In partnership with

Cystic Fibrosis why we're here

British Thoracic Society

BIPRS

Peer review report

Southampton Regional Centre and Local District Hospitals 'Central South Coast' Paediatric Cystic Fibrosis Network

November 2013

1. Executive summary

1.1 Overview of the service

The 'Central South Coast' paediatric cystic fibrosis network comprises the regional specialist centre at Southampton Children's Hospital (SCH), nine UK network clinics and patients from Jersey and Guernsey. It provides care for around 220 patients.

Regional centre

Southampton Children's Hospital provides high-quality, full cystic fibrosis (CF) care to 55 patients, and largely has 'excellent' or 'good' patient feedback. The number of joint network clinics has increased (to around 80 per year) to ensure patients are seen at least twice a year by the Southampton-based specialist multidisciplinary team (MDT). The regional centre has been proactive in issuing a generous proportion (70%) of CF tariff to network clinics to strengthen local MDTs. The consultants from SCH have met with managers in their shared care units and a great deal of work had been done in relation to service level agreements (SLAs) and funding. Three shared care managers, as well as the SCH management team and Chief Executive, attended the peer review visit. SCH has an established research programme.

Network service

Around 160 (75%) children primarily receive care at network clinics. These clinics vary considerably in size – from 8 to 35 patients. Local MDTs are very committed to providing good care for their patients, but many staff have little or no recognised time for CF in their job plans. They often work well beyond their contracted hours. The availability of MDT review is therefore variable and many essential standards of care are not met. Patients' feedback on their local teams is generally good, but there is concern that some patients/parents are unaware of what is not provided, but could or should be. The local teams generally felt very well supported by University Hospital Southampton (UHS).

At the time of the peer review, most local clinicians were not aware of any implementation of the new tariff to fund the service improvements that they needed. It may not be possible to adequately resource all network clinics to meet the standards for seven-day MDT cover outlined in the Cystic Fibrosis Trust's 'Standards of Care (2011)'. Some innovative working and possibly difficult decisions are needed to ensure all children receive care as described by the national service specification, wherever they live.

1.2 Good practice examples

- Well-established and enthusiastic network service that strives to provide excellent care.
- Good transition programme, supported by a close relationship with the UHS adult CF service.
- Active research programme that aims to extend access to all patients in the network. Majority of network clinics are signed up to the 'TORPEDO-CF' study.

1.3 Key recommendations

- Review the practicality of sustaining a relatively high number of network clinics, particularly those with small patient numbers where there may be difficulty in achieving adequate seven-day MDT levels and meeting the Cystic Fibrosis Trust's Standards of Care, including those for inpatients. Projection of clinic numbers, particularly potential newborn screened (NBS) infants, could be based on local birth rates.

- Southampton clinicians and contracts/service managers must continue working with their counterparts in network clinics to ensure that staffing levels and the Cystic Fibrosis Trust's Standards of Care are met through the tariff provided. This should include the provision of CF in the job plans of staff in network clinics, as well as adequate cover arrangements. Strong support from specialist commissioners will be essential to achieving this, and this should be taken into account along with point 1 above.
- Increased bed capacity at SCH to ensure that admissions for local patients and from network clinics can be achieved in a timely and appropriate fashion.
- Increased time from centre pharmacist(s) to support network clinics' pharmacists, particularly for the complexities of financing expensive therapies and homecare IVs.
- Increase in psychology and social work support across the region – either as joint posts with other chronic illness specialities such as diabetes, and/or peripatetic staff from the regional centre regularly visiting network clinics.
- Administrative staff posts should be secure, and recognise the significant amount of service management that is done. Consideration should be given to a dedicated service manager position.

1.4 Areas for further consideration

- The need to attend the regional centre should not be seen as an exceptional occurrence. Efficient communications and feedback will strengthen rather than undermine the local team. A protocol should be developed to support families to attend SCH when needed.
- Involvement of patients and parents from network clinics, and of Cystic Fibrosis Trust advocate(s), in planning any significant changes to services.
- Review of 'CF-suspected' newborn screening process, particularly in smaller clinics, and to include assessment of sweat testing process across the region, in accordance with the Association for Clinical Biochemistry and Laboratory Medicine (ACB) standards.
- Continued development of 'virtual' cystic fibrosis-related diabetes (CFRD) clinic – comprising SCH diabetologists, dietitians and nurses linked with local teams to provide consistent guidance, management and support to children in network clinics.
- Ensure comprehensive and current management guidelines are in place and easily accessible for network clinics, eg via a web-based intranet.
- Training of respiratory grid trainees in all aspects of CF care (a problem for all paediatric specialist centres).

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

2.1 Models of care

Summary

Centre care at Southampton Children's Hospital

Full annual reviews are performed for the 55 patients attending the Southampton service by the extended MDT. Results are fed back effectively and an action plan made with the child and family.

Network care

There is a strong ethos of providing care at a local level wherever possible, and many patients rarely, if ever, visit SCH. There is a widespread view that patients and parents are unwilling to travel to Southampton. While this model has much in its favour, there are potential problems, particularly in those clinics with 10 or fewer patients.

Annual review investigations (except bone mineral density (DEXA) scans) are done at the network clinic prior to a visit from the Southampton team. A full clinical assessment is carried out by the CF consultant and regional MDT on the day. Results and an action plan are discussed on the day with the local service and fed back to the child and parent(s) by both teams.

