since the peer review, the situation has changed; whilst weekend physiotherapy provision for the whole hospital increased from five to seven, this was unsustainable due to vacancies in the department and is now six. This equates to 1.6 WTE physio for paediatrics at weekends. This is of concern). Weekend cover in the shared care centres is often covered by adult teams.
- Exercise sessions are problematic for all centres, with limited access to gyms or staffing. The RBH is looking at novel ways to address this by working with the local authority sports centres.

Clinics

- RBH clinics are well covered, however shared care clinics have variable cover from the local physiotherapists.
- A sputum induction clinic has been set up at the RBH by the physiotherapy service.

Newborn screening

- All families are seen at the RBH, with follow-up in the community by the RBH homecare team. Transfer to the local team is variable with some shared care physiotherapists reporting that they are unaware of new diagnoses until they transfer.

Transition and annual review

- Both are done at the RBH with no input from the shared care teams.

CPD

- RBH staff are members of Association of Chartered Physiotherapists in CF (ACPCF) along with some of the shared care physiotherapists. The RBH-run study days are well attended and the local teams report this to be excellent and valuable to their CPD. The RBH team has attended and presented at both European and North American Cystic Fibrosis Conference (NACF) conferences.

Areas of good practice:

- There is a cohesive MDT at the RBH that communicates well.
- Shared care physiotherapists feel they are well supported by the RBH with easy access to advice.
- The RBH study day is well supported by shared care teams, which view this as an excellent way to do CPD.
- Equipment budget is identified within the tariff, although shared care may benefit from holding a small stock.

Areas for improvement:

- Lack of physiotherapy prescribers needs to be addressed.
- Increased access to gym facilities – currently being addressed. Utilising the local sports centre facilities. There is no on-site gym, which would be very useful.
- Named physiotherapists should be available in all shared care centres.
- Increased verbal communication, rather than relying on paper communication.

Recommendations:

- Increase hours of 0.5 Band 4 assistant to full time, which would improve capacity to accommodate exercise sessions.
- Rotational Band 6 physiotherapist to work between inpatients, home care and providing further support for shared care.
- Physiotherapist prescriber.
- The physiotherapist at Frimley Park Hospital is on maternity leave, therefore physiotherapy cover is ad hoc; this should be addressed.

Dietetics

Staffing

- Adequate staffing at RBH with 2 WTE (although currently a vacancy, it is being filled).
- Variable staffing across shared care centres, and four clinics have no dietetic support.
- Cover for annual leave is variable with the majority unable to cover clinics during leave.

Experience and CPD

- The dietitians were without exception enthusiastic and seemed dedicated to the service.
- Not all are members of UK Dietitians' Cystic Fibrosis Interest Group (UKDCFIG), although all have had access to CPD, in the form of the RBH study day, which was valued by all. Some dietitians have attended UKDCFIG meetings, national meetings and the RBH team has attended European and NACF conferences.
- Dietetic experience varied from one to twenty years.

Inpatients and inpatient food provision

- All inpatients were reviewed at least twice weekly and more often if necessary. Food provision was good at all centres, including access to children's menus and snacks. RBH and Frimley Park commented specifically on the quality of their food, cooked from fresh.

Annual review

- Carried out by the RBH team, as is transition, apart from some patients transitioning via Frimley Park. Dietitians attend transition at both of these units.

MDT meeting and ward round

- Attendance is variable.

Audit and research

- All are willing, however audit has only taken place for dietetics at RBH.

Areas of good practice:

- Excellent attendance and value put on RBH study day, enabling all to receive CPD.
- Communication between centres and enthusiasm of individuals.
- All shared care dietitians using centre protocols.
- Audit, CPD and staffing at RBH excellent.
- Good dietetic teaching resources for families at RBH.
- Food provision good across network, excellent at RBH and Frimley Park.

Areas for improvement:

- Care is currently very centre focused and, with resourcing, the shared care clinic dietitians could provide an excellent resource for families local to their homes and accessible between clinic visits if necessary.
- Inadequate staffing: no cover in some clinics, and low levels of annual leave cover in shared care clinics.
- Lack of engagement in the network by some dietetic departments, with a lack of awareness of BMI and outcomes for their clinic.
- Difficulty in ring-fencing staffing and maintaining expertise in very small clinics.
- Not all dietitians are members of UKDCFIG.
- Audit is done only at Brompton.

Recommendations:

- The shared care clinics have variable dietetic input, with no cover in some centres, and no cover for annual leave in many.
Although the RBH dietetic team attends shared care clinics regularly, there should be adequate provision locally, such that families could access dietetic support from their shared care clinic between clinic attendances.
- Local dietetic support should be available, relative to the clinic size, in all shared care clinics; however, the small WTE required for the very small clinics may mean that it is not a viable option to identify an individual with time ring-fenced in their job plan, with sufficient time for CPD and the development of specialist knowledge for each clinic.
In this case, consideration should be given to pooling resources between two or more local shared care clinics, to make a sustainable local part-time post, with a second individual trained to provide cover for annual leave.
- A network-wide audit would enhance collaboration and increase awareness of outcomes in the shared care clinics.

Pharmacy

Brompton

Pharmacist input to care of paediatric CF patients at RBH is provided by a team of pharmacists led by two experienced lead paediatric pharmacists (1 WTE). Support is provided by a Band 8a specialist paediatric pharmacist, Band 7 paediatric pharmacist and rotational Band 6 pharmacist. The team covers all paediatric inpatient beds at RBH and inputs to the department's general on-call and weekend working.

There are 339 (200 shared care) patients under the RBH CF service, with currently 0.7 WTE designated pharmacist time at RBH. The CF Trust 'Standards of Care (2011)' quotes one WTE per 150 patients; therefore, with 22% timeout allowance, there is a CF total pharmacist time shortfall of 2 WTE. This shortfall may not all be at RBH, depending on the requirements at the larger shared care clinics. This figure might not also capture the additional workload to pharmacy that the repatriation of high-cost therapies will bring.

Areas of good practice:

- Paediatric pharmacists who are integrated within CF MDT.
- Experienced pharmacist involved in the preparation of the RBH CF guidelines, which are fundamental for specialist and shared care clinic prescribing.
- Implementation of self-administration of medications policy for CF inpatients on the ward.

Areas for improvement/development:

- Increase involvement with outpatients through attending outpatient CF MDT meetings.
- Attend annual reviews and perform medicine reviews for all RBH and shared care hospital patients as part of MDT, as per CF pharmacist 'Standards of Care (2011)'.

Recommendations:

- Increase clinical pharmacist time to meet the CF Trust's Standards of Care staffing recommendations to enable pharmacist attendance at annual reviews, further input in outpatient clinics and develop pharmacist links in shared care clinics.
- Invest in specialist pharmacist prescriber(s) to assist with the prescribing burden that repatriation of HCDs will bring.
- Agree a plan for repatriation within centre and shared care hospitals. In particular, clarity is required on pathway at shared care hospitals, which share care for patients with other local CF specialist centres. Ensure accurate assessment and appointment of appropriate staff within pharmacy to manage the prescribing, administration and clinical pharmacist review of HCDs for CF patients.

Shared care clinic

There is a variety of input from varying grades of pharmacist in the shared care hospitals with no specialist CF pharmacist input in outpatient clinics. All CF inpatients at a shared care hospital receive basic clinical pharmacist review, Monday to Friday.

Areas of good practice:

- Enthusiastic clinical pharmacists in many shared care hospitals. Good links with local CF MDT team at Watford, St Richard's and Worthing, East Surrey, Frimley Park, St Helier and Lister.

Area for improvement/development:

- Increase communication across network with shared care patients to ensure equity for pharmacy provision particularly with HCDs and access to pre-made IV antibiotics for home administration.

Recommendations:

- All pharmacists involved with CF patients to be a member of the UK Cystic Fibrosis Pharmacist Group (CFPG).
- Ensure support in all shared care centres to general pharmacists working with CF patients to ensure access to colleagues for support, particularly if junior (below Band 7).

Psychology

Areas of good practice:

Psychology at RBH

Since the last review, the clinical psychology team at the RBH has worked hard to restructure its service and increase the amount of psychology time. Increased dedicated psychology time has allowed RBH clinical psychologists (CPs) to provide input into annual reviews for all RBH CF patients and to have an increased presence at RBH clinics and on the wards. The psychology service at RBH appears integral to the CF MDT and has a good presence on the ward. RBH CPs are able to attend 100% of inpatient and outpatient MDT discussions, they regularly provide teaching and training with the CF MDT and input into the newly-diagnosed education day. The RBH psychology team attends at least one UK Psychosocial Professions in CF (UKPP-CF) study day, regional meeting and CF international conference a year. CPs have involvement at key life stages for CF patients, such as diagnosis and transition. CPs support research in the MDT and undertook an audit of CP service users in outpatients in 2014.

Key areas of good practice that the panel were particularly struck by are:

- Psychology is instrumental in pre-admission plans for patients who require complex care (for instance, those with significant procedural distress or patients on the autistic spectrum) and this is greatly valued by ward staff.
- CPs offer video-conferencing for internet psychology sessions to try and mediate the long distances patients may need to travel and reduce hospital appointments.
- Before a patient is considered for a gastrostomy, a psychologist, dietitian and CF nurse have separate meetings to talk through eating issues for that patient and whether this is the right way forward for them.

Psychology at shared care (SC) clinics

Three SC clinics (Hillingdon, St Helier and East Crawley) have designated psychology time (0.1 WTE). However, there have been difficulties in recruiting to post in East Crawley. In the other SC hospitals, good links were described both ways between CPs and RBH psychologists. Due to limited time, the CPs in these SC clinics effectively use a stepped care model of service delivery, using consultation with the MDT and seeing patients on a referral basis. The CP at St Helier is currently seeing patients for AR, although RBH CPs still deliver a psychological screening tool at AR as well.

The majority of the SC clinics (both with and without designated psychology time) appear to have good liaison with RBH CPs, refer patients appropriately and value RBH psychology input, finding them very responsive. Between RBH and many of the SC clinics, there are opportunities to discuss issues whether because the SC team comes to clinics at RBH or by telephone.

Areas for improvement

There is a shortfall in psychology provision for RBH and the SC clinics (see below for details). Except for AR, current access to psychology is not equal across the RBH network and this needs to be taken into consideration related to where additional psychology time may be placed. There is currently no designated CP service at the following SC hospitals: Southend; Whipps Cross; Watford; St Richard's and Worthing; St Peter's; QEII; Frimley Park; Epsom; Barnet and Chase Farm. Psychological input is either covered by referrals to RBH or to local child and adolescent mental health services (CAMHS), the former may prove difficult for some patients to get to and the latter option might not be of use, as CF patients might not meet the cut-offs or, if they do, long waiting times are involved.

CP input for inpatients at shared care hospitals

While there might be opportunities for CPs to see patients if they are started on IVs at RBH and then go to SC or for those that need a mid-IVs review at RBH, there is little routine input by CPs for inpatients in SC clinics. At Southampton, St Helier and Hillingdon, CPs may see CF patients on the ward if they are referred.

CP input at clinic at SC hospitals

RBH CPs do not currently attend clinics at any of the SC hospitals. Referral to psychology in hospitals where there are no CPs is currently managed by the RBH CNS when they attend SC clinics with the rest of the MDT. The RBH psychology service has said that it would be happy to attend SC clinics if they have an uplift in psychology time, in the meantime it is looking into the possibility of attending clinics at Watford once access to a room for CPs has been established. Some SC clinics did not seem to be as forthcoming as others in terms of communicating with RBH CPs and referring patients.

Other than where there is dedicated time, some hospitals are lucky in that they have arrangements with local paediatric psychologists, who do not have dedicated CF time but, due to their goodwill, offer psychology input to CF patients (Southend, QEII, Watford). This is obviously a precarious arrangement that could change if individuals leave the service and/or local management questions this. Elsewhere, Barnet and Chase Farm has input from Liaison Psychiatry to a weekly MDT CF meeting, which is valuable although it should not be seen to replace the role of a specialist CP in CF. This means that involvement of CPs in patients' key life stage events, such as transitioning to adult care, in some instances is limited. Additionally, this raises some concerns over the CPD of general paediatric CPs who are inputting into CF at SC clinics. For instance, their general awareness of the UKPP-CF group and attendance at specialist CF meetings and/or CF conferences may be difficult due to limited hours.

Recommendations:

- While RBH psychologists do get to meet most families in the network once a year at AR, it was felt that improving access to psychology in SC clinics would be beneficial to allow preventative work with families, so that smaller issues can be dealt with before becoming crises. This might be achieved either by having a minimum attendance per year of the CP with the MDT at SC clinics where there is no CP or by introducing dedicated CF time at strategic SC clinics.

CP staffing compared with recommendations:

- Dedicated CP staffing at RBH and shared care clinics is 1.8 WTE (1.5 at RBH and three posts of 0.1 at three SC clinics).
- It should be 2.3 WTE (full care and shared); shortfall = 0.5 WTE.

As there are two psychologists at RBH, they can cover across the week at RBH, but there is no cover for absences. It is recognised that CPs at RBH spend a considerable amount of time dealing with social work issues and doing their own administrative tasks, which take them away from their primary role. Employing a social worker and having increased administrative support for CPs would mean using their time more efficiently.

Social work

Currently there is no social work provision that meets the Standards of Care requirements at the RBH or at any of the shared care clinics. One WTE qualified and experienced social worker is indicated.

Areas of good practice:

- The Family Liaison Service within the RBH works closely with the inpatients and has developed a robust support service in this context.
- The majority of the shared care clinics report having strong support from and good general communication with the RBH team.
- In the absence of a social worker, various arrangements are made to take on aspects of the role. There is access to the Safeguarding Children Advisor (employed by RBH), access to a Welfare Rights Team (again a hospital wide post at the RBH) and minimal support from a social worker employed by Royal Borough of Kensington and Chelsea (less than an hour a week). Some aspects of the role are undertaken by CF nurses and psychologists where they are available.

Areas for improvement:

- Availability of social work to outpatients at the RBH and the shared care clinics would bring improvements for the patients and the team.
- Patients should have the opportunity to build a relationship with a social worker. This would be of value in terms of prevention and normalising support, prior to any crises occurring. It would allow for home visits and annual assessment. In addition to direct input, social workers could signpost and liaise with local services. Specialist nurses and psychologists would be freed up from those aspects of the role that they currently cover and would be able to develop their roles within the service.
- Availability of both social work and psychology at shared care clinics would greatly improve the accessibility of the service. This is likely to be particularly the case for adolescents for whom less universal services will be available locally and for whom using centralised services will have an increased cost and time implication.

Recommendations:

- The appointment of one WTE social worker employed directly by the NHS Trust. Local authorities are now seldom involved in specialist social work provision and many trusts employ directly.
- The social worker should be a senior social worker with considerable experience. This is because of the range of areas covered within the role and the nature of being a single professional within a multidisciplinary team.
- The social worker would attend shared care clinics with the rest of the RBH team. This would allow equality of service provision to all patients and normalisation of support.