Port CF

All patients in network and centre care have completed data on the UK CF Registry, as is essential for tariff. There are some inconsistencies between the number of patients in each clinic and those with full data on Port CF, as a result of new patients in their diagnostic year who don't have an annual review (AR) within the time frame of cut0off dates. Data for Port CF is collected during the centre team's visits to network clinics, and issues were raised about some difficulties faced by the UHS clerical team in getting full data.

2.2 Multidisciplinary care

Summary

Southampton Children's Hospital

Patients are seen routinely every two months and are almost always seen by a consultant, as well as the MDT, on each visit. Respiratory grid trainees are often unable to attend due to ward duties or British Medical Association – European Working Time Directive (EWTD) time-off – which impacts on their training.

The tariff has been used effectively to improve the previous shortfall in staffing levels, which now meet the Cystic Fibrosis Trust's Standards of Care. The only deficiency is a social worker, but an appointment is pending.

The service is administered by two, cross-covering Band 4 secretaries, with support from the lead CF specialist nurse. Effective and established administration of such a large network is essential for good clinical care, and it is strongly recommended that these administrative post(s) are secure and recognised as clinical coordinators (or similar). 'Secretarial' posts are often victim to restructuring as part of general cost savings.

Annual appraisals, including professional development programme (PDP) review, is well embedded at SCH for all staff, and regular, relevant study leave for meetings and conferences is well supported.

Pathways are in place for referral to nominated consultants in Southampton, or other centres (eg for organ transplant) when other specialist management is required.

The specialist team has produced several editions of a published book describing CF management. While a very good resource, it has the disadvantage of being difficult to update as treatment changes. Cystic Fibrosis Trust guidelines are used where appropriate and there are some excellent MDT-specific guidelines produced by the centre team.

HPA Laboratory Services use MOLDI-TOF species identification routinely on CF samples, which exceed the existing Cystic Fibrosis Trust's Standards of Care. Annual review samples are processed for extended species identification as per Trust guidelines.

Only one patient has CFRD and a joint consultation is held with the diabetologist.

2.3 Multidisciplinary care

Summary

Network clinics

New service level agreements (SLA) service specifications are for bi-annual follow-up visits from April 2013. Recent regional centre MDT expansion will enable this standard to be fulfilled, but does mean that approximately 80 network clinic visits per year will be required. This number of visits may be very physically and mentally demanding for the centre team, and significant travel time is not always recognised. Two previously stand-alone clinics joined the network in 2013, adding an extra 45 patients.

MDT levels, experience and availability varies considerably across the network. Many staff have no funding or allocated time in their job plans for CF, but they have significant CF commitments and much of their work is done through goodwill, or outside contracted hours. There is often no cross-cover for leave. Despite the services' best efforts, there are differences across the region in the extent to which patients are able to routinely access specialist CF care from an MDT. Effective implementation of the tariff would go some way to addressing this issue. Like many paediatric services, some physiotherapy, nursing and dietetic staff are managed/funded by acute (hospital) and at other times by community trusts. Where staff are based in the community, the implementation of the tariff from the acute trust is complicated.

Nationally, it is unlikely that the tariff available for small clinics will be sufficient to provide the level and experience of staffing required to meet the Cystic Fibrosis Trust's Standards of Care on a 365-day basis, when the needs of patients with CF are often unpredictable and no cross-cover is available. A pragmatic approach will be required to ensure the optimal management of children with complex and rare conditions in the changing NHS.

Most staff were reported to have an annual appraisal and professional development profile (PDP) review.

Pathways for referral to other specialists were clearly laid out in the SLA. The centre felt it was important that all patients be managed by specialists (eg ENT) with expert knowledge and experience in treating children with cystic fibrosis.

All clinics were aware of the UHS management book and the Cystic Fibrosis Trust's guidelines, although a number had their own in-house policies – which might possibly lead to inadvertent variations in care. Most clinics felt that they had adequate microbiology provision, which was supported by objective assessment from the Southampton microbiological services.

Southampton Children's Hospital's lead diabetologist for CF-related diabetes has developed good practice with an established network of care, identifying individuals with CFRD and leading on management as delivered by local teams.

2.4 Principles of care

Summary

Southampton Children's Hospital

There is an overarching aim to minimise opportunities for cross-infection. There are more than three cubicles available, but none are en suite, although these are planned in the real estate build for the new children's hospital in Southampton. Dedicated toilet facilities for specific patients can be made available within the ward environment.

Patients are cohorted in clinic where possible, and a total isolation policy for all individuals is operated as far as is practical. Height/weight and spirometry measurement, and respiratory sample collection, are performed in clinic rooms. Few patients are recorded as having chronic Pseudomonas aeruginosa (PA) or other complicated infections.

All new positive isolates of PA receive eradication therapy and are invited to participate in the TORPEDO-CF study to determine the treatment received. There is a low level of chronic PA infection (as defined in Port CF) across the region, but SCH proactively uses positive antibody serology as an additional indication of chronic infection and therefore many more patients remain on suppressive nebulised antibiotics than fulfil the definition for chronic infection.

No delays in admissions of seven or more days were reported by the centre. However, some of the network clinics said they had had difficulty getting their patients admitted to Southampton when needed.

Tobramycin levels are provided routinely within 24 hours, and the centre was not aware of any exceptions. Amikacin levels take at least 48 hours as they are not assessed in house.

There was a shortfall in screening for CFRD – due to patient DNA or their lack of fasting.

Most had had liver ultra sound scans (USS), but a much lower proportion had had a DEXA scan as recommended.

Discussions about fertility with teenage boys had been conducted in an ad-hoc way, but are now a formal part of the 'Ready, steady, go' transition programme.

The use of mucolytics, particularly Dornase alfa, is favoured for all patients over the age of six years.

There is variable use of azithromycin for those with, and without, chronic PA infection.

Network clinics

Most local hospitals have good, appropriate in and outpatient facilities, including access to en suite cubicles. Admissions were generally not delayed. Mostly there are good measures in place to minimise cross-infection in clinic, which includes cohorting patients who have, or are clear of, particular organisms. However, a couple of clinics appeared to let patients mingle. The use of one, sometimes a small, room for patients for spirometry measurements was of concern, as this may generate a high number of airborne bacteria in a confined space. Many clinics were signed up to the TORPEDO-CF trial and all recognised the importance of trying to eradicate *Pseudomonas aeruginosa*.

A lot of network clinics expressed frustration that results of Tobramycin levels sent to UHS took three to five days to be returned. Surprisingly, none of them seemed to have told the Southampton team about this – and when the latter discovered this on peer review day they immediately committed to addressing the problem. Screening for CRFD, performance of liver USS and fertility discussions with teenage boys was very variable, with few, if any, clinics achieving the Cystic Fibrosis Trust's Standards of Care. DEXA scans are only carried out at UHS (apart from Portsmouth and Poole). A significant proportion of patients had not received or attended an appointment for this investigation.

2.5 Delivery of care

Summary

Southampton

Overall, there is very good delivery of specialist CF care. In particular, there is great attention to detail from the whole clinical team for both in and outpatients, with adequate cross-cover for all staff. Communication following care episodes is efficient. The lack of a social worker is being addressed imminently.

IV antibiotics are mostly given in hospital.

Network clinics

In three of the clinics there is only one consultant looking after children with CF. They work with great enthusiasm and care for patients. The cross-cover when they are on leave or busy elsewhere is for the local team to call Southampton for advice. Written communication is good.

The major problem for a significant number of network clinics is the extremely limited availability of the MDT.

In small clinics, patients are often seen on an ad-hoc basis in the consultant's general paediatric clinic, which makes it difficult for any MDT member to attend in a time-efficient way – if they can attend at all.

Inpatient care can be unsatisfactory in some hospitals. For instance, it was reported by local teams that there may be only one weekday session of physio, none at weekends, and treatment provided by adult-trained physios unfamiliar with cystic fibrosis. A treatment session by a parent or nurse may be felt to be equivalent, or patients regularly miss sessions by going home or to school between IV doses. In such instances, there seems little to be gained by the IV course being given in hospital.

These issues are most apparent in hospitals where patients are only admitted occasionally. Dietetic provision can be scarcer than physiotherapy.

Specialist nursing support is generally much more available.

Psychosocial input was difficult to assess, as the regional psychologist was on maternity leave and a locum was unavailable for discussion. It was reported, however, that the larger clinics have excellent psychology support routinely available in the OP clinic. For the rest, the regional psychologist aimed to provide outreach services, accepting regional referrals and organising region-wide parent group meetings prior to her maternity leave.

Few home IV courses are performed.

Newborn screening

Infants suspected of having CF by the national newborn screening service are managed from the outset by their local hospital. This raises concerns where clinical teams only see such an infant every few years. They lack the experience in managing this critical and potentially complicated situation, where the child's condition and parents' reaction to the diagnosis are very unpredictable at the first visit. Nutritional management of these infants can be quite challenging and parents generally need a great deal of supportive care.

In smaller hospitals, the sweat testing process may be such that staff lack the experience or skills recommended by the Association of Clinical Biochemists. The Southampton service routinely provides confirmatory sweat testing for patients if there are difficulties in obtaining an adequate sample from small infants.

While there is always close liaison between the local team and the regional centre when a new CF diagnosis is made, and specific management guidelines exist for infants, consideration should be given to whether those from clinics with limited experience should receive confirmation of diagnosis and initial management by a team with greater expertise.

2.6 Commissioning

Areas of good practice:

- Low numbers of complaints across network.
- Low numbers of clinical incidents reported.
- Shared care centres appear well funded (70% of tariff) for children with cystic fibrosis.
- The clinical team has stated that it is not only complying with the national service specification (A01/S/b), but that it exceeds its standards.
- The teams were aware of who their local commissioners were and how to access them.
- Bi-annual reviews for children performed by the lead centre.

Areas for improvement:

- User survey not undertaken within prescribed time periods (ie every three years) routinely across all providers within the network.
- Not all shared care centres reported that they had service level agreements in place. The Care Group Manager from Southampton assured they were all in place and stated he would forward them on to the commissioner rep on the team, but at the time of reporting they had not been received.