5. User feedback

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	9	8	15	3
Female	9	11	12	4

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	46	9	2	2
From the ward staff	28	10	4	0
From the hospital	35	14	5	1

Areas of excellence

1. Accessibility
2. Cleanliness – outpatients
3. Availability of team members

Areas for improvement

1. Admission and outpatient waiting times
2. Inpatients – food, ward facilities
3. Parking

6. Appendices

Appendix 1

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

Report and actual compliance below follows a Red, Amber, 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 all the Cystic Fibrosis Trust's Standards of Care with urgent action required

Hospital name

Royal Brompton 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%	Unknown	Unknown	

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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green	Green	
	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%	Amber	Amber	Actions in place to correct this.
	% 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%	Amber	Amber	Difficult to see how this will change given number of available beds.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Amber	Amber	Difficult to see how this will change given number of available beds.
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 CGMS done at AR	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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% 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%	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 at weekends	100%	Green	Green	
	% 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%	Green	Green	
	% availability of a clinical psychologist at clinic	100%	Green	Green	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red Available via telephone	Red	There is a need for social work input at specialist centre.
	% availability of a social worker for inpatients	100%	Red Available via telephone	Red	There is a need for specialist social work input at specialist centre.
	% availability of a pharmacist at clinic	100%	Red No time allocated to clinic	Red	There is a need for pharmacist input into annual assessments.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0.60%	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	39 incidents	Unclear	Difficult to be clear on CFT numerator and denominator.
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	

Appendix 2

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Royal Brompton Hospital
Consultant 1	0.5	1	1	1.9 WTE
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	3 WTE
Specialist nurse	2	3	4	4.8 WTE
Physiotherapist	2	3	4	4 WTE
Physiotherapist assistant				0.5 WTE
Dietitian	0.5	1	1.5	2 WTE
Clinical psychologist	0.5	1	1.5	1.6 WTE
Social worker	0.5	1	1	1 non CF SW allocated; available via telephone
Pharmacist	0.5	1	1	0.7 WTE
Secretary	0.5	1	2	1 WTE
Database coordinator	0.4	0.8	1	
Admin assistant				1 WTE

Appendix 3

UK CF Registry data

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

CF Registry data – 2013	
Demographics of centre – Royal Brompton Hospital	
Number of active patients registered (active being patients within the last two years)	319
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	312
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	60 (19%)
	4–7 years	70 (22%)
	8–11 years	66 (21%)
	12–15 years	86 (28%)
	16+ years	30 (10%)

Genetics	
Number of patients and % of unknown genetics	28 (9%); live registry data 2015: 3 (1%)

Body Mass Index (BMI) (ref: 1.13 Annual Data Report 2013)	
Patients with a BMI percentile <10th centile on supplementary feeding	n = 24; 10 (42%)

FEV ₁ (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Number of patients and % with FEV ₁ <85% by age group and sex	0–3 years	0	0
	4–7 years	4 (8%)	1 (2%)
	8–11 years	10 (21%)	12 (27%)
	12–15 years	22 (46%)	23 (52%)
	16+ years	12 (25%)	8 (18%)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic <i>Pseudomonas aeruginosa</i> (PA)		
Number of patients in each age group	0–3 years	60
	4–7 years	70
	8–11 years	66
	12–15 years	86
	16+ years	30
Number of patients with chronic PA by age group	0–3 years	1
	4–7 years	2
	8–11 years	3
	12–15 years	12
	16+ years	5
<i>Burkholderia cepacia</i> (BC)		
Number and % of total cohort with chronic infection with BC complex	5 (2%)	
Number and % of <i>cenocepacia</i>	1 (0.3%)	
Meticillin-resistant <i>staphylococcus aureus</i> (MRSA)		
Number and % of total cohort with chronic infection with MRSA	8 (3%)	
Non-tuberculous mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	10 (3%)	

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary <i>aspergillosis</i> (ABPA)	
Number and % total cohort identified in reporting year with ABPA	33 (11%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	23 (7%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	2 (0.5%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (0.3%) PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantation assessment in reporting year	3
Number of patients referred for transplantation assessment in previous three years	9
Number of patients receiving lung, liver, kidney transplants in previous three years	3

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	245
	4–7 years	552
	8–11 years	577
	12–15 years	1,141
	16+ years	325
Number of days of home IV therapy in reporting year split by age group	0–3 years	44
	4–7 years	167
	8–11 years	141
	12–15 years	478
	16+ years	98
Total number of IV days split by age group	0–3 years	289
	4–7 years	719
	8–11 years	718
	12–15 years	1,619
	16+ years	423

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	n = 208; 105 (51%)
If not on DNase % on hypertonic saline	9 (4%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	23 (7%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	20 (87%); live registry data 2015: 100%
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	12 (52%) with chronic PA; 68 (24%) without chronic PA

Appendix 4

Patient/parent survey

The survey return numbers are low due to a snapshot being sent out to 150 patients, including the network clinics.

Patient survey

Royal Brompton Hospital

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	9	8	15	3
Female	9	11	12	4

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	46	17	3	2
Communication	36	24	5	3
Out-of-hours access	29	12	9	2
Homecare/community	35	15	5	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	36	22	9	1
Waiting times	18	25	15	2
Cross-infection/segregation	28	28	10	3
Cleanliness	40	24	4	0
Annual review process	26	24	6	3
Transition	9	4	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	12	17	8	3
Cleanliness	12	21	4	6
Cross-infection/segregation	13	13	7	6
Food	8	19	6	7
Physiotherapy availability to assist/assess airway clearance and exercise during weekdays	26	11	1	2
Physiotherapy availability to assist/assess airway clearance and exercise during weekends	21	10	3	4

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	10	3	2	1
Availability of equipment	20	19	2	2
Car parking	3	6	3	26

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	46	9	2	2
Of the ward staff	28	10	4	0
Of the hospital	35	14	5	1

Comments about CF team/hospital

“Physiotherapy weekends – we did everything ourselves – no help from staff at all.”

“Rose ward has very few individual rooms with their own bathroom. I refused to let my daughter be admitted unless she had her own room and own bathroom, so we were fine. But it is not appropriate for kids to be on a ward together sharing a bathroom with other people. We had a specific issue with her bronchoscopy, when it was discovered after the operation that the bronchoscope was infected with a form of Pseudomonas. There is a cross-infection inquiry ongoing, but we have not been informed about the action. I think also that it should be easier to do home IVs; we managed to do it a bit, but the staff are not available to come and do it as much as we wanted.”

“We are really happy with the service we receive from the Brompton. Only a couple of minor issues: they could be a bit more proactive over when the dosage of drugs should change and maybe over parent training on how to use antibiotic (IVA) pumps.”

“Brompton is excellent, but there are not enough beds or inpatient facilities and, because we have a long journey with lots of equipment, we have to drive and parking is a big problem, even just for dropping off stuff on admission. Also they need more spaces – segregated spaces for day case visits (eg Amikacin levels, as I’m still doing IVs at the time I’m travelling and on the ward).”

“I have found them very helpful in answering my questions when I phone up or ask at clinic. The psychology service was particularly helpful in dealing with my daughter’s phobia regarding needles and hospital admissions. The school teachers were great when she was admitted.”

“The team does excellent work, but the hospital ward is old and the facilities team does not respond to requests to mend broken or faulty structures in a timely manner. This results in inadequate bathroom facilities. There are not enough to properly manage infection control and some bathrooms have leaks or faulty plumbing, which causes damp and mould.”

“From day one, the support care from everyone, including the receptionist staff at clinic, has been totally amazing. I cannot begin to image what we would do without our angels. Thank you all so very much.”

“Generally, we are very happy/impressed with the care given. In terms of potential areas of improvement: 1) Sometimes we have to wait for the clinic room to be available and segregation in the waiting room does not take place. Suggest that parents could receive a text when room is available and thus wait off-site. 2) There is a tendency among one or two healthcare professionals to address all comments queries to ‘Mum’ (in one particular case as though Dad wasn’t there); acknowledge both parents. 3) There are various toys in the waiting rooms used by the children and I am not sure how clean these are – are they an infection risk? 4) We do see quite a variety of clinicians. In principle this is OK, but sometimes I am not sure how up to speed they are on our daughter’s history/specific treatment requirements. 5) In the past, we have received reports on clinics (written) which are hard to decipher for the ‘lay person’ and this is potentially confusing/concerning if not explained (we have provided this feedback in the past).”

“I am very happy with my CF team, they are helpful and understand. I have never had a problem and I have always gotten the best care, service and support I have needed.”

“Very happy with everything Brompton have done. Very confident in care given.”

“The CF nurses offer a huge amount of support to both my daughter and myself. They are really great. The staff we meet at appointments are friendly, polite and explain everything they are doing to my daughter. Her experience on the ward is made as good as it can be considering she is going in to receive IVs.”

“We have only recently transitioned so our exposure to the adult team is limited – the ward is fabulous, and the staff arranging our outpatient visit. I have been disappointed by failure to return messages left with specialist nursing team.”

“The team are great, I feel very lucky to have them looking after us.”

“Not the CF team’s fault, but the waiting time to pick prescriptions up from the Brompton is at least 45 minutes, last time it was 1hr 15mins. Thankfully, the physio took it down for me, but this is a long time with small ones. Cross-infection risk also in waiting area for prescriptions.”

“Unfortunately, standards in the home care team have fallen since (home care nurse left in July). We are still awaiting clinic letters and annual review letters outstanding from March and September. Still trying to organise transition meeting with school and home care team, which has been ongoing since September. Rose ward is overcrowded and food is terrible, not enough facilities for ward. Hospital in disrepair, handles falling off doors, needing a serious facelift.”

“Great support from home care team, always there when we need to talk to them, especially the CF nurse and physiotherapist, as well as the dietitian. We talk to them the most. Luckily our daughter hasn’t been in inpatient care yet, so we don’t have an opinion on that.”

“At clinic, segregation is excellent, however there are occasions at annual assessment whereby you will sit in a waiting room of other patients waiting for tests, not knowing if they are CF or not.”

“CF team is great, outpatients and home care excellent, hospital rooms need updating, staff brilliant; don’t like shared bathrooms (on last admission, the shared bathroom was out of order for a week before we arrived, as the notice on the door was dated; we had to leave it to use the shared ward bathroom!). No kitchen facilities for parents to prepare food or a drink; two weeks’ stay is a long time with no facilities and no fridge in room, which would make a big difference. Schooling and physio services on ward are fantastic. Outpatients clinic is fantastic, just would be great if the consultants were more consistent, as they are different every time. Team is excellent, helpful and accommodating every time, giving full support; fantastic staff all round, giving great support and service 24/7.”

“We think the CF team at Brompton is excellent. You cannot fault any of them. They take their time to discuss anything with you and are very happy to advise you, as well as providing a very friendly and welcoming atmosphere.”

“Brompton seems to be focused on the unwell CF population, not so interested if the child is a little unwell.”

“We have had excellent care. Annual assessments have been a bit disorganised, but OK. We have been very fortunate that our son has only been admitted into hospital four times, as he keeps very well.”

“Only issue is having to chase results – cough swabs, etc. Easier point of contact is secretary or results line; would spare us having to bombard clinical staff like the nurses.”

“Overall, very happy with the team and all the services. Always willing to help, very good.”

“Overall, Brompton is very good.”

“Very professional. Always there when you have a question or need help.”

“The Brompton team is fantastic and provides the clinical care and hope that all families need.”

“Excellent support.”

“Great team, don’t know what I would do without them.”

Appendix 5

Patient/parent interviews

Royal Brompton Hospital Paediatric Centre and Network Peer Review Parent interviews, January 2015

Parent A

Parent A felt that outpatient segregation measures had improved over the years, adding that it works if a parent secures the first or early appointment, otherwise there is still some waiting in an open area at times at a clinic shared with cardiac patients. Parent A explained that toys are covered up for CF clinics.

Parent A arrives and is led with her child straight to one of ten consultation rooms. She explained that sometimes there is a shortage of consultants. She feels that hand hygiene and wiping down of equipment between patients is very thorough with 'disinfectant everywhere' and admits she's obsessive about this.

Parent A felt the CF team make decisions collaboratively with the parent regarding her child's treatment, adding that the team members always discuss matters and are 'very available'. Her child has an assigned nurse who covers a number of patients, giving an honest overview of the clinic situation, which Parent A feels is a major improvement. She is happy that the consultant talks to her child and then recaps with the mother.

Parent A explained that the CF MDT rotates between patients to further reduce the cross-infection risk, although the wait at pharmacy remains a concern for her at a chest hospital.

Inpatient care (ward):

Not applicable.

Annual review:

Parent A found it a long, stressful day, including what she termed 'a stupid, general questionnaire' to fill in. All her child's assessments take place on one day at the RBH. She questioned the timing of blood tests in the afternoon in relation to oral glucose tolerance testing, adding that morning blood tests are better so that her child can eat at normal times. Her child's annual review outcome used to be reported back in a letter, but Parent A now relies on the CNS to telephone her if there is any concern, or the parent phones the nurse, who is quick to respond to her emails.

Home care:

Parent A's child does not have home visits which the parent believes is due to being outside the M25 corridor.

Good practice:

"Assigned nurse – it's great!"

"Prof. Bush/Dr Davies' consultation."

"Consultations and feedback via email from consultants within 30 minutes – they're a pillar of strength."

"Level of commitment from MDT is wonderful."

Areas for improvement:

"Could improve outpatient clinic timings – staff to be on time."

"Too many trainees who don't know the patient – reduce their usage."

"Improve reporting back of annual review outcomes and the length of annual review day."

Parent B

Parent B felt segregation measures had improved in a busy outpatient clinic, but that there is potential for patient contact. Now she waits for the consultation room to be cleaned. She confirmed that staff clean their hands, but is unclear how the room air is cleaned.

Parent B feels that the CF MDT is amazing, adding that she feels more experienced consultants listen more and make decisions collaboratively with her and her child. She quoted her consultant's comment, "parents know best, what do you think?".

Parent B's child sees or has access to all of the CF MDT at clinic, although she is not aware of a social worker being in post. They have seen the clinical psychologist when on the ward, but not as an outpatient.

Inpatient care (ward):

Parent B explained that it is a problem to get a bed. Her child is regularly admitted to the only ward. Recently, she had waited for longer than a week after the bed was scheduled for her child and an urgent admission took one month to materialise.

Parent B's child will not eat the food on the ward, so the parents bring food in and the staff heat it up. Her child is on overnight feeds. She explained that cake is provided, as a snack, on the ward in the afternoon.

Physiotherapy is always provided, Parent B adds that an exercise bike is provided in her child's room and that the physios take the children outside for exercise.

Annual review:

Parent B's child is offered an annual review each year and has had this year's assessment, including a letter outlining the results. She felt that it would be better if feedback were provided at a dedicated appointment. She added that some assessments take place during the year whilst her child is admitted.