Recommendations:

- Review of the 70/30 funding split to ensure sustainability. Is 30% adequate to allow the lead centre to input care at the level they may be inputting? The lead centre needs to be clear as to the level of time and resource they are committing to shared care services, both within shared care centres and also within the lead centre, to ensure the split is adequate to maintain ongoing service provision.
- The lead centre is responsible for governing all children's CF activity across the network. The lead centres managerial team needs to be confident that it has the capacity and assurance mechanisms in place to support this. The lead centre was not aware that one of the shared care centres was experiencing problems related to the reporting of Tobramycin levels.
- The team is so busy with clinical matters that there is no time to thoroughly review services and explore areas for service improvement or potential reconfiguration. Should the network consider investing in a manager (even if fixed term, initially) to undertake a full review of what activity is undertaken where, by whom and how much it costs? This may offer significant support for the team and allow it to prioritise and build on its objectives for the coming years.

Wider observations:

- Service sustainability may need to be reviewed in relation to practitioners working single-handedly in some centres. Where required, adequate cover is needed to allow business continuity.
- Families can be resistant to travelling to the lead centre. Has this been fully explored to understand the true reasons why?
- There are two shared care centres where it is felt that infection control and prevention measures are not as stringent as they need to be (stated within the initial presentation). What measures are being taken on this?
- Transition clinics are well established within the lead centre but are less developed in the DGHs.
- Lead centre team acknowledged that there needs to be shared network guidelines available electronically to all team members to support shared care centres/ensure treatment protocols are standardised.
- It was reported that radiology lacks consistency within the shared care centres, but there are probably wider inconsistencies. The network needs to define what a minimum standard should look like in each area and iron out inconsistencies across the board.
- It would be worth exploring appointments that cover more than one hospital, eg physio, dietician, psychologist, medical social worker.
- Delays in accessing paediatric beds in Southampton were highlighted, with up to two weeks reported. The managerial team said they were not aware of this. There needs to be a clear process in place to escalate admission delays where they occur in the future.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	48

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and % of patients with FEV1 <85% by age group and sex	0–3 years	0	0
		4–7 years	1 (4%)	0
		8–11 years	1 (4%)	2 (9%)
		12–15 years	3 (12%)	1 (4%)
		16+ years	1 (4%)	2 (9%)

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	1 (2%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	2 (4%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	0
	Number and % of patients on chronic macrolide without chronic PA infection	9 (19%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

Southampton Children's Hospital

The lead and second consultant each have 0.4 whole time equivalent (WTE) for CF and extensive experience; a third consultant is 0.3 WTE and also very experienced. They run a consultant-led service in clinic, with support of respiratory trainees on the ward. On-call support is shared with other respiratory consultants. Their network clinics are shared between them, with each having allocated clinics. They work well together and are proactive in driving up standards. They also provide great support for their colleagues in the network clinics – who also manage non-CF respiratory patients. A wider network of CF services in the South West has existed for many years and has a bi-annual educational meeting for the MDTs. The more experienced network clinicians are encouraged to contribute to the education and development of this wider network.

Attendance at national and international meetings is supported and encouraged. There is a strong research base in respiratory medicine, including in-house and multi-centre CF studies.

Areas for consideration:

- A lead to be taken on actively supporting their network colleagues to develop their services. Rationalisation of the number of network clinics may be the only way to achieve adequate MDTs and a (relatively) local service that can provide good care for patients.
- Review of higher band patients and some newborn screened infants at UHS does not need to undermine local services if communications and mutual feedback are good.
- Unified guideline development – with help from experienced network clinical teams.

4.2 Specialist nursing

Staffing:

Southampton General Hospital

55 patients + 166 shared care

- Nurses are members of the Cystic Fibrosis Nurses Association (CFNA).
- CF MDT meetings attended.
- The team is able to ensure cover during absences.
- International meetings.
- Studies.
- The team shares the workload, with all involved in newborn screening, inpatients, home IVs, transition, in-house education, nursery, schools, college.
- Twice yearly reviews.

Areas of good practice:

- Excellent link with professionals.
- Good work rate/ethic, particularly on transition.

Areas for improvement:

- Inpatients: No en suite facilities – access to facilities is at end of ward.

4.3 Physiotherapy

Southampton

- A physiotherapist attends annual Wessex regional meeting, open to all shared care. Annual Allied Health Professional (AHP) meeting – case studies shared. Both Band 8a physios and the Band 5 are members of the Association of Chartered Physiotherapists in CF (ACPCF); accredited airway clearance (AC) instructor.
- A physio attends MDT meeting on Monday morning, acute/wards and calls discussed. On Wednesday morning the full MDT with four consultants meets to discuss patients in clinic, and annual review (AR) patients. On Friday afternoon the MDT reaudits, research and education.
- Physios cover 32 hours over five days – Band 8a, three days Band 8a, Band 7 and Band 6, Band 5 rotational for paediatric patients. Physio service also supports inpatients, with 0.5 WTE Band 6 covering full care clinics and also inpatient care. 0.5 WTE Band 7 soon to be appointed to take a regional clinic and also attend full care clinic.
- Attended European and North American Cystic Fibrosis Conferences – abstract priority, case study is no issue, but funding tighter; charity trust.
- Commercially-funded research, ie TORPEDO-CF, Mannitol for paediatric patients. Welcome Trust: audit, annual review and use of hypertonic saline (HTS) – change in practice two years ago; all patients will have HTS during two-week stay – poster presentation. Use of baby PEP poster; presentation five years ago.
- Diagnosis: Full care from initial consultation/home visit if required, transition: three to four clinics a year 'messy clinic' for 14yrs + joint clinic with adult team, whole children's outpatients holds an 'Adolescent Week' for 11+. No transplant/end-of-life – group of patients is well. Good practice – attends all networks except Channel Islands, full care patients = three clinics a week, three staff.

4.4 Dietetics

Dietetic summary for CF centre and shared care hospitals

Until recently Poole, Portsmouth, Basingstoke and Winchester were standalone clinics. Since April 2013 they have had two patient visits from the Southampton dietetic team. Basingstoke and Winchester have recently joined paediatric services across the region, ie become one department. Yeovil, Salisbury, Dorchester, Swindon and the Isle of Wight have had input from the Southampton CF centre for many years.

Due to the differences in input from Southampton between shared care hospitals – ie some are well established and some are new shared care clinics – the dietetic care is only just looking at how it will be best delivered across the region.

Number of CF patients = 213 in South West region.

- WTE dietitians as recommended by the Cystic Fibrosis Trust's Standards of Care: 0.5 WTE for 75 patients = 1.42 WTE for 213 patients.
- Actual funded time across region is 1.68 WTE dietitians (1.1 WTE from Southampton), compared with WTE 1.42 = 213 in the Cystic Fibrosis Trust's Standards of Care.

Therefore, there appears to be adequate funding within the region. Travel time and two yearly reviews to all shared clinics: some of the allocated time is used for travel, which reduces time spent with patients.

The dietetic care at the following hospitals meets the Cystic Fibrosis Trust's Standards of Care:

- Southampton (SOH)
- Poole

- Basingstoke, although the dietitian is apparently new and has limited CF experience.
- Winchester – now linked with Basingstoke.

The following shared care hospitals are struggling to meet the Cystic Fibrosis Trust's Standards of Care. This is due to the lack of funded dietetic care at these shared care hospitals, which impacts on routine CF care. All hospitals are delivering CF care but are compromised by lack of allocated CF dietetic time.

- Portsmouth: 27 patients – goodwill – covers all CF care at a good level, despite no allocated funds.
- Salisbury: 19 patients – one hour a week, needs 5.6 hours a week.
- Swindon: 24 patients – no dedicated time, so dietetic care is comprised.
- Dorchester: 8 patients – no dedicated time, but CF patients are seen.
- Isle of Wight: 9 patients – goodwill, no funding, but sees all CF patients and provides good standard of care.
- Yeovil: 9 patients – no local funding, but all CF patients are seen.

Due to the high number of centres, including some with a very small number of patients within a wide geographical area, it may be extremely difficult to optimise dietetic care without adequate funding.

The following summarises the CF care delivered at each of the individual hospitals.

Southampton – 55 patients – recommended = WTE 0.36 for 55 patients

- Total 213 patients, including shared care 1.42 WTE recommended.
- Funded WTE 1.1 lead dietitian Band 7 (0.5 WTE), additional Band 6 (0.6 WTE).
- Excellent care for all patients at Southampton and during transition.
- Since April 2013, dietetic reviews performed in all shared care hospitals.
- Attends monthly review meetings, Wessex meetings twice a year, UK CF Special Interest, European meeting two years ago, involved with some research on vitamin D and obesity.
- Mean BMI – 46th centile.

Areas of good practice:

- Home visits.
- Feeding group with psychologist.

Recommendations:

- Continue developing partnerships, audit and centre-based literature with local dieticians.
- Rationalise workload with Poole and Basingstoke as these have funded posts, with many years of CF experience. This may allow more time for the centre dietitian to spend time with other shared care clinics, training, audit and research.

Dorchester – 8 patients

- Goodwill WTE 0.025 – not funded, needs 0.05 WTE according to the Cystic Fibrosis Trust's Standards of Care.
- Bands 6/7

Areas of good practice:

- CF trained with 20 years' experience.
- Attended cystic fibrosis meetings in Prague and Dublin .
- Wessex MDT meetings.
- Has done school visits.

Concerns from Dorchester dietitian:

- Not properly funded.
- Finds it difficult to cover workload.
- Reviews with SOH are all day, and she has other commitments in the afternoon so cannot be there for the whole day.
- Unhappy to cover without full funding, feels patient not getting regular, consistent care from a dietitian.

Recommendations:

- Fund local dietitian.
- Continue training and improving shared care with SOH.

Isle of Wight – 9 patients

- No funding, but spends 0.025 WTE on CF care.
- Cystic Fibrosis Trust's Standards of Care require 0.06 WTE.
- Has worked in CF for eight years.
- Not a member of UK Dietitians Cystic Fibrosis Interest Group – membership lapsed.
- Attends monthly MDT meetings, sees all outpatients/inpatients as needed. Has cover when on annual leave.
- No concerns about hospital catering.
- CF patients all seen by MDT, cover is provided at the expense of other paediatric workload, no concerns with cover.
- CF trained but would like more regular CF training.
- Good liaisons with SOH, who cover all reviews.

Recommendations:

- More funded CF time.
- More time for training.
- Become a member of UK Dietitians Cystic Fibrosis Interest Group.