Home care:

Parent B's child has home care from Abbott for PEG feeding equipment, including good advice, in addition to an excellent dietitian at the Brompton Hospital and good diabetes support from Chelsea and Westminster Hospital. Parent B's child has mostly pre-mixed home IV antibiotics and inhaled antibiotics via a good BUPA service.

Good practice:

"Attitude of staff."

"Research put into practice."

Areas for improvement:

"Bed situation – improve the shortage of beds/admission waiting times."

"Update the old-looking ward."

"Improve schooling support on the adult unit, if there's any suggestion of earlier transition."

Parent C

Parent C's child attends the RBH and Queen Mary's Hospital for shared CF care. Her child attends RBH three times a year and for annual review. Her child's IV courses are provided at Queen Mary's Hospital, with diabetes care at St Helier's clinic.

Parent C felt that outpatient segregation at Queen Mary's Hospital was "OK". The waiting room is large; patients wait on the corridor or in the large waiting area to reduce cross-infection risk. She explained that there are two consultation rooms and only two patients in clinic at a time. Parent C sees good use of hand gels and wiping down of equipment between patient use at Queen Mary's Hospital paediatric clinic. They see all of the CF team at clinic, occasionally seeing a clinical psychologist, but always have access to one. Parent C feels that decision making on her child's treatments is collaborative. She felt that in some ways the care is better at Queen Mary's Hospital than at the RBH in terms of always seeing the same members of staff, although she added that the "Brompton is better for staff absence cover" and "it's very much segregated at the Brompton".

Inpatient care (ward):

Not applicable. Last admission four years ago.

Annual review:

Parent C's child is offered annual review each year at RBH and has attended this year's review. They see the whole CF MDT, feedback is provided on the day and a letter home sets out the annual review results.

Home care:

Parent C has access to the clinical nurse specialist at either the RBH or Queen Mary's Hospital. They have no home visits nowadays, but know that if unwell the clinical nurse specialist would see them, a named CNS from the RBH and Queen Mary's Hospital CF nurse.

One medication is provided by Healthcare at Home, a service which Parent C has described as "shambolic".

Good practice:

"A very personal service and keen interest in my child's care from Brompton and Queen Mary's hospitals."

"Access to huge amount of expertise, particularly at the Brompton Hospital – eg my son's CFRD."

"Opportunities to take part in clinical trials and the advantage of this."

Areas for improvement:

"More vulnerable to staff leaving and back-filling of posts at Queen Mary's Hospital – ie more staffing needed."

"Reduce expensive car parking charges or provide concessions at Queen Mary's Hospital – expensive when clinic overruns."

Parent D

Parent D explained that segregation at the RBH is “good when it works, unless clinics overrun”, which results in waiting in the corridor in the second clinic session. They see all of the MDT, although they haven’t encountered a social worker. They found the clinical psychologist very helpful when needed to support needle phobia.

Parent D felt that CF team decisions on her child are made collaboratively, adding that she puts her views forward in the joint decision process. She felt that there is good hand hygiene practised at clinic and sees equipment wiped down.

Inpatient care (ward):

Not applicable.

Annual review:

Parent D’s child is offered annual review each year and has had this year’s assessment. They see all of the MDT available at annual review, feedback is provided on the day, the parent is contacted if urgent matters arise and later receives a copy of the written report detailing outcomes. Parent D feels that communication from the CF team at the Brompton Hospital is good; the CNS answers her messages promptly.

Home care:

The CNS has made home visits for lung function testing and for taking cough swabs and to do mid-course lung function whilst child is on oral antibiotics.

Good practice:

“Feel like they (the Brompton CF team) have got a lot of expertise and know what they are talking about.”

“Team work well together.”

“Child friendly – eg the team’s handling of needle phobia.”

Areas for improvement:

“Reduce the waiting time at clinic. The wait at clinic is sometimes a long time.”

“Speed up prescription processing at pharmacy.”

Parent E

Parent E's child has shared CF care at both the RBH and St Richard's Hospital (Chichester), attending the RBH just for annual review. At St Richard's Hospital, they are directed straight into a clinic consultancy room and stay there throughout clinic. Parent E feels that the team always listen to her and her child, adding that she likes to know all the details about her child's health. She felt that they are rushed at annual review clinic at the RBH. The annual review appointment is followed by a letter home detailing the annual review outcome.

They see all members of the CF MDT at outpatient clinic and annual review, but Parent E was unsure if there is psychosocial support at either hospital. Parent E referred to a long wait at pharmacy at St Richard's Hospital, 45 minutes usually, but recently it was just 20 minutes. She felt that it seemed clean and sterile at the outpatient clinic at St Richard's Hospital, where "they always open new packaging and use hand gels".

Inpatient care (ward):

Not applicable.

Annual review:

Parent E's child is offered annual review each year and has had this year's assessment at the RBH. She receives a letter three months after annual review, outlining the assessment outcome, the last one notifying her of additional calcium supplement requirement. Parent E finds communication from her local CF team at St Richard's Hospital (the nurse especially) to be good. They regularly phone Parent E to see if her child is OK.

Home care:

None provided.

Good practice:

"Good communication from a friendly team at St Richard's Hospital."

Area for improvement:

"Provide greater notice of annual review appointment please."

"Improve communication between Royal Brompton and St Richard's Hospital, so that the message and advice is consistent."

Parent F

Parent F's child attends both RBH and Watford General Hospital. She felt that segregation measures at the outpatient clinic in Watford are absolutely fine and states that patients are isolated from one another. She sees all of the CF team at clinic and when the RBH team attends Watford. She occasionally feels that the team dictates treatment decisions to her and does not agree with continual use of nebulised anti-pseudomonal antibiotics, as she is concerned that her child will become resistant to them. She does not need to attend the hospital pharmacy, as prescriptions are processed through her local pharmacy and GP.

Inpatient care (ward):

Not applicable.

Annual review:

Parent F's child is offered annual review each year and has had this year's assessment, carried out in full on the same day at the RBH. They see all of the specialist CF MDT.

Home care:

Parent F explains she was assessed for her IV competence whilst her child was an inpatient, over two days. She mixes the IVs herself at home for her child. Antibiotic levels are checked either at home by the community nurse or sometimes the mother travels back to Watford General Hospital for levels to be checked.

Good practice:

"Main nursing and doctor team at Brompton and Watford hospitals remain the same."

"Fantastic staff at both Brompton and Watford who know when you've had enough."

Areas for improvement:

"Insufficient bed/nursing capacity for dated Watford General Hospital. Suggest that they re-open Hemel Hempstead hospital or provide an additional alternative."

Parent G

Parent G's child attends Royal Surrey Hospital and the RBH respectively for shared care. She attends Royal Surrey Hospital twice a year, the remainder of the care provided by the RBH.

Parent G felt that segregation measures at the outpatient clinic at the RBH are generally acceptable. They are put into a consultancy room on arrival, unless arriving too early. She felt there is definitely collaboration with her over decision making on treatments and they see all of the MDT at clinic appointments. Parent G sends her own mother to pharmacy to collect prescriptions, to avoid potential risk of cross-infection at the RBH due to the lengthy wait required.

Inpatient care (ward):

Not applicable.

Annual review:

Parent G's child is offered annual review each year by the RBH and had the last assessment in summer 2014. She explained that they see the whole MDT at annual review. She also explained that the outcome of annual review is reported back quite a few weeks later, which she finds frustrating – ie a month or so later.

Parent G felt that there should be a psychotherapist at clinic prior to the annual review clinic, to prepare children for the fright of scans, explaining that a play specialist was utilised at short notice.

Home care:

Parent G's child hasn't required home visits since 2013. The mother has a lot of telephone communication with the CNS at the Brompton Hospital and so feels that communication is very good here. She regrets the loss of the retired CF home care nurse.

Good practice:

"Clinical nurse specialist at the Brompton is invaluable. The whole service is supportive."

"Home care service and physiotherapy support."

"Ability to provide clinic appointments at short notice when child is ill."

Areas for improvement:

"Improve strategies/distractions for keeping child in consultancy room – eg wipeable toys."

"Royal Surrey hospital is not set up for safe segregation – it's a general paediatric clinic", ie enhance segregation measures at Royal Surrey Hospital paediatric clinic.

"Lack of continuity in consultants we see at Royal Brompton Hospital", ie would like to see same doctor more regularly.

Parent H

Parent H's child receives full care from the RBH. She finds the segregation measures at outpatient clinic perfect, although she feels that parents do not always adhere to the guidelines to keep children in rooms. She feels the outpatient clinic has improved a lot.

Parent H's child sees all of the CF MDT at each clinic appointment, decisions are made collaboratively with her and her child, adding "our opinions always count". Mother feels that the wait at pharmacy can be an issue, with the worry about which other bacteria her child may be exposed to and whether they have sufficient parking time (up to four hours).

Inpatient care (ward):

Not applicable.

Annual review:

Parent H explains that, as of last year, they have changed annual review and that her child was caught in the changeover. There was no DEXA scan and she "missed a year out" and they used to get a printed report of outcomes – e.g. vitamin levels, ABPA data, whereas now they receive only a "summary". Parent H adds that she'd prefer a full report.

Home care:

Patient H's child has no home visits from the CF team, but has Healthcare at Home delivery of Tobramycin, Colobreathe and DNase. She feels the service provided is really good.

Good practice:

"I know I can rely on the CF team. Their support is amazing. I can't praise them highly enough and never want the clinical nurse specialist to leave."

Area for improvement:

"Annual review assessment and its reporting back process."

"Reducing waiting time and risk of cross-infection at pharmacy."

Parent I

Parent I's child receives shared care at the RBH and St Peter's Hospital (Ashford). They only attend St Peter's Hospital for joint clinics with the RBH team. She is extremely happy with the segregation measures in place, the hygiene and wiping down of equipment which she sees. Her child sees each member of the CF MDT at outpatient clinic and they have met the social worker and clinical psychologist. Parent I is happy with the consultations, where the consultant listens to the parent as part of the decision-making process on treatments. She added, "We very much lead the sessions".

Parent I avoids any issues around pharmacy waiting times by lodging the prescription straight away, to pick up later or take to her local chemist.

Inpatient care (ward):

Not applicable.

Annual review:

Parent I's child is offered annual review each year at the RBH. They see all of the CF MDT at annual review, except the dietitian at the last annual review who was off ill. However, Parent I explained she has regular communication with the dietitian and at annual review on this occasion the doctor covered the dietetic issues. Annual review outcome is reported back to parents at clinic and any matters arising by telephone.

Home care:

Parent I took her child to monthly clinics until recently; now clinics are every other month for this child. In between clinics, her child has a home visit from a physio or dietitian and to take cough swabs if ill, due to new growth of *Pseudomonas aeruginosa*. After beginning a trial of Tobi, the physiotherapist followed up with another home visit.

Good practice:

"Very efficient, approachable, accommodating CF team."

Areas for improvement:

"There is no cross-infection procedure at Ashford – it needs monitoring."

"There is a lack of equipment at Ashford – it needs increasing."

"Slow movement of patient notes at Ashford – still awaiting November's notes. Royal Brompton's communication is sharp though."

Patient and parent interviews on peer review day

Patient A

A mother and her 14-year-old daughter. Patient A was diagnosed at four months old and has attended the RBH since birth. The family lives in Romford and travels to the hospital by car and finds the parking a real issue.

Sometimes Patient A feels isolated in her room, staff members pop in and out, however do not stay long; she would welcome a laptop facility to communicate with others and the teachers.

Areas of excellence:

- The team is friendly, very nice and bubbly, which makes her feel better.
- The room/ward is always clean.
- The food is not too bad and she can have extra from the trolley or go to the canteen for more.

Areas for improvement:

- When her mother goes home the staff are not very quick to answer the buzzer and she does not like to keep asking for drinks or to get something from the fridge. The nurses are so busy she sometimes does not have enough water to take her medication; more housekeepers could improve this.
- Parking. On admittance the daughter has many personal belongings, overnight feeds and medication to bring, her father usually drives her in and last time the parking attendant allowed them only five minutes to unload their car; it took three trips to the ward and the father did not get to say goodbye properly to his daughter as he had to move the car. They have suggested a drop-off time long enough for this.

Patient B

A female patient of 16 years old, who was diagnosed at four months at Ashford and St Peter's and then referred to the RBH. Patient B lives in Twickenham and travels to the hospital sometimes by car or by public transport. She is taking part in a study where her appointment can take up to five hours, as she has to arrive two hours prior to her appointment; this can incur a possible £25 parking charge. She asks her consultant for her prescription at the beginning of her appointment to save time collecting her medications.

Areas of excellence:

- The school is really good; the teacher will call and give a choice of either attending the school or carrying on work on own project work.
- The rooms are really nice; she was originally admitted to a bay, however, she was moved after a few days to her own room due to her age and need for some privacy.
- The food is good; she can store extra food in the kitchen fridge and the dietitian can issue extra food. For breakfast, she has a cooked breakfast and she has the choice of having it delivered to her room or going to the restaurant to eat it; she likes to get out of her room.
- The team are all excellent; the play team took her to decorate biscuits recently and she enjoyed the contact and, on occasion, she has been taken out to the cinema.
- Patient B has been assigned a specific nurse whom she can contact at any time; she also visits her at home. Patient B struggles to carry out her physiotherapy exercises and the nurse contacts her weekly to see how she is getting on and to encourage her.

Areas for improvement:

- Car parking spaces are hard to find and have changed, they could previously park for free after 6pm and Sundays. The market car park has a link with the hospital and if you show your appointment letter you can get a discount if there is a space.
- The staff do their best with cross infection, however it has been confusing to know which toilet/bathroom she was supposed to be using, due to other isolated patients.

Patient C

A 13-year-old female diagnosed before birth at the 20-week scan and her mother were interviewed. Patient C receives full care at RBH, however she does also go to Guildford once a year to keep in touch.

Areas of excellence:

- Staff are all lovely and friendly, both mother and daughter feel confident in their care. Very happy with the service.
- Ward and clinics are always clean.
- Exercise, dancing, assault courses are all brilliant and fun, as are the staff delivering this service.

Areas for improvement:

- Reinstating parent kitchen to be considered, as it would be useful to be able to prepare toast and drinks or microwave meals once more.
- A gym or dance studio would be wonderful.
- An outdoor gym area with colourful tarmac and equipment would be much appreciated.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Royal Brompton 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	Large waiting area. Nine cubicles, staggered appointments. Nine patients are seen at 13:45, further nine at 15:15.
Do patients spend any time in the waiting room?	Yes	Occasionally.
Is there easy access to toilets?	Yes	Male and female.
Where do height and weight measurements take place? Is this appropriate?	Yes	Clinic room.
Where are lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	No	Due to cross-infection control purposes, no toys.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Joint monthly clinic and seen in diabetic clinic as well if required, and on-ward by diabetic team.
Transition patients – can they get a tour of outpatient facilities?	Yes	If required.
Transition/new patients – do they get an information pack?	Yes	Use CF Trust information.