Salisbury – 19 patients

- Band 6.
- 0.03 WTE funded = four hours a month. Cystic Fibrosis Trust's Standards of Care recommend 0.13 WTE.
- Has worked in CF for one year.
- Attended Wessex CF club study day for AHPs.
- Attended training with centre dietitian.
- Average BMI 44th centile.

Concerns from Salisbury dietitian:

- Not properly funded, only one session per month, need 1.3 sessions per week.
- Dietitian very keen to increase training in CF.
- Finding it very difficult to cover, pulled between workload: only covers one clinic a month, inpatient care very poor, catering facilities very poor.
- Difficult to get catering to provide high energy meals and snacks.
- Lack of inpatient cover for patients and no cover when on annual leave.
- Concern because more children coming in for IVs.

Recommendations

- Increase funding for local dietitian.
- Become a member of the UK Dietitians Cystic Fibrosis Interest Group.
- Look at how inpatients' catering at Salisbury can be improved/liaise with SCH centre for support with catering issues.
- SCH to look at providing cover for local dietitian for annual leave and clinics.

Yeovil – 9 patients

- Good local cover with no funding; Cystic Fibrosis Trust's Standards of Care recommend 0.06 WTE.
- Band 6/7.
- Cross-cover from Dorchester; 20 years' experience.
- Attended cystic fibrosis meeting in Dublin.
- Wessex MDT meetings.
- Band 7 – for ward cover.
- No dedicated CF time. Paediatric time recently funded by Yeovil hospital; not specifically allocated to CF but includes cover to CF clinic with an MDT. (Prior to this no dietetic service to provide cover to CF service).
- Reviews covered by SOH – inpatient stay covered by local dietitian.

Recommendations:

- Fund routine CF care.
- Ensure patients receive consistent care as there are two local (inpatient and outpatient) dietitians, and SOH all involved with nine patients.
- Improve training/liaison with SOH (was unable to attend CF AHP's study day in 2013).

Poole – 38 patients – also covers annual reviews in Dorchester – 8 patients

- Band 7 funded = WTE 0.35; Cystic Fibrosis Trust's Standards of Care recommend 0.25 WTE.
- Is a member of the UK Dietitians Cystic Fibrosis Interest Group, attends meetings and MDT Wessex meeting annually. Also attended European Cystic Fibrosis Conference in 2010. Provides excellent service to all CF patients, no concerns, even providing input to CF care for children in Albania. Does home visits, school visits and transition clinics.
- Meal provision in hospital excellent.

Recommendations:

- More liaison with SOH, consider the reviews service again as up until April 2013 all reviews were done by a dietitian with 25 years' CF experience.
- Consider utilising skills between SOH and Poole for shared care clinics.
- Needs opportunity for study leave.

Basingstoke – 18 patients – also covers Winchester – 8 patients

- Funded WTE 0.2; Cystic Fibrosis Trust's Standards of Care recommend 0.17.
- Band 7.
- Has worked in CF for three years.
- Member of the UK Dietitians Cystic Fibrosis Interest Group – has not been to a meeting yet.
- No concerns with care; cover available when on annual leave.
- Good catering facilities.
- No involvement with research and audit, but would like to do some joint work with SOH (Southampton).
- Beginning to develop good relationships with SOH dietitians as only recently started coming to clinics in April 2013.

Recommendations:

- Develop more shared care working with SOH, as was previously a stand-alone hospital providing all reviews.
- If funding available, perform MSc project in CF.
- Attend a UK Dietitians Cystic Fibrosis Interest Group meeting.
- Discuss use of CF time in review clinics as there may be a different way of utilising time, audits etc (with less experienced CF dietitians, it is important for both local and CF centre dietitians to be present in clinic).
- Consider cover for all local care for Winchester CF patients, as the dietitians became one department in April.

Portsmouth – 27 patients

- WTE – goodwill 0.2; Cystic Fibrosis Trust's Standards of Care recommend 0.18 WTE.
- Band 6/7 worked in CF for 10 years and has an MSc project in CF.
- Is a member of the UK Dietitians Cystic Fibrosis Interest Group.
- Attends Wessex MDT meetings and pre and post-clinic meetings.

- Review done by SOH. No time to attend national meetings but attends local Wessex meeting twice a year.
- No time to do audits or research.

Areas of good practice:

- Attends clinics and reviews inpatients when available; has good knowledge.
- Food service funded by local CF charity for children.
- Average BMI = 53rd centile.

Recommendations:

- Ensure allocated CF funding or ring-fencing; currently goodwill sessions?
- Continue to improve communications with SOH.
- Liaise with SOH as there is no cover when dietitian is on annual leave.

Swindon – 24 patients

- Band 6.
- No dedicated CF time. The Cystic Fibrosis Trust's Standards of Care recommend 0.16 WTE.
- Has done training in CF module.
- Not a member of the UK Dietitians Cystic Fibrosis Interest Group, therefore no ongoing training in CF care due to lack of funding.

Concerns of the Swindon dietitian

- Very little time for CF patient care. There is no cover if on annual leave and very little cover for patients. Little clinic cover available. Reviews done by SOH twice a year, but feels dietetic care very patchy for 24 patients, as there is no dedicated time and has even less time since the review clinics.

Recommendations:

- Fund CF dietetic time.
- Increase input from SOH until local dietitian care is funded.

Winchester – 8 patients – 0.5 WTE

- CF care funded by Basingstoke.
- Local dietitian new to paediatrics and CF covered by Basingstoke CF dietitians.
- Inpatients covered by Basingstoke dietitians, although it is unclear how often each patient is reviewed.
- Catering is good, no concerns.

Recommendations

- Consider having the eight patients looked after by Basingstoke dietitian, and reviews with SOH
- Give training to new dietitian for cover arrangements and inpatient care

4.5 Pharmacy

Site	Number of patients	WTE spent on CF (WTE)	Cystic Fibrosis Trust's Standards of Care recommendations (WTE)	Shortfall (WTE)
Southampton	54/159	0.5	0.89	0.39
Dorset	8	0.01	0.05	0.04
Isle of Wight	10	0.03	0.07	0.04
Poole General	35	0.2	0.23	0.03
Portsmouth	25	0.05	0.17	0.12
Salisbury	19	0.03	0.13	0.1
Swindon	23	0.05	0.15	0.1
Winchester	8	0.05	0.05	0
Basingstoke	15	0.1	0.1	0
Yeovil District	9	0.05	0.06	0.01
				0.83

Note: There is currently no information available for Jersey and Guernsey.

The total shortfall across all sites is just under 1 WTE, with the biggest shortfall (0.39 WTE) currently at Southampton Children's Hospital. The position at Southampton is held by a Band 8B Directorate Pharmacist who is highly experienced in CF, and the Chair of the CF Pharmacist Group. Additional pharmacist resource is required to enable more effective cover in the lead's absence, support increased homecare and allow for annual review clinics to be consistently attended by a pharmacist. At the shared care sites, the shortfall means that pharmacists are unable to contribute to clinics or regularly attend MDT meetings.

None of the sites have support from a technician for medicines management. Due to the volume of work, this has the most significant impact at Southampton, and use of technicians would lead to an improved skill mix and allow pharmacists to use their time more effectively on clinical work.

Inpatient services

- Apart from the Isle of Wight, all inpatient charts are reviewed daily and pharmacists provide medicine reconciliation. Medication counselling is only carried out on an ad-hoc basis, as and when required.
- There is good availability of a pharmacist for responding to queries; there is an on-call pharmacy service at all sites for out-of-hours use.
- Most pharmacists try to attend MDTs when possible, but are not always able to due to competing work pressures. At Southampton, attendance at MDT meetings is felt to be appropriate – one hour a week when patients are discussed after annual review. However, there is no cover when the CF lead is off.

Outpatient services

- The Southampton pharmacist attends 70% of all annual review clinics, including doing drug histories and counselling, with concordance issues and relevant information disseminated to GPs and the MDT.

- None of the pharmacists, with the exception of the Salisbury one, attend CF clinics or carry out medication reviews in clinic. However, they are contactable via bleep if required. The pharmacist in Salisbury is able to attend about 40% of clinics and provides advice on any medication-related issues, helps with the annual review and liaises with GPs if required. Competing work pressures don't allow for more regular clinic attendance.

Service developments

Southampton to set up homecare service around new high cost drugs. Pharmacist is involved in prescribing or screening the scripts, however, she has no extra time allocated to do this.

Other

- Finance report provision is mixed, with some providing no reporting, and others providing it as part of general paediatric reports. In the case of Swindon, some specific CF-related drugs are reported on separately from general paediatric reports.
- Larger research project conducted around medicines and other audit work done at the centre. None of the shared care site pharmacists have been able to contribute to research or audit projects.
- Local pharmacist network generally works well, and education and development opportunities are available. However, not all shared care pharmacists are able to take part due to time constraints.
- UK Cystic Fibrosis Pharmacist Group membership is reliant on individuals' interests and is mixed, with two pharmacists being members (Salisbury and Dorset). Two sites aren't able to join due to IT issues that are in the process of being resolved.
- Liaison with respective adult pharmacist at transition ('Ready, steady, go' programme) at Southampton works well.

Areas of good practice:

- In general, pharmacists feel they have good working relationships with the CF team and that inpatient service provision is good.
- The network relationship among pharmacists is described as very good, although some units engage more than others.
- Pharmacists are involved in writing guidelines and other formulary work.
- Overall, pharmacist involvement with the CF patients has recently increased, particularly as pharmacists gradually try to attend more MDT meetings.

Areas for improvement:

- There is currently insufficient staffing, which impacts on the service pharmacists are able to provide. The largest shortfall is at the centre, especially in view of the repatriation of high cost drug prescribing; this needs to be urgently addressed. Time constrains are also a major issue for the shared care units. Areas that are affected and should be addressed are pharmacist attendance in the annual review clinic to allow for involvement in medicine reviews, MDT meetings and attendance of study days/conferences to keep abreast of new developments.
- No pharmacy technician support for medicine management; would need more support with that.

- Level of service provision depends largely on historical service provision. Generally improvements have been made, with pharmacists starting to attend MDTs more. But service provision still relies largely on an individual's level of interest, and very often competing job pressures don't allow enough time to be allocated to cystic fibrosis. Set standards for pharmacy service provision in the shared care setting would be useful.
- Sharing of guidelines could be improved.