Additional comments:

- Outpatients is located on the first floor, the patients are directed to the clinic rooms and the team rotate to the rooms. All clinic rooms are of a good size, clean and well-equipped for use. Two of the clinic rooms are newer and have been erected using parent funding.

Environmental walkthrough: ward

Ward name: Rose

Microbiology status: Cardiology/respiratory

		Hospital name	Royal Brompton Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		9	Will have one extra room in April 2015.
Do the en suites have:	Toilets?	5	3 fully en suite. 4 cubicles with sink and shared shower/toilet = (cater for 2 CF). 2 cubicles with sink and communal bathroom/toilet. 3 x 5 bedded bays (cater for 3 CF).
	Wash basins?	5	
	Bath or shower?	3	
Do CF patients have to share any bathroom facilities?		Yes	Patients could have to share facilities if not allocated an en suite. They would not share with other CF patients.
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	
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Z-beds can be used in the cubicles.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Fridge in ward kitchen for staff to use for patients' food/drinks. No microwave and no parent kitchen.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		No teenage room due to cross-infection purposes. Wii Fit, Wi-Fi, TV, dance mat.
Is there access to a gym or exercise equipment in the rooms?	Yes	No gym. Bike or trampette can be used in the room. Exercise staff take patients individually outside and encourage exercise in rooms as well.
What facilities are there to help with school and further studies?		Very impressive primary and senior school rooms with music room catering for 3 to 18-year-olds. Both have two rooms with dividing glass partitions for multiple students without cross-infection risk. The school is open all year except for two weeks at Christmas. Teachers are term time. The school is run by teachers and special needs experts; there are career advisers and volunteers and they can cater for multiple subjects and exam sitting. The teachers have strong links with schools. During holiday time activity classes run and siblings can join in.
Is there a relatives' room?	No	
What internet access is there?		Guest Wi-Fi.
What facilities are there to enable students to continue work and study?		School is equipped with computers, laptops, iPads. Patients can use laptops in room and video-conference into lessons.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Sinks in room. See also nebuliser cleaning protocol provided as evidence.
What facilities are provided for those with MRSA?		Total isolation in room with en suite.
What facilities are provided for those with <i>B. cepacia</i> ?		Total isolation in room with en suite.
What facilities are provided for those with other complex microbiology?		Total isolation in room with en suite.
Are patient information leaflets readily available on ward?	Yes	Many general leaflets displayed. CF information can be printed or directed to CF Trust website.
Transition patients – can they get a tour of ward facilities?	Yes	Pre-transition clinic at 15 years; patients will meet adult consultants and be given a tour of the ward.

Environmental walkthrough: other

	Hospital name	Royal Brompton Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	For newborn screening admittances and planned inpatient admittances.
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?		X-ray and DEXA – pre-arranged appointments, large waiting area. Pharmacy – the pharmacy counter is located in the corridor; there is a large waiting area nearby. Parents will often go away and come back rather than wait.
Do patients have to wait at pharmacy for prescriptions?	Yes	Prescriptions are taken to pharmacy by the team to be collected by patient/parent on their way out to avoid waiting; alternatively patients can be called to collect medications.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	
Are there patient comment/feedback boxes?	Yes	Boxes on ward and at outpatients. ‘Friends and Family’ surveys and comment/suggestion boxes.

7. Barnet and Chase Farm Hospitals

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 RBH	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green RBH	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green RBH	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 an annual review)	95%	Green RBH	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Green	Green	
	% of MDT who receive an annual appraisal	100%	Green RBH	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Red	Red	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green RBH	Green	
	Are there local operational guidelines/ policies for CF care?	100%	Green RBH	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 RBH	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%	N/A No admissions	N/A	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	N/A No patients meet	N/A	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (PA) in the previous 12 months	100%	Green RBH	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green RBH	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	N/A Only performed at RBH	N/A	
3.4 Cystic fibrosis related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green RBH	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green RBH	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green RBH	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green RBH	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%	NA No admissions	N/A	
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%	NA No admissions	N/A	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green RBH	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	NA No admissions	N/A	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green RBH	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	NA No admissions	N/A	
	% availability of a CF specialist dietitian at clinic	100%	Red RBH	Red	

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%	NA No admissions	N/A	
	% availability of a clinical psychologist at clinic	100%	Red	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	NA No admissions	N/A	
	% availability of a social worker at clinic	100%	Red	N/A	Social worker compliance virtually impossible in most units.
	% availability of a social worker for inpatients	100%	N/A No admissions	N/A	
	% availability of a pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	N/A No admissions	N/A	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green RBH	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green RBH	N/A	

5 Commissioning

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

Patient survey

Chase Farm Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

None.

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Chase Farm 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	The reception desk is situated at the main entrance to the clinic. The waiting room is a separate room off the reception area.
Do patients spend any time in the waiting room?	No	Patients do not go into the waiting room, they are allocated a time. If they arrive early, they are asked to return for their appointment time, they are offered contact by phone.
Is there easy access to toilets?	Yes	The nurse will clean between patients.
Where do height and weight measurements take place? Is this appropriate?	Yes	In the allocated rooms. There are a stadiometer and scales in each.
Where are lung function tests done for each visit?		In the allocated room.
Are clinic rooms appropriately sized?	Yes	There are three larger rooms and one smaller room. A patient is allocated a room and the MDT members rotate between them. Signs on the doors indicate who is in the room and also who has already seen the patient.
For annual review patients, are any distractions provided?	N/A	RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		None seen at Chase Farm.
Transition patients – can they get a tour of outpatient facilities?		Transition clinics are at Brompton.
Transition/new patients – do they get an information pack?		Transition clinics are at Brompton.

Additional comments:

- Twelve patients. Clinics are held every three months. Three slots of appointments, three patients at each time, a total of nine patients can be seen at clinic.
- The children's unit is to the rear of the main hospital in a separate building. The outpatients' area looks drab, tired and in need of refurbishment. However, there are plans in place for a new building on the hospital grounds to house the Urgent Care, Children's Outpatients (with four clinic rooms) and Paediatric Assessment Unit. This building is to be completed by 2018 when they will move there.
- The receptionist and the nurse are key parts of the team; the receptionist is aware of the patients and notifies the team who has arrived, admits them to the room and will send them away if early. If a patient has used the toilet, the receptionist will notify the nurse, who will clean the room in between each patient. The nurse is also responsible for cleaning all the rooms between patient appointments.

Environmental walkthrough: ward

Ward name: Galaxy

Microbiology status: General

		Hospital name	Barnet Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			Suitable for care.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		13	Three rooms have full en suite facility. There are a further seven cubicles and each of those can be dedicated a toilet/bathroom.
Do the en suites have:	Toilets?	3	Two have bath/shower + one with full wet room.
	Wash basins?	3	
	Bath or shower?	3	
Do CF patients have to share any bathroom facilities?		No	Very unlikely, as they would be allocated a full en suite cubicle. Due to low patient numbers, unlikely.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		N/A	Medications are locked away in individual patient containers and stored in the drug room.
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	Each room has a folding bed.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open for parents; other visitors may visit 10:00–20:00.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Parent room facility with both microwave and fridge.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		Play specialists are able to give out iPads, Gameboys, DVDs, and Wii, etc. There is also a well-equipped teenage sitting room, which has a TV, computer, Xbox, table football, games, table and chairs.
Is there access to a gym or exercise equipment in the rooms?	No	The physiotherapist will visit twice daily.
What facilities are there to help with school and further studies?		Computer use. Free Wi-Fi.
Is there a relatives' room?		Sofa seating, table and chairs, TV. Kitchen facilities with free tea and coffee provided. Pay phone. Toilet and shower.
What internet access is there?		Wi-Fi available 24/7.
What facilities are there to enable students to continue work and study?		Full-time teachers from education services, schoolroom with computers.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in side room.
What facilities are provided for those with MRSA?		Isolation and follow guidelines.
What facilities are provided for those with <i>B. cepacia</i> ?		Isolation and follow guidelines.
What facilities are provided for those with other complex microbiology?		Isolation and follow guidelines, or may be admitted to the Brompton Hospital.
Are patient information leaflets readily available on ward?	Yes	General information leaflets available.
Transition patients – can they get a tour of ward facilities?		Seen at the Brompton Hospital; could have a tour if requested.

Additional comments:

- Barnet Hospital is a modern new building. Galaxy ward is modern, bright and appears spacious and the side rooms are a good size and very well equipped.
- There is a Paediatric Assessment Unit on the ground floor, which is open 09:00– 21:00, with three cubicles for patients to go to instead of A&E.
- There is a playroom for younger children; well equipped with table football, a very large selection of toys, books and games. An outside play area is in the process of being refurbished.

	Hospital name	Barnet and Chase Farm Hospital sites
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Matron can sign permit for weekly parking fee of £12.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	At both sites.
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	Pharmacy – advised not to wait. X-Ray – by appointment, or at the end of the day. If urgent, have portable x-ray machine. DEXA – at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	Patients are advised to drop off prescriptions and go away from the area, returning to collect drugs. Prescriptions are arranged and the drugs are given to take away on discharge.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?		PALS office at main entrance at Barnet. Leaflets displayed at both.
Are there patient comment/feedback boxes?		Patient experience tracker on the ward.

8. Crawley and East Surrey Hospitals

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green RBH	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green RBH	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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green RBH	Green	
	Are there local operational guidelines/ policies for CF care?	100%	Red follow RBH; team only in place 11 months	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%	N/A no patients	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 <i>Pseudomonas aeruginosa</i> (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 RBH	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green RBH	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green RBH	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green RBH	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%	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 at weekends	100%	Red	Seen once daily due to staff shortage	Red	
	% availability of a CF specialist dietitian at clinic	100%	Green	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%	Red Access if required	Red	
	% availability of a clinical psychologist at clinic	100%	Red Unable to appoint	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Red	Unclear	
	% availability of a social worker at clinic	100%	Red Access through RBH	N/A	Social worker compliance virtually impossible in most units.
	% availability of a social worker for inpatients	100%	Red Access through RBH	N/A	Social worker compliance virtually impossible in most units.
	% availability of a pharmacist at clinic	100%	Red Access if needed	N/A	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	2	Unclear	Unclear numerator and denominator.
5.3	User survey undertaken a minimum of every three years	100%	N/A	Red	
5.4	Service level agreements in place for all	100%	N/A	Red	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Crawley and East Surrey Hospital
Consultant 1	0.5	1	1	0
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	0.5 WTE
Physiotherapist	2	3	4	0.2 WTE
Dietitian	0.5	1	1.5	0.2 WTE
Clinical psychologist	0.5	1	1.5	0.2 WTE Funding available, not yet appointed
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

Patient survey

Crawley and East Surrey Hospitals

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	3	0	0	0
Waiting times	3	0	0	0
Cross-infection/segregation	2	1	0	0
Cleanliness	2	1	0	0
Annual review process	2	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	1	0	0
Cross-infection/segregation	1	1	0	0
Food	1	0	1	0
Physiotherapy availability to assist/assess airway clearance and exercise during weekdays	1	1	0	0
Physiotherapy availability to assist/assess airway clearance and exercise during weekends	1	1	0	0

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	0	1	0	0

How would you rate the overall care?

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

Comments about CF team/hospital:

“It would be beneficial if nurses on the ward were more aware of CF, its information and impact on family (parents/siblings).”

Environmental walkthrough: outpatients department

Outpatients/CF clinic – Jumbo Children’s Unit

	Hospital Name	Crawley 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	Separate waiting room equipped with many toys, not for CF use.
Do patients spend any time in the waiting room?	No	Patients are directed to clinic room on arrival.
Is there easy access to toilets?	Yes	Male and female.
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight room, cleaned in between patients.
Where are lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	Very large, bright, clean and very well equipped rooms with great views from windows.
For annual review patients, are any distractions provided?	N/A	RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	None.
Transition patients – can they get a tour of outpatient facilities?	Yes	New – if required.
Transition/new patients – do they get an information pack?	Yes	RBH pack.

Additional comments:

- The children’s unit is located on the fifth floor and accessed via four lifts. Ten patients attend the unit for their clinic visit. There is a security camera and door on entry. The unit is very spacious, clean and bright with impressive views from the windows.

	Hospital name	Crawley Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	£1 per hour. 5–12 hours costs £5. Over 12 hours costs £25. Car park and also metered street parking.
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?		Have arrangements with Boots chemist to deliver prescription to local Boots pharmacies. Radiology – pre-planned visits if required. DEXA scan – RBH.
Do patients have to wait at pharmacy for prescriptions?	No	If necessary, staff will drop the prescription at pharmacy for collection on way out.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	No	Any concerns will be dealt with by reception staff, as run by the same trust.
Are there patient comment/feedback boxes?	No	

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	East Surrey 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	30+ seats. Patients do not wait; they are sent directly to the clinic room.
Do patients spend any time in the waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight room, which is cleaned in between patients.
Where are lung function tests done for each visit?		In clinic room with mobile equipment.
Are clinic rooms appropriately sized?	Yes	Six clinic rooms, bright, clean and well equipped.
For annual review patients, are any distractions provided?	N/A	RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	None at present.
Transition patients – can they get a tour of outpatient facilities?	Yes	
Transition/new patients – do they get an information pack?	Yes	RBH pack. Team would tailor to patients' needs.

Additional comments:

- The paediatric outpatients is located in a Portakabin accessed outside of the main building. A dedicated CF clinic is held each Friday. Ad hoc patients can be seen either at clinic or on ward in the Critical Assessment Unit (CAU).

Environmental walkthrough: ward

Ward name: Outwood (21-bedded ward)

Microbiology status: General paediatrics

		Hospital name	East Surrey Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	The rooms are bright, clean and well equipped for use.
Number of side rooms?		4	
Do the en suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		Yes	Each room has a lockable cupboard.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Wall-mounted TVs.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Three of the rooms have pull-down beds.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open hours.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	The rooms have fridges and there is a microwave for use in the parents' room.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		There is a TV/DVD player for use. Patients usually bring in own IT.
Is there access to a gym or exercise equipment in the rooms?	Yes	Step available for room use.
What facilities are there to help with school and further studies?		Parents liaise with school.
Is there a relatives' room?	Yes	Parents' room/kitchen with toaster, kettle, microwave, TV and seating.
What internet access is there?		Wi-Fi.
What facilities are there to enable students to continue work and study?		Patients bring in own IT for school work.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sluice with nurse assistance. Sink in room.
What facilities are provided for those with MRSA?		Isolation, following guidelines.
What facilities are provided for those with <i>B. cepacia</i> ?		Isolation, following guidelines.
What facilities are provided for those with other complex microbiology?		Isolation, following guidelines.
Are patient information leaflets readily available on ward?	Yes	Information from Brompton/CFT and also on request.
Transition patients – can they get a tour of ward facilities?	Yes	If required.

Additional comments:

- Total of 18 CF Patients, 10 attend Crawley and 8 attend East Surrey outpatient clinic. Average of only one patient admitted every two months. Only nine patients have been admitted this year, of which one had home IVs.
- On entry to the ward is a large noticeboard with photos of the team along with artwork and leaflets.
- The CNS has a dedicated mobile for patient contact. For patients who require it, the mobile number of the consultant is available for emergency contact.
- Food – alternatives to the menu can be requested, and larger portions.
- CAU – large with waiting area and treatment rooms, patients can be seen here before admittance. The ward can be reached directly from the CAU.
- The team has grown in the last couple of years and now has a physiotherapist, dietitian and CNS along with the consultant. They are planning to make many improvements to the service such as developing information leaflets on nebuliser cleaning for patient use.

- They would like a shared drive to enable them to share patient information in the future.
- The physiotherapist plans to approach charities in order to get more gym equipment for patient room use. The physiotherapist and the CNS would like to plan a more structured day for each patient with regard to exercise and treatments.
- The dietitian is looking to approach charities in the hope of purchasing and issuing a book, *Carbs and Cals*, to each patient.
- They are also looking into buying a laptop dedicated for patient use.
- The team has no local cross-cover at the moment, except the RBH, and has talked of a rotation system along with St Helier, Epsom, Crawley and East Surrey, where cover could be rotated amongst them.

Environmental walkthrough: other

	Hospital name	East Surrey Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Fixed price for inpatients. A ticket can be issued by the ward for concession of £3 per day.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Colour coded.
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?		Pharmacy – long-term drugs are sent to local Boots pharmacy for collection. The CNS can also deliver drugs on home visits, or drugs can be delivered to the ward. X-ray is booked. DEXA scan – RBH.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Clear signage on entry to the PALS office.
Are there patient comment/feedback boxes?	Yes	'Friends and family' boxes on ward.

Additional comments:

- There are 258 parking spaces, of which 68 disabled. Up to 15 minutes free for drop-off.
- Up to 2 hours – £2.20.
- Up to 3 hours – £3.20.
- Up to 4 hours – £4.00; each additional hour – £1.00.

9. Epsom General Hospital

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	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 RBH	Green RBH	

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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Green	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	RBH	Green	
	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	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 <i>Pseudomonas aeruginosa</i> (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red Do not know the time	Unknown	
3.4 Cystic fibrosis related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green RBH	Green RBH	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green RBH	Green RBH	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green RBH	Green RBH	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green RBH	Green RBH	

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%	Amber	Amber	Difficult as good model with nurse covering both Epsom and St Helier.
	% 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 at weekends	100%	Red	Amber	No weekend cover.
	% availability of a CF specialist dietitian at clinic	100%	Red	Red	
				Red	Dietitian not available for local centre run clinics

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 General paediatric dietitian not specialist	Red	
	% availability of a clinical psychologist at clinic	100%	Red Not available ad hoc	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Green	Green	
	% availability of a social worker for inpatients	100%	Green	Green	
	% availability of a pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	N/A	
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 in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
5.3	User survey undertaken a minimum of every three years	100%	RBH	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	Epsom General Hospital
Consultant 1	0.5	1	1	1.5 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.4 WTE
Physiotherapist	2	3	4	0.2 WTE
Dietitian	0.5	1	1.5	Paediatric dietitian, not CF specialist
Clinical psychologist	0.5	1	1.5	CAMHS
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	0.8 WTE
Database coordinator	0.4	0.8	1	

No patient surveys received.

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Epsom General 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	Large waiting room with many seats and reception desk on entry. Large selection of toys (not for CF use).
Do patients spend any time in the waiting room?	No	The reception staff and team know their CF patients well. The patients will always see the same team. The patients are measured and weighed and then taken directly to the clinic room. The team rotates between the rooms.
Is there easy access to toilets?	Yes	Plus disabled.
Where do height and weight measurements take place? Is this appropriate?	Yes	Designated room, appointments are staggered and the equipment is cleaned in between patients.
Where are lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	Good size, well equipped and fully fit for purpose.
For annual review patients, are any distractions provided?	N/A	Annual review at RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	No CFRD patients. (One patient with type 1 non-CF related diabetes attends shared clinic at RBH and also separate clinic at Epsom.)
Transition patients – can they get a tour of outpatient facilities?	N/A	New patients would be offered a walkthrough prior to regular appointments.
Transition/new patients – do they get an information pack?	Yes	Information pack from RBH.

Additional comments:

- There are 18 patients. The clinic has use of up to four clinic rooms. Patient appointment times are staggered every half hour. The clinic shares the waiting room with antenatal. When CF clinic takes place, all toys are removed from the clinic rooms.

Environmental walkthrough: ward

Ward name: Casey

Microbiology status: General

		Hospital name	Epsom General Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	The rooms are a good size, have been repainted, and are clean and well equipped. The bathroom was dated, however very clean and fit for purpose. Outside each room are the patient notes and hand gels.
Number of side rooms?		6	Usually have one patient admitted at any one time.
Do the en suites have:	Toilets?	5	
	Wash basins?	5	
	Bath or shower?	5	
Do CF patients have to share any bathroom facilities?		No	One room without full en suite, could have a bathroom designated if required.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		Yes	Bedside lockers. Most patient medication is kept in a designated cupboard.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	All cubicles have wall-mounted TVs.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Pull-down beds.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open hours.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Fridge and microwave in parents' kitchen.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		PS/DVDs for use. Patients are encouraged to attend school daily.
Is there access to a gym or exercise equipment in the rooms?	Yes	Gym located very near to the ward is more suitable for younger patients, consists of a soft-play area. Assault courses can be created with equipment, trampette and climbing frames. All equipment is cleaned after use. Older patients prefer to go to the physiotherapy gym – appointments can be made for this. Equipment: treadmill, bikes, weights, trampette, cross trainer, exercise ball.
What facilities are there to help with school and further studies?		Patients bring in own IT. Admissions are planned to minimise disruption to study. School work can be arranged in advance of admission or the team will liaise with school if required.
Is there a relatives' room?	Yes	Small room with mural on wall. Kitchen area with fridge, microwave and kettle. Free tea/coffee available.
What internet access is there?		Payable Wi-Fi at £12 per week via overhead TV/phone/Wi-Fi system (free movies). Some side rooms have this, others have TV only.
What facilities are there to enable students to continue work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Parents tend to bring in own sterilisers; these can also be provided in the rooms. Some parents prefer to take equipment home for cleaning. There is also the sink in the room for this purpose.
What facilities are provided for those with MRSA?		Isolated as standard, depends on individual needs.
What facilities are provided for those with <i>B. cepacia</i> ?		Isolated as standard, depends on individual needs.
What facilities are provided for those with other complex microbiology?		Isolated as standard, depends on individual needs.
Are patient information leaflets readily available on ward?		General leaflets are displayed. Can print CF information on request and signpost towards CF Trust website.
Transition patients – can they get a tour of ward facilities?		New patients will get a tour if requested. The team advises a tour prior to first admission for familiarisation.

	Hospital name	Epsom General Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	£5 per week. If an outpatient appointment overruns, the patient can claim back the additional payment by taking the ticket to main reception.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	To outpatients and ward. The main building entrance is not signposted as 'main entrance', it is listed as a wing of the 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	Pharmacy – open waiting area with seating along corridor. Pharmacy is run on a ticket system.
Do patients have to wait at pharmacy for prescriptions?	No	Parents call the CNS/consultant for prescriptions and can pick these up from the ward. For urgent prescriptions, the team/parent will take the script to pharmacy or can call ahead; paediatrics are prioritised. Parents are encouraged to have a stock of meds at home. Radiology – pre-planned appointments at end of patient list if possible.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Signage to PALS. Plans for a stand in main entrance in near future.
Are there patient comment/feedback boxes?	Yes	On the ward, in outpatients and on day ward. 'Friends and Family' questionnaires can be obtained.

Additional comments:

- On entrance to the front building, all departments can be accessed under one roof.
- They are in the process of looking at re-planning the signage and have recruited a group of patients who visit the hospital to give their ideas for improvements. The group has pointed out minor maintenance works throughout the hospital and since then the hospital has employed two handymen for minor works.

10. Frimley Park Hospital

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	RBH	Green RBH	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	RBH	Green RBH	

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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green	Green	
	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%	Unknown	Unknown	
	% 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	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%	Red Only 1 patient in at a time. If 2 then isolated	Green	Walkthrough suggests Green.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (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%	N/A	N/A	
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	N/A	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% 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%	Red This has been rectified since August 14	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%	N/A No nurse employed	Red	A major concern.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	N/A No nurse employed	Red	A major concern.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	Red Attempted to be seen twice	Amber	Audit suggests standard not achieved due to patients at school or parents administered.
	% 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%	Green	Green	
	% availability of a clinical psychologist at clinic	100%	N/A No psychologist	N/A	
	% availability of a clinical psychologist for inpatients	100%	N/A No psychologist employed	Unclear	
	% availability of a social worker at clinic	100%	Red Social worker not required at clinic	Red	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Red Not available for children in hospital	Red	Social worker compliance impossible in most units.
	% availability of a pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	N/A	
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 in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
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	Frimley Park Hospital
Consultant 1	0.5	1	1	2 hrs per week
Consultant 2	0.3	0.5	1	1
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	
Physiotherapist	2	3	4	1
Dietitian	0.5	1	1.5	0.2
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

Patient survey

Frimley Park Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	0	2	1	0
Waiting times	0	1	1	1
Cross-infection/segregation	0	1	1	1
Cleanliness	1	1	1	0
Annual review process	0	0	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	2	0	0	1
Cross-infection/segregation	2	0	1	0
Food	0	1	1	1
Physiotherapy availability to assist/assess airway clearance and exercise during weekdays	0	1	1	0
Physiotherapy availability to assist/assess airway clearance and exercise during weekends	0	1	0	1

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“All CF staff are friendly, approachable and are available as much as their individual diaries allow.”

“We stopped using Frimley Park Hospital as the consultant’s knowledge of CF was not good. She was a nice person, but the doctors at the Brompton are better by miles.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Frimley Park 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	Large waiting area with seating for approximately 16. Distractions – TV and toys.
Do patients spend any time in the waiting room?	No	Patients do not wait, they are checked in and taken directly to the clinic room.
Is there easy access to toilets?	Yes	2 x male; 2 x female.
Where do height and weight measurements take place? Is this appropriate?		Equipment is taken to clinic room and cleaned after use.
Where are lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	All clean and well equipped. 8 rooms in use.
For annual review patients, are any distractions provided?	No	For cross-infection purposes, they do not supply toys. There is a sign 'bring your own toys'. Patients/parents bring in toys.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	None	
Transition patients – can they get a tour of outpatient facilities?	N/A	
Transition/new patients – do they get an information pack?	Yes	Diagnosed patients are given a pack at RBH. The Frimley Park team are in the process of having laminated contact cards printed.

Additional comments:

- Outpatient clinic is located on the ground floor.

Environmental walkthrough: ward

Ward name: F1 Children's Unit

Microbiology status: General

		Hospital name	Frimley Park Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Due to low numbers the rooms are not often used as patients like to mix. If this is appropriate they are put in the bays with other non-CF patients.
Number of side rooms?		6	
Do the en suites have:	Toilets?	Yes	A bathroom or shower room can be designated.
	Wash basins?	Yes	
	Bath or shower?	No	
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	Free up to 9pm watershed.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Pull-down beds in rooms. Camp beds can be supplied on ward.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open hours.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Teenage kitchen has a microwave and fridge and is fully stocked with snacks for patients to take at any time. Milk room also has microwave/fridge facility.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		Teenage room is equipped with sofa seating, TV, table football, air hockey, PS, DVDs.
Is there access to a gym or exercise equipment in the rooms?	Yes	No equipment is put in the room, physiotherapists prefer to take the patients out to the gym.
What facilities are there to help with school and further studies?		Play therapists can liaise with school.
Is there a relatives' room?	Not at present	Can use the teenage sitting room. However, there are plans for a parent sitting room, which is to be located near a fully equipped (microwave and fridge) parent kitchen. There is also a parent shower room and two toilets for use.
What internet access is there?		Free Wi-Fi.
What facilities are there to enable students to continue work and study?		School room, with three play therapists.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink either in room or on ward.
What facilities are provided for those with MRSA?		Isolation (no patients).
What facilities are provided for those with <i>B. cepacia</i> ?		Isolation (no patients).
What facilities are provided for those with other complex microbiology?		Isolation.
Are patient information leaflets readily available on ward?	Yes	General leaflets on ward, CF leaflets are given on request due to low patient numbers.
Transition patients – can they get a tour of ward facilities?	N/A	

Additional comments:

- The children's unit is located on the first floor of the hospital and appears clean and bright. There are 19 patients.
- Appointments are arranged as follows: three patients at 09:00, three at 10:00, then three at 11:00. The patients never arrive together.

Environmental walkthrough: other

	Hospital name	Frimley Park Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Signage throughout hospital was very clear.
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?		X-ray – large seated waiting area, CF patients do not wait, and the appointments are pre-booked. DEXA scan carried out at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	Parents collect drugs – can be given a pager which notifies when prescription is ready for collection, or can be phoned.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	At main entrance there is a large PALS office.
Are there patient comment/feedback boxes?	Yes	On the ward there are boxes displaying happy/sad faces and the patients can put a token in which box they feel relevant to their stay. iPad – every patient at outpatients completes a survey.

Additional comments:

- Two-storey car park. On leaving the hospital mid-afternoon, there was a queue of approximately eight cars waiting to get through the barrier to park, due to the car park being full.
- Charges are:
 - Up to 15 minutes drop time – free
 - 15 minutes to 2 hours – £2.70 2–3 hours – £4.50
 - 3–4 hours – £5.00 4–5 hours – £6.00
 - Over 5 hours – £7.50 7 day ticket – £15.00
- At main reception – patient lounge, for patients waiting for transport.
- Baguette shop, book store, newsagent and café.

11. Hillingdon Hospital

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	RBH	Green RBH	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	RBH	Green RBH	

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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% of MDT who receive an annual appraisal	100%	Amber	Amber	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green RBH	Green	
	Are there local operational guidelines/ policies for CF care?	100%	Green RBH	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care'	100%	Unknown Not specifically checked	Unknown	
	% 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 Do not keep track of this, creating a proforma	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (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%	Amber	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	Red	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/ shared care consultant/ patient or carer within 10 days of consultation	100%	Amber	Amber	
	% 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 at weekends	100%	Amber	Amber	
	% 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%	Red Creating an admission proforma	Red	Plan in place.
	% availability of a clinical psychologist at clinic	100%	Red Referral basis only	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Green Available for planned admissions	Green	
	% availability of a social worker at clinic	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Green	Green	
	% availability of a pharmacist at clinic	100%	Red	N/A	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	N/A	
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 in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
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	Hillingdon Hospital
Consultant 1	0.5	1	1	1 PA/week
Consultant 2	0.3	0.5	1	TBA
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.5 WTE
Physiotherapist	2	3	4	Funded for 4 whole-day clinics 8 half-day clinics 12 MDT meetings all IP requirements
Dietitian	0.5	1	1.5	Funded for 4 whole-day clinics 8 half-day clinics 12 MDT meetings all IP requirements
Clinical psychologist	0.5	1	1.5	See OP requests within 6 weeks, provide planned inpatient support
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	1 dedicated ward pharmacist general outpatient pharmacy
Secretary	0.5	1	2	No specific funding
Database coordinator	0.4	0.8	1	

Patient survey

Hillingdon Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“Physios at Hillingdon had no replacement parts for pep or acapella. As an inpatient, had to share ward facilities. Didn’t have room with own toilet. Ward was understaffed and struggled to accommodate 3/4 CF patients. The staff (Peter Pan) were fantastic and friendly but overworked.”

“Brompton – parking is very bad. Sometimes at annual review too many long waiting times between appointments. Hillingdon – parking is very bad. Some ward staff very unfriendly.”

“The recommended life of an acapella is 3-4 months (as advised by supplier), we only get one acapella per year so have to buy our own. As we use the spioballs, we also have to buy these (we use two per month due to cleaning/germ reduction); this should not happen should it? I would like to formally say that the nurse is outstanding in our CF support for our whole family.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic – Hillingdon consulting rooms

	Hospital Name	Hillingdon 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	Seating for 12.
Do patients spend any time in the waiting room?	No	Patients are directed by one of the health care assistants (HCA) to either the height and weight room or their clinic room on arrival.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Designated room which is cleaned thoroughly after use.
Where are lung function tests done for each visit?	–	Height and weight room.
Are clinic rooms appropriately sized?	Yes	Well equipped for use.
For annual review patients, are any distractions provided?	N/A	This takes place at RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Two patients attend specialist clinic at RBH and see local diabetic team.
Transition patients – can they get a tour of outpatient facilities?		New patients can have a tour of all facilities.
Transition/new patients – do they get an information pack?	Yes	Issued at RBH.

Additional comments:

- On average, 13/14 patients are seen at clinic. There are two HCAs who attend clinic and usher patients to either the clinic room or height and weight room, keeping patients apart.

Environmental walkthrough: ward

Ward name: Peter Pan

Microbiology status: General paediatrics

		Hospital name	Hillingdon Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Rooms could be allocated and use of a bathroom arranged.
Number of side rooms?		3	Total of 13 side rooms, 3 suitable for CF patients with full en suite facilities.
Do the en suites have:	Toilets?	3	
	Wash basins?	3	
	Bath or shower?	3	
Do CF patients have to share any bathroom facilities?		No	It would be unusual for patients to have to share facilities due to low CF patient numbers.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		Yes	Each room has a lockable drug locker.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Each room has a wall-mounted TV.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	All rooms have a pull-out bed. There are also facilities of parent shower, toilet and separate room, where they could stay overnight.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open to family.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	All rooms have a fridge and parents can use the microwave in the ward kitchen.
What facilities are provided for teenagers?			PS games. TV. Table football and a good selection of toys in the play room. Patients usually bring in own IT.

Environmental walkthrough: other

	Hospital name	Hillingdon Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Inpatients for two-week stays can get parking for £25 inclusive.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Good signage.
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?		CF patients do not wait at either. X-rays would be pre-planned. DEXA scan – carried out at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	The Health Care Assistants (HCA) take prescriptions to pharmacy and patients/parents collect on way out.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	PALS office, clearly advertised on direction signage.
Are there patient comment/feedback boxes?	Yes	Also patient questionnaires and audits of patient experience.

Additional comments:

- The hospital can be reached by multiple bus services. Queues for the car park form on the main road, as parking is limited. There is a drop-off point where 0–10 minutes is free.

Charges:

10–30 mins – £1.60
 30 mins–1 hr – £2.70
 1–1.30 hrs – £3.20
 1.30–2 hrs – £3.60
 10–24 hrs – £10.60.

12. Queen Elizabeth II and Lister Hospitals

No risk matrix or staffing levels submitted.

Patient survey

Queen Elizabeth II and Lister Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital:

“We couldn’t wish for more from our CF team, just wish they were a little closer sometimes.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Queen Elizabeth II Welwyn Garden City
	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	Each child is allocated their own room and this is cleaned after use.
Do patients spend any time in the waiting room?	Yes	The clinic often has non-CF patients, who are slotted in between CF patients. If the children arrive at their allocated time they will not overlap. Children who arrive too early and cannot be accommodated are asked to go and have a drink elsewhere until their appointment time. After checking in with reception, they are taken direct to the clinic room.
Is there easy access to toilets?	Yes	Male and female.
Where do height and weight measurements take place? Is this appropriate?	Yes	Separate height and weight room. Surfaces are wiped down after use by CNS.
Where are lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	Yes	All three clinic rooms are adequately sized and equipped, fit for purpose.
For annual review patients, are any distractions provided?		Takes place at RBH. Clinic patients are asked to bring own distractions; they receive a letter requesting this.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Three patients. Not seen in diabetes clinic at present due to hospital move. They are seen at Chelsea and Westminster.
Transition patients – can they get a tour of outpatient facilities?	N/A	
Transition/new patients – do they get an information pack?	No	This is given at their tertiary centre.

Additional comments:

- The hospital is in a transition state. On-site there is a new large, impressive outpatients building which opens for use next May. This will not have any wards; patients will be admitted to Lister Hospital.
- The hospital at present is quite sparse and 'ghostly' as all of the wards and most departments have moved out. The building looks very tired, there is no one manning the main reception or PALS desk.
- The CNS does not know what facilities they are going to have as of yet in the new building.
- The CNS cleans the rooms in between use.
- The dietitian and the physiotherapist come to clinic from RBH.
- There is an entrance and exit door for cross-infection purposes.
- There is always a spare clinic room available for urgent patients and always a spare appointment at the end of clinic for these.

Environmental walkthrough: other

	Hospital name	Queen Elizabeth II Welwyn Garden City
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	0–15 minutes drop-off is free of charge; 0–2 hours £3.40; 2–5 hours £5.30; 5–24 hours £7.70.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	To outpatients department.
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?		Radiology – currently only used for urgent patients, never two CF patients at any one time. Pharmacy – unlikely to mix due to low patient numbers and staggered appointments. DEXA scan – at Lister or on annual review at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	Health Care Assistant can collect prescriptions.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	No	PALS desk has closed down due to the planned hospital move.
Are there patient comment/feedback boxes?	Yes	'Friends and Family' at outpatients reception and also a young people's survey form for completion.

Additional comments:

- Pharmacy on level one has seating for twelve.
- X-ray, situated on level five, has a large waiting area.
- Pathology is housed in a separate building on site. Bloods are always booked at QEII; HCA takes bloods for under-fives, CNS over-fives.

Environmental walkthrough: ward

Ward name: Bluebell ward

Microbiology status: General

		Hospital name	Lister Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			Ward suitable for CF care.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		8	
Do the en suites have:	Toilets?	2	
	Wash basins?	8	
	Bath or shower?	2	
Do CF patients have to share any bathroom facilities?		Yes	If not in one of the en suite cubicles.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)			This is a children's ward. There are facilities to lock away medicines by the side of the bed if appropriate.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	The service is free.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Parents are able to stay overnight.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	There is free visiting on the ward for family members.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	We have a fully refurbished parents' kitchen and rest area.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		They have a choice of cubicle if available. There is also a separate teenage sitting room.
Is there access to a gym or exercise equipment in the rooms?	No	We are a children's ward in a district general hospital.
What facilities are there to help with school and further studies?	No	We liaise with schools and also link with the home tuition service.
Is there a relatives' room?	Yes	
What internet access is there?	Yes	Wi-Fi. There is internet access on the ward and children have access to computer games and iPads.
What facilities are there to enable students to continue work and study?		They can use the teenage room or other areas of the ward.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sinks in rooms.
What facilities are provided for those with MRSA?		Any patient with MRSA is isolated in one of the cubicles.
What facilities are provided for those with <i>B. cepacia</i> ?		Again, the patient will be in a cubicle.
What facilities are provided for those with other complex microbiology?		It will depend on the bug that is grown.
Are patient information leaflets readily available on ward?		We share care with regional units and the information leaflets are generally supplied there. We do have access to information electronically and share that with patients.
Transition patients – can they get a tour of ward facilities?	N/A	

Additional comments:

- Patients attend outpatients at QE11 Hospital in Welwyn Garden City. All wards are now at Lister.

	Hospital name	Lister 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	Clear signage for the children's ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	No, not in all areas	Children's appointments arranged with outside departments to avoid this.
Do patients have to wait at pharmacy for prescriptions?		When on the ward the medicines are arranged to be delivered to the ward, before the child goes home.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	
Are there patient comment/feedback boxes?	Yes	

13. Queen Mary's (St Helier) Hospital

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	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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green	Green	
	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	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 <i>Pseudomonas aeruginosa</i> (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%	Amber	Amber	Audit data.
3.4 Cystic fibrosis related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Red	Red	
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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% 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%	Amber	Amber	
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	
	% 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 at weekends	100%	Green	Green	
	% 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%	Red	Amber	
	% availability of a clinical psychologist at clinic	100%	Green	Green	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red Contact duty social worker	N/A	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Red Contact duty social worker	N/A	Social worker compliance impossible in most units.
	% availability of a pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% 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 in the past 12 months	<1%	1	Unclear	Unclear numerator and denominator.
5.2	Number of clinical incidents reported within the past 12 months	<1%	3	Unclear	Unclear numerator and denominator.
5.3	User survey undertaken a minimum of every three years	100%	Red	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	Queen Mary's (St Helier) Hospital
Consultant 1	0.5	1	1	1.5 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.4 WTE
Physiotherapist	2	3	4	0.15 WTE
Dietitian	0.5	1	1.5	0.15 WTE
Clinical psychologist	0.5	1	1.5	0.1 WTE
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	1 WTE
Database coordinator	0.4	0.8	1	

Patient survey

Queen Mary's (St Helier) Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“We are especially happy with the physio and dietitian at Queen Mary’s. We are especially happy with the support given by the diabetic team for CFRD. We are very pleased if we have a consultation with Prof. Jane Davies at the Brompton, as she is always thorough, approachable and conscientious, takes time to explain everything, and we feel she always puts our child and his needs before everything else.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Queen Mary's Children's Hospital (St Helier)
	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	Appointments are staggered every half an hour.
Do patients spend any time in the waiting room?	No	Patients check in and are sent directly to either the height and weight room or the clinic room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Separate room, cleaned in between patients.
Where are lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	Yes	Good size, bright and well equipped.
For annual review patients, are any distractions provided?	N/A	RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	One patient. Arrange for endocrinology team to attend clinic appointment, occasional separate visit to diabetes team.
Transition patients – can they get a tour of outpatient facilities?	Yes	New patients.
Transition/new patients – do they get an information pack?	Yes	RBH.

Additional comments:

- Queen Mary's Children's Hospital has 18 patients and they range from 6 to 17 years old, mostly 12 to 14-year-olds.
- The outpatients department has a very large waiting room equipped with a vast amount of seating and many toys. The walls are decorated with child-orientated artwork.
- Toys are removed from the clinic rooms to minimise cross-infection.

Environmental walkthrough: ward

Ward name: Children's ward

Microbiology status: All microbiology

		Hospital name	Queen Mary's Children's Hospital (St Helier)
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		6	
Do the en suites have:	Toilets?	1	1 with full en suite facilities.
	Wash basins?	1	
	Bath or shower?	1	
Do CF patients have to share any bathroom facilities?		No	There would rarely be 2 patients admitted at any one time. If necessary a bathroom could be allocated and the patient would be admitted to a room at either end of the ward.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		No	Drugs are kept locked away in the treatment room.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	TV is free to children, along with a free phone service.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Pull-down bed.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open to all.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Both appliances in the parents' kitchen/room; none in the side rooms.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		Access to Wii/Starlight, DVDs, games.
Is there access to a gym or exercise equipment in the rooms?	Yes	Patients are taken to the gym daily. Physiotherapy gym equipped with good selection of exercise balls/steps, bike, treadmill, therapy bed, Xbox, Wii Fit and loose weights.
What facilities are there to help with school and further studies?		1:1 one-hour tuition daily with teacher who can also liaise with the school. Patients can bring in own IT.
Is there a relatives' room?	Yes	Equipped with microwave, fridge, free tea and coffee making facility and seating.
What internet access is there?		Wi-Fi, payable.
What facilities are there to enable students to continue work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Patients bring in own steriliser unit or this can be provided for stay. Use of sink in room.
What facilities are provided for those with MRSA?		(One patient) Isolation, follow guidelines.
What facilities are provided for those with <i>B. cepacia</i> ?		Isolation, follow guidelines.
What facilities are provided for those with other complex microbiology?		Isolation, follow guidelines.
Are patient information leaflets readily available on ward?	Yes	Racks of general leaflets in outpatients and on ward. CF leaflets can be issued on request.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: other

	Hospital name	Queen Mary's Children's Hospital (St Helier)
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Concessions for inpatients of £5 per week. Improvements have recently been made, adding extra parking spaces.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Wall boards also in lifts.
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?		Pharmacy – enclosed space, however patients do not wait. Prescriptions can be sent to pharmacy and collected on way out or CNS can collect and take to ward. X-ray – located next to outpatients. Patients are sent directly from clinic or can be phoned ahead. DEXA scan at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Fully manned office with many leaflets displayed.
Are there patient comment/feedback boxes?	Yes	Many feedback boxes located throughout the ward/outpatients.

14. Southend Hospital

No risk matrix or staffing levels submitted.

Patient survey

Southend Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“Royal Brompton – terrific team, solid strength, in depth and high levels of expertise in many areas. However, the team are clearly stretched and availability of key members is a struggle. Ward conditions are poor with shared and dated bathroom facilities a particular concern. Overall, great team – we wouldn’t trust anyone else with our son’s care – but they need much more support and updated facilities. Southend – lack of leadership of CF team, low levels of expertise, regular changes in staff and CF care is clearly not a priority.”

“Regarding Southend care, we have often been given advice that has been overruled by the Brompton. Locally, we feel we are advising doctors about cystic fibrosis procedures rather than the other way around. Local CF nurse is hard to get hold of, whereas Brompton always return calls. We have now opted to travel to London for clinics rather than attend a clinic local to us, as we don’t feel confident in the care provided.”

“They are OK, but they don’t always keep appointments.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Southend 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	Large seated waiting area.
Do patients spend any time in the waiting room?	No	Staggered appointments. Patients are checked in and directed to the clinic room where the team will visit the patient.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight room. Equipment is cleaned by the CNS after use.
Where are lung function tests done for each visit?		Dedicated room. Machine is cleaned after use and the room is left to air.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	N/A	Annual review at RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Approximately 6–8 patients, who attend Chelsea and Westminster.
Transition patients – can they get a tour of outpatient facilities?	N/A	
Transition/new patients – do they get an information pack?	Yes	Receive new patient pack from RBH.

Additional comments:

- Carlingford Centre is a separate children's outpatient building to the rear of the main hospital. The centre was built eight years ago. There is a further parking area nearer to the outpatient building.
- There are six clinic rooms available for use, all of a good size, clean, bright and well equipped. The patients are sent directly to the clinic room and the staff rotate around them. One of the rooms is used by the staff.
- On diagnosis, parents are given physiotherapy training at the RBH during a two-day stay. They then receive a follow-up home visit. The CNS makes four home visits a year.

Environmental walkthrough: ward

Ward name: Neptune (1st Floor) 27-bedded children's ward

Microbiology status: General paediatrics

		Hospital name	Southend Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable (26 CF patients).
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		6	15 side rooms in total, 6 fit for CF patients.
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.)		N/A	All drugs are kept in a locked drug room. These are prepared and checked before dispensing.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Each side room has a wall-mounted TV.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull-down beds.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open hours to parents.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Not in side room; in parents' room.
What facilities are provided for teenagers?			Portable DVD players. Over-12s room, small room with desked area, equipped with Wii, Xbox, keyboard and computer. Portable PS can be put in room.

	Hospital name	Southend Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Charges are: Up to 30 minutes – free; 0–3 hours – £3.00; 3–6 hours – £4.00; 6–12 hours – £6.00; 12–24 hours – £10.00. 7 day concession £10.00 for inpatients only.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Colour-coded signage.
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?		Pharmacy – two drop-off counters and a collection counter. Patients take a ticket and disperse. There is no room to wait in pharmacy. At the main reception area there is a large coffee shop with seating. Large TV screens display the ticket number for collection of prescriptions when ready. X-ray – Large waiting area. Patients requiring urgent x-rays would wait. Due to low CF patient numbers, unlikely to mix. Routine x-rays can be booked; staff can call ahead of visit. DEXA scan at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	PALS office near lift to ward.
Are there patient comment/feedback boxes?	Yes	On ward.

Additional comments:

- Cars queue along main road waiting to gain entrance to car park.

15. St Peter's Hospital

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Red	Red	

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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	No	Amber	
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green RBH	Green	
	Are there local operational guidelines/ policies for CF care?	100%	Green RBH	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	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 Single cubicle, en suite not always available	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	

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%	Red	Red	
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	
	% 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%	N/A Shared care	N/A	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	N/A Shared care	N/A	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	Green	Amber	Unclear that specialist physio covers at weekends.
	% availability of a CF specialist dietitian at clinic	100%	Amber Shared care	N/A	Dietitian covers one clinic a month (0.025 WTE).

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%	N/A Shared care	Red	
	% availability of a clinical psychologist at clinic	100%	Red Not available	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Red	Unclear	
	% availability of a social worker at clinic	100%	Red Not present in clinic	N/A	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Red	N/A	Social worker compliance impossible in most units.
	% availability of a pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	N/A	
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 in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
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	St Peter's Chertsey
Consultant 1	0.5	1	1	1.0 WTE
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	0.7 WTE
Physiotherapist	2	3	4	2.0 WTE
Dietitian	0.5	1	1.5	0.8 WTE
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	0.8 WTE
Secretary	0.5	1	2	0.8 WTE
Admin assistant				0.8 WTE
Database coordinator	0.4	0.8	1	

Patient survey

St Peter's Hospital, Chertsey

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“The staff at the Brompton are always helpful, attentive and supportive. The home care team is always available and very flexible. We have had issues in the past at St Peter’s getting an appointment in clinic and find their cross-infection procedure almost non-existent (especially if attending a non-joint clinic due to no spaces at a joint one). Feel more comfortable making the extra travel to Brompton.”

“I think bloods should be done the months before the annual review, as this would give the results on the assessment day. Be nice to see the child’s psychotherapist. Been happy with the Brompton nurse, who is amazing, we love her. Like the combined clinic at St Peter’s too.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	St Peter's Hospital, Chertsey
	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	Seating for 25. TV and toys for use.
Do patients spend any time in the waiting room?	No	All appointments are timed and staggered in order that patients do not to meet at any time.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	There are two rooms used for this and cleaned in between patients by the clinical nurse specialist.
Where are lung function tests done for each visit?		In clinic room using portable machine.
Are clinic rooms appropriately sized?	Yes	Well equipped, bright and clean.
For annual review patients, are any distractions provided?	N/A	Annual review at the RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	One patient has recently been diagnosed and attends Chelsea and Westminster or RBH for appointments at present.
Transition patients – can they get a tour of outpatient facilities?	N/A	New patients can have a tour if required.
Transition/new patients – do they get an information pack?	Yes	Information pack from RBH. Team at St Peter's Hospital is in the process of compiling a contacts leaflet at present.

Additional comments:

- Dedicated CF outpatient clinics are held on the second Wednesday of the month. There are two clinic rooms available for use, along with the two height and weight rooms. Patients are taken directly to a clinic room after being measured and weighed on arrival. The physiotherapist and CNS visit the patients in their clinic rooms. All rooms are cleaned in between patients. The patient is then taken to see the consultant in his own room and this is also wiped down between patient use. Improvements could be made if the consultant were to visit the patients without moving them.

Environmental walkthrough: ward

Ward name: Ash Ward – inpatients; 10 patients

Microbiology status: General paediatrics

		Hospital name	St Peter's Hospital, Chertsey
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		3	Two side rooms have full en suite facilities. A further room is available for use for a baby, as this does not have bath/shower facility.
Do the en suites have:	Toilets?	2/1	
	Wash basins?	2/1	
	Bath or shower?	2	
Do CF patients have to share any bathroom facilities?		No	Only if the third side room is in use, then a bathroom would have to be cleaned before and after use.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		N/A	All medications are kept in the general medicine cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Pull-down bed in one room and also use of parent accommodation, which consists of one bedroom with shower and toilet, a fully equipped kitchen and sitting room.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open to immediate family.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	These can be found in the parents' kitchen or the over-12s room.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		Room for over-12s equipped with couch, microwave, kettle, fridge, TV and games. There are mobile games, iPads and laptops available for use in side rooms.
Is there access to a gym or exercise equipment in the rooms?	Yes	No equipment for rooms. Patients prefer to go with the physiotherapist to the gym.
What facilities are there to help with school and further studies?		There is a very well-equipped school room with three computers for use. Teachers do a tour of the ward each morning and can liaise with schools along with parents for school work.
Is there a relatives' room?	Yes	Parent sitting room with kitchen equipped with kettle, microwave, facility for tea/coffee making.
What internet access is there?		Wi-Fi.
What facilities are there to enable students to continue work and study?		School room – as above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sterilising containers with tablets available.
What facilities are provided for those with MRSA?		Inform infection control and follow guidelines.
What facilities are provided for those with <i>B. cepacia</i> ?		Inform infection control and follow guidelines.
What facilities are provided for those with other complex microbiology?		Inform infection control and follow guidelines.
Are patient information leaflets readily available on ward?	Yes	General leaflets, and give guidance and information on request.
Transition patients – can they get a tour of ward facilities?		New patients can have a tour.

	Hospital name	St Peter's Hospital, Chertsey
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	A disc allowing free parking can be issued at the team's discretion. A ticket for free parking could be issued if the clinic were to run late.
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?		Pharmacy – patients are not given prescriptions to collect in the hospital, they are issued FP10 for outside pharmacies. Inpatients are issued their drugs on discharge or can take the form to their GP. Radiology – routine x-rays are carried out at RBH. Due to low patient numbers it is unlikely patients would meet. DEXA scan at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	As above.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	On noticeboard at outpatients clinic and also on the ward.
Are there patient comment/feedback boxes?	Yes	'Friends and Family' box at outpatients clinic and also on ward reception.

16. St Richard's and Worthing Hospitals

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green RBH	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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% 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%	Amber	Amber	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Red RBH	Green	Applies RBH pathways.
	Are there local operational guidelines/ policies for CF care?	100%	Green RBH	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	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%	Red	Red	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% 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%	Amber	Amber	
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 at weekends	100%	Green	Green	
	% 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%	Red	Red	
	% availability of a clinical psychologist at clinic	100%	Red	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Red	Unclear	
	% availability of a social worker at clinic	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a pharmacist at clinic	100%	Red No pharmacist advice available	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
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	St Richard's and Worthing Hospitals
Consultant 1	0.5	1	1	0.1 WTE
Consultant 2	0.3	0.5	1	0.05 WTE
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.8 WTE
Physiotherapist	2	3	4	0.5 WTE
Dietitian	0.5	1	1.5	0.1 WTE
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	N/A
Pharmacist	0.5	1	1	0.05 WTE
Secretary	0.5	1	2	0.1 WTE
Database coordinator	0.4	0.8	1	

Patient survey

St Richard's Hospital, Chichester

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“The annual review process at the Brompton is poor. We come a long way and appointments are scattered. When we returned for the second half of the review, results weren’t available and the report sent home called my child by the wrong name – doesn’t instill much confidence!”

“St Richard’s – excellent. Royal Brompton – no relationship with any of the team there.”

Patient survey

Worthing Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“Most of his care has come from Worthing Hospital under the doctor and his CF nurse. I cannot fault the care, help and professional attitude of all the team, as they are wonderful. Initially, we went to the Brompton when he was born and once again I would like to thank everyone involved as they gave him and us truly amazing care.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	St Richard's Hospital, Chichester
	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	Staggered appointments. Four slots at 2.30pm. Four slots at 3.30pm.
Do patients spend any time in the waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Two dedicated rooms, babies/children. Rooms cleaned in between patients.
Where are lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?		Five rooms: one for team, four for clinic. Rooms are pre-allocated with child name door signs.
For annual review patients, are any distractions provided?	N/A	
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	No patients. Would be a joint appointment with paediatric diabetes service.
Transition patients – can they get a tour of outpatient facilities?	Yes	For new patients.
Transition/new patients – do they get an information pack?	Yes	From RBH. Local staff information and numbers are given.

Additional comments:

- Clinic is held monthly and patients are seen bi-monthly.
- A tick sheet is used when the team rotates between rooms. The team members sign in and out to confirm that the patient has been seen.

Environmental walkthrough: ward

Ward name: Howard Children's Unit

Microbiology status: General paediatrics

		Hospital name	St Richard's Hospital, Chichester
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		6	One CF specific cubicle is funded by charity.
Do the en suites have:	Toilets?	6	Each have wet rooms.
	Wash basins?	6	Two of the cubicles would have a dedicated bathroom allocated. However, they are never usually needed due to one admission at any one time.
	Bath or shower?	6	
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	Medications are kept in drug room. There is also a lockable cabinet in each cubicle.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free, with Freeview and DVD.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	All cubicles have a Z-bed.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open for parents; otherwise 8am–8pm
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	In parents' kitchen. Patient fridge also in ward kitchen. Food is labelled and stored here.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		TV/DVD/Wi-Fi. Teenage sitting room: if there were more than one CF patient, which would be unusual, its use would be timetabled. Well-equipped room with table football, games, sofa seating, board games and music.
Is there access to a gym or exercise equipment in the rooms?	Yes	Wii Fit can be used in the room. Gym equipped with toys, trampet, and equipment to create obstacle course. Younger patients are encouraged to bring in their own scooters for exercise around ward. The adult gym is appropriate for teenagers, equipped with bikes, treadmill, trampette, rowing machine, bars steps and therapy beds, a good-sized room. There is an open courtyard to take children to play.
What facilities are there to help with school and further studies?		Wi-Fi. The team can contact the school if needed. Children are encouraged to attend school and treatment timetables facilitate this. The two play therapists can support the children with school work.
Is there a relatives' room?	Yes	Parent kitchen and sitting room. Facility for free tea and coffee, seating for six, kitchen area with microwave and fridge.
What internet access is there?		Wi-Fi. The password/user can be used at Worthing. Five patients can sign in at any one time.
What facilities are there to enable students to continue work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Use of sinks. Nurses will clean if parents prefer. Some parents take home equipment to clean. Steam sterilisers can be used.
What facilities are provided for those with MRSA?		Follow infection control and RBH guidelines.
What facilities are provided for those with <i>B. cepacia</i> ?		Follow infection control and RBH guidelines.
What facilities are provided for those with other complex microbiology?		Follow infection control and RBH guidelines.
Are patient information leaflets readily available on ward?	Yes	General leaflets. Can direct to appropriate literature or website.
Transition patients – can they get a tour of ward facilities?	Yes	Would take on tour at first CF clinic appointment.

		Hospital name	St Richard's Hospital, Chichester
		Yes/no/number/N/A	Notes/comments
Car parking			
Any concessions for patients and families?	Yes	Patients can receive a permit on admittance to obtain free parking for inpatient stay. Never long queues to park, ample parking; have in-house attendants. Charge: 4+ hours = £6.	
Other hospital areas			
Clear signage to CF unit and or ward?	No	No signs directing to outpatients from entrance. Patients have to walk through antenatal to get to the entrance to the paediatric waiting room/clinic.	
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?		Pharmacy: electronic number collection system. 36+ seats. Patients could go to café nearby if having to wait. X-ray: more than one waiting area. DEXA: Bognor War Memorial by appointment.	
Do patients have to wait at pharmacy for prescriptions?	Yes	10–45 minutes. Potentially patients could mix. However, not many prescriptions are issued. Patients are usually issued rolling prescriptions. Patient awareness is used. There has never been an issue with the system.	
Patient information			
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	At main reception, a large manned office, leaflets and signposted.	
Are there patient comment/feedback boxes?	Yes	Periodic surveys, iPad feedback surveys. Outpatient satisfactory survey. Ward satisfaction survey.	

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Worthing Hospital
	Yes/no/number/N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room etc.)	Yes	Patients do not wait here.
Do patients spend any time in the waiting room?	No	Taken to height and weight room, then to clinic room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Dedicated room, cleaned and labelled in between.
Where are lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	No	Clinic rooms are fairly small generally and would not accommodate a buggy. There is also one room that could be used for clinic, however it does not have a sink.
For annual review patients, are any distractions provided?		RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Joint clinic (one patient).
Transition patients – can they get a tour of outpatient facilities?	Yes	New patients.
Transition/new patients – do they get an information pack?	Yes	RBH pack and also given local leaflets.

Additional comments:

- Clinic is held every two months. There are four rooms for clinic. In addition, one room for the team. There are a further two rooms for use in children's speech therapy, which could be used, however one of those does not have a sink. The waiting room is large with a good-sized play area. However, this is not used for CF patients.
- Physiotherapy room off outpatients. Trampoline, exercise ball, TV/games and various equipment to create obstacle courses.
- There is a well-equipped sensory room.

Environmental walkthrough: ward

Ward name: Blue Fin

Microbiology status: General paediatrics

		Hospital name	Worthing Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		8	Total of eight rooms; usually only have one patient admitted at any time.
Do the en suites have:	Toilets?	4	The ward was fully refurbished two years ago.
	Wash basins?	4	
	Bath or shower?	4	
Do CF patients have to share any bathroom facilities?		No	Due to low numbers, never more than one room used.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		Yes	Locker in cubicle. Medications are kept in the drug room.
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	All rooms have Z-beds.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open visiting.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In parents' kitchen and ward kitchen.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		'Charlie's Room' – teenage room. This is a large room, very well equipped with its own kitchen area. Pool table, table football, sofa, TV games.
Is there access to a gym or exercise equipment in the rooms?	Yes	Child-friendly gym with adjoining sensory room; age dependent and also use of the adult gym. Can have trampette and games in room, also Wi-Fi and play station. Park next door for outdoor activity.
What facilities are there to help with school and further studies?		Use of iPads.
Is there a relatives' room?	Yes	Parent's sitting room with starlight TV, with kitchen area and free tea/coffee.
What internet access is there?		Wi-Fi. Free to CF patients, usually £5 per day/£10 per week.
What facilities are there to enable students to continue work and study?		Encouraged to attend school.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Use of sink in room, use of steriliser unit.
What facilities are provided for those with MRSA?		Follow guidance and infection control.
What facilities are provided for those with <i>B. cepacia</i> ?		Follow guidance and infection control/ isolation. One patient – after discharge, room is cleaned using Biquel.
What facilities are provided for those with other complex microbiology?		Follow guidance and infection control.
Are patient information leaflets readily available on ward?	Yes	General leaflets available, specific on request or guide to website.
Transition patients – can they get a tour of ward facilities?	Yes	Would give tour at first appointment.

	Hospital name	Worthing Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	Parking is controlled by an external company. 1 hour – £1.30; up to 6 hrs – £5.90; up to 24 hrs – £7.60. Seven-day tickets are available. Patients should contact attendants for this.
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?		Pharmacy – has seating for 15, patients would only collect. Volunteers are assigned to the clinic to take the prescriptions to pharmacy. X-ray – appointments booked. Large amount of seating and more in corridor. DEXA – at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	Very occasionally.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Main entrance office with general leaflets displayed.
Are there patient comment/feedback boxes?	Yes	At outpatients and on ward. Conduct iPad surveys on ward.

Additional comments:

- Pharmacy is located next door to the outpatients clinic.

17. Watford General Hospital

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green RBH	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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes however do not have CF CNS	Amber	No CF CNS.
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green RBH	Green	
	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	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%	Red Strict segregation from other CF patients	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	N/A	N/A	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (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 RBH	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green RBH	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green RBH	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%	Unknown	Unknown	
	% 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%	Red No CF CNS Always CF link nurse or community nurse	Red	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Red No CF CNS Always CF link nurse or community nurse	Red	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	Green	Green	
	% 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	
	% availability of a clinical psychologist at clinic	100%	Red	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Red Access to CAMHS	Unclear	
	% availability of a social worker at clinic	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a pharmacist at clinic	100%	Red	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% 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	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
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 Not been agreed yet	Red	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Watford General Hospital
Consultant 1	0.5	1	1	11 PAs
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	0 Link nurse and community nurse
Physiotherapist	2	3	4	0.4 + 1.0 WTE
Physiotherapist assistant				0.4 WTE
Dietitian	0.5	1	1.5	0.6 WTE
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.4 + 0.4 WTE
Secretary	0.5	1	2	0.3 WTE
Database coordinator	0.4	0.8	1	
Play therapists				2.0 WTE
ESTMA teacher				0.6 WTE

Patient survey

Watford General Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	1	2	1	0
Waiting times	1	1	2	0
Cross-infection/segregation	0	4	0	0
Cleanliness	0	3	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	2	0	0
Cleanliness	0	2	1	0
Cross-infection/segregation	0	2	1	0
Food	0	0	1	2
Physiotherapy availability to assist/assess airway clearance and exercise during weekdays	0	2	1	0
Physiotherapy availability to assist/assess airway clearance and exercise during weekends	0	1	1	1

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“Full trust in clinical care and decision making. Excellent relationship with CF nurses, who are always available and will always return calls. Physio will come out if needed and is very supportive. Good joint working with local (Watford General) and Brompton. Consistency in care and advice. Overall, cannot fault care.”

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Watford General 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	On arrival, patients booked in at reception are weighed and measured, then shown to a pre-designated clinic room, where they will stay until the clinic visit is over. Maximum number of patients per clinic is 7. 33 patients attend Watford in total. In reality, rooms may not be left empty for 30 mins after cleaning.
Do patients spend any time in the waiting room?	No	
Is there easy access to toilets?	Yes	Room 6 and separate baby change area within clinic area.
Where do height and weight measurements take place? Is this appropriate?		Communal room and baby room. Cleaned as per infection control directions in between patients. In reality, room not left empty for 30 mins after cleaning.
Where are lung function tests done for each visit?		Lung function and physio assessment performed individually in each clinic room. The lung function testing machine is moved between the rooms and cleaned after each use, as stated in the cleaning protocol. 3 machines. One for CF, another for CF and other respiratory patients, and one for other infections. Follow deep cleaning protocol.
Are clinic rooms appropriately sized?	Yes	Large rooms with windows. All communal toys removed before clinic starts.
For annual review patients, are any distractions provided?	N/A	No annual reviews performed at Watford General Hospital.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Same clinic area. Same guidelines apply. CF patients are not segregated from other non-CF diabetic patients.
Transition patients – can they get a tour of outpatient facilities?	Yes	No adult CF care at Watford General. However, paediatric patients can/have been taken on tours of tertiary adult CF services.
Transition/new patients – do they get an information pack?	Yes	This is from specialist centre as per their instruction. Either GOSH or RBH.

Additional comments:

- The outpatient area is clean. However, it is in urgent need of refurbishment, to enhance the dowdy and tired environment.

Environmental walkthrough: ward

Ward name: Starfish ward

Microbiology status: All

		Hospital name	Watford General Hospital
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	General paediatric ward with strict segregation. No more than 2–3 inpatients at one time. For West Hertfordshire Hospitals NHS Trust there is a strategic health plan to build a new acute hospital, which will include paediatrics. However, this project is not green lit as yet, despite being many years in the making.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Cubicles are not always available. CF patients can be managed in one of two four-bedded bays. Any patient with an infectious respiratory illness is not allowed to be managed in the same bay. In practice, other patients are often surgical, orthopaedic or general paediatric. This can be difficult to manage in winter time when there is an increased incidence of respiratory illness in the population as a whole.
Number of side rooms?		4	Includes two positive or negative airflow cubicles with en suite facilities. However, these are often in use for oncology. Also, four baby cubicles without en suite facilities, in practice are rarely used for CF patients, who tend to be older.
Do the en suites have:	Toilets?	Yes	Shower. Bath available on ward.
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Y/N	If in four-bedded bay, will share bathroom with other non-CF patients only.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward.)		N/A	All patients' own medication is stored in the locked drug room. Currently advise if parents giving medication, a nurse must countersign the drug chart. Aware that parents do administer medication and children self-medicate.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	

	Yes/no/ number/ N/A	Notes/comments
Are there facilities to allow parents/ carers/partners to stay overnight?	Yes	Every bed has a fold-down parents' bed next to it.
Visiting hours – are there allowances for CF patients' families out of normal hours?	Yes	Parents' visiting is 24/7. Open visiting during the day for other family members.
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 with computers, TVs and games consoles. Information leaflets on noticeboard. No grown-ups allowed!

Environmental walkthrough: other

	Hospital name	Watford General Hospital
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Parents pay £12 a week for a concessionary permit.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Patients are managed on paediatric ward. No dedicated CF centre.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	Patients always escorted by a nurse or play therapist who are aware of segregation policy.
Do patients have to wait at pharmacy for prescriptions?	N/A	Patients do not go to pharmacy. If an inpatient pharmacist faxes prescription, nurse picks it up.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Also a parent support group for Starfish ward run by volunteers who can provide information for parents.
Are there patient comment/feedback boxes?	Yes	'Friends and Family'.

Additional comments:

- Good availability of beds at Watford. Admissions are generally within 24–48 hours. Poor availability of beds for patients who require admission to Brompton for IVs. They may have to wait two weeks for a bed. This system is not working. Requires consideration.
- Commissioning 55/45 split Watford/Brompton makes it difficult to finance Watford service.

Areas of good practice:

- Clinic segregation.
- An enthusiastic MDT with good clinic input including play therapist.
- Good communication with Brompton.

Areas for improvement:

- Commissioning arrangements and SLA discussions.
- Protected time for pharmacists to allow more clinic involvement.
- Prioritise CF prescriptions at pharmacy.
- Inequitable home care. Brompton patients have more ready-prepared home IVs.

Recommendations:

- CF specialist nurse Band 7 required to coordinate care.
- Consider closer working arrangements with business manager.
- Consider cross-cover for annual leave and sickness. For example, CF consultant has no on-site cover. Arrangements are in place to call Brompton for advice.

18. Whipps Cross Hospital

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	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	RBH	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 an annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Green	
	% 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%	Red	Red	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	RBH	Green	
	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	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%	N/A	N/A	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (PA) in the previous 12 months	100%	N/A	N/A	
	% 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%	RBH	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	RBH	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A	N/A	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	RBH	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%	Amber	Amber	
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%	Same day discharge summaries	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Red no CNS	Red	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Red	Red	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	Amber	Amber	Weekend cover lacking.
	% availability of a CF specialist dietitian at clinic	100%	Red	Red	

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	
	% availability of a clinical psychologist at clinic	100%	Red	N/A	? Requirement for routine clinic.
	% availability of a clinical psychologist for inpatients	100%	Red	N/A	
	% availability of a social worker at clinic	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a social worker for inpatients	100%	Red	Red	Social worker compliance impossible in most units.
	% availability of a pharmacist at clinic	100%	Red	Red	
	% availability of a pharmacist for inpatients	100%	Red	Green	
4.3 Home care	% 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%	Red	Unclear	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Whipps Cross Hospital
Consultant 1	0.5	1	1	No specific PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	
Physiotherapist	2	3	4	No specific WTE
Dietitian	0.5	1	1.5	
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	Part of normal job
Database coordinator	0.4	0.8	1	

No patient surveys received.

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Whipps Cross 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	Large waiting room with seating.
Do patients spend any time in the waiting room?	No	Patients check in and are directed to the clinic room, where the staff rotate around the patients.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight room. Nurse calls patient out for this. The room is cleaned after use and a 30-minute gap is left between patients to air room.
Where are lung function tests done for each visit?		The physiotherapist uses a portable machine, which is cleaned between patients.
Are clinic rooms appropriately sized?	Yes	All rooms are well equipped and clean.
For annual review patients, are any distractions provided?	N/A	Annual review at RBH.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	None. If they had any patients they would attend a joint clinic.
Transition patients – can they get a tour of outpatient facilities?	Yes	New patients can have a tour.
Transition/new patients – do they get an information pack?	Yes	Pack from RBH.

Additional comments:

- There are five rooms available: 2–3 rooms are used at clinic. Two appointments at 9am, two at 10.30am.

Environmental walkthrough: ward

Ward name: Acorn Children's Unit, 27-bedded ward (10 CF patients)

Microbiology status: General paediatrics

		Hospital name	Whipps Cross
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		5	15 side rooms in total, 5 suitable for CF patient use.
Do the en suites have:	Toilets?	Yes	3 rooms have full en suite facilities and 2 rooms have sink with toilet. If there were more than 1 CF inpatient, then rooms at each end of the ward can be allocated. The patients can then use separate entrance/exit doors to the ward.
	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	Each room has a wall-mounted, lockable drugs cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free until 8pm, after which parents can pay for further viewing.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Beds available for the rooms.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open to parents/siblings. Others are restricted to times, 10am–8pm with restricted meal times.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	In parents' room.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		Adolescents' room equipped with TV, DVDs and seating. Most teenagers prefer to stay in room and bring in own IT.
Is there access to a gym or exercise equipment in the rooms?	Yes	Patients can have skipping ropes and balls in room. Physiotherapist prefers to take patients to gym or outside for exercise. All patients are offered two physiotherapy sessions daily; whether they have both treatments depends if the patient is available, eg if at school.
What facilities are there to help with school and further studies?		Patients can use a laptop from the school room.
Is there a relatives' room?	Yes	The parents' room is equipped with coffee table and seating. There is a kitchenette with fridge and microwave, also a shower and toilet for use.
What internet access is there?		Internet connection in the school room only.
What facilities are there to enable students to continue work and study?		Five teachers rotate daily. There are also play therapists available. Children are expected to go out to school if well enough. The school room is fully equipped and quite impressive with IT, books, games and art/craft work. There is access to an outside play area.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Steriliser in room for use.
What facilities are provided for those with MRSA?		Isolation policy, follow guidelines.
What facilities are provided for those with <i>B. cepacia</i> ?		Isolation policy, follow guidelines.
What facilities are provided for those with other complex microbiology?		Isolation policy, follow guidelines.
Are patient information leaflets readily available on ward?	Yes	On request or website.
Transition patients – can they get a tour of ward facilities?	Yes	New patients can be given a guided tour by the consultant if requested.

	Hospital name	Whipps Cross
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free drop-off and pick-up points. Up to 2 hours – £2.50; 4 hours – £4.00; 6 hours – £6.00; 8 hours – £8.00; 24 hours – £15.00. Inpatients can get free parking. The CNS signs the ticket and the patient presents it to parking; this is for one week.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Colour-coded areas. Maps are displayed on the walls displaying 'you are here'.
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?		Pharmacy – CF patients are given outside prescriptions. Outpatient x-ray timings are controlled. DEXA – at RBH.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Office located near to main entrance. PALS leaflets displayed at outpatients reception desk.
Are there patient comment/feedback boxes?	Yes	At outpatients reception desk.

Additional comments:

- There are regular bus services which run through the hospital site.

19. Panel members

Iolo Doull*	Consultant	University Hospital of Wales
Maya Desai*	Consultant	Birmingham Children's Hospital
Lucy Paskin	CF Specialist Pharmacist	Birmingham Children's Hospital
Sally Hutchison	CF Specialist Pharmacist	Sheffield Children's Hospital
Alistair Duff	CF Clinical Psychologist	Leeds Royal Infirmary
Harriet Conniff	CF Clinical Psychologist	Norfolk & Norwich Hospital
Kathryn Azzopardi	CF Clinical Nurse Specialist	University Hospital of Wales
Wendy Nixon	CF Clinical Nurse Specialist	Birmingham Children's Hospital
Carolyn Patchell	CF Specialist Dietitian	Birmingham Children's Hospital
Helen McCabe	CF Specialist Dietitian	Royal Victoria Infirmary
Kate Lindsay	CF Specialist Physiotherapist	Bristol Royal Children's Hospital
Pamela McCormack	CF Specialist Physiotherapist	Alder Hey Hospital
Angela Mills	CF Social Worker	Nottingham University Hospital
Claire Oliver	CF Social Worker	Southampton General Hospital
Carrie Gardner	Commissioning	London Area NHS England
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

**Clinical leads for peer review.*

Bold text: attended on day of peer review.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2015. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: 2nd Floor, One Aldgate, London EC3N 1RE.