Recommendations:

- Provide sufficient staffing levels as per the recommendations in the Cystic Fibrosis Trust's Standards of Care to allow for consistent pharmacy service provision (please see above for details of the shortfall), including regular pharmacy attendance at annual review clinics and MDT meetings.
- Improve support from medicine management technicians; estimated 0.3–0.5 WTE required at the centre to do medication reconciliation at ward level and help administer homecare.
- Provide guidance on what is expected of shared care pharmacists to enable a consistent pharmacy service across all shared care sites.
- If it is not possible to achieve required level of pharmacy service due to fragmentation of the service and small numbers of patients, assess whether having regional pharmacists leading cross-site might be a viable option.
- Look at a platform of how guidelines and information can be shared more effectively with shared care units.

4.6 Psychology

Psychology in the centre service is held in high regard by the team, which is particularly positive about the newly developed drop-in groups for parents of babies and young children. Centre patients are seen at annual review and there is also involvement in transition, on request. Inpatients have access to the psychologist, and this would also be an opportunity for patients across the region to be seen by the centre psychologist. The current psychologist is now on maternity leave, but a replacement is available and there is also an agreed increase in psychology time for the centre.

Additional psychology time is available in some of the regional clinics. However, this is not available to all patients, so an overall comment would be that the service is understaffed for the number of patients and made complicated by the wide region covered by this service. It would be an improvement to see some shared-care pathways that enable patients across the region to receive similar psychological care.

In addition to developing shared-care pathways, questionnaires to assess psychological needs could be used at clinics where there are no psychologists. Any patients or parents identified as requiring support could then be given access to the centre psychologist.

Another way of devolving psychological support to the network clinics would be to offer psychological teaching to the nursing groups in these clinics. This would raise awareness of unmet patient or parent needs, and support for these patients or parents could be provided by the centre psychologist over the telephone. Additional examples would be to offer some guidelines for managing procedural anxiety and for supporting patients in the network who are moving on to adult services.

Parent groups have already proved successful at the centre, as have parents' evenings for those with children in the region who are in transition to adult services.

4.7 Social work

There is funding available for a CF social worker at the centre, but this post is yet to be recruited. Currently most of the social work duties are undertaken by a very dedicated nursing team. There is one social worker who works for the Basingstoke/Winchester area. However, this post is not currently CF funded.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	5	1	12	2
Female	3	3	11	2

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	16	12	3	0
From the ward staff	8	8	4	2
From the hospital	10	8	7	1

Areas of excellence:

1 Availability of team members
2 Cross-infection control
3 Continuity of staff

Areas for improvement:

1 Car parking
2 Waiting times

6. Appendices

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Southampton Children's Hospital

1 Models of care

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

2 Multidisciplinary care

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

2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Red	Red	Various documents, some need updating. Easy access for network teams required, eg web-based guidelines.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	Rarely see anyone other than consultant.
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red	Red	One patient, but joint consultation.

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	Red	New build should address this.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Don't cohort – operate total isolation policy.	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Amber	Reports of network patients not being admitted.

3.3 Complica-tions	% 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	Amber	Not 100%.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Amber	Not 100%.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red	Red	Being addressed.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	Needs attention across whole service.

4 Delivery of care

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

4.2 Inpatients/ outpatients	% availability of social worker at clinic and for inpatients	100%	Red	Red	New appointment pending.
	% availability of pharmacist at clinic and for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	None currently do home IVs.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	2		Addressed appropriately.
5.2	Number of clinical incidents reported within the past 12 months	<1%			
5.3	User survey undertaken a minimum of every three years	100%	Red	Red	Recent survey needs repeating.
5.4	Service level agreements in place for all	100%	Green	Red	Not according to network clinicians.

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Southampton Children's Hospital – 55 full care, 166 shared care
Consultant 1	0.5	1	1	0.4
Consultant 2	0.3	0.5	1	0.4
Consultant 3			0.5	0.4
Staff grade/fellow	0.5	1	1	N/A
Specialist registrar	0.3	0.5	1	0.25
Specialist nurse	2	3	4	1.85 + 0.5 TBA
Physiotherapist	2	3	4	1.8 + 0.5 TBA
Physiotherapy assistant				0
Dietitian	0.5	1	1.5	1
Clinical psychologist	0.5	1	1.5	0.85
Social worker	0.5	1	1	0.5 TBA
Pharmacist	0.5	1	1	0.5
Clinicians' assistant				0
Secretary	0.5	1	2	0.5
Admin assistant				0
Database coordinator	0.4	0.8	1	
CF unit manager				0

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Southampton Children's Hospital	
Number of active patients registered (active being patients within the last two years)	58
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	48
Median age of active patients in years	7
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	10 (21%)
	4–7 years	15 (31%)
	8–11 years	11 (23%)
	12–15 years	7 (15%)
	16+ years	5 (10%)

Genetics	
Number of patients and % of unknown genetics	2 (4%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	1 (2%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	1 (4%)	0
	8–11 years	1 (4%)	2 (9%)
	12–15 years	3 (12%)	1 (4%)
	16+ years	1 (4%)	2 (9%)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	10
	4–7 years	15
	8–11 years	11
	12–15 years	7
	16+ years	5
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	2
	12–15 years	0
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	2 (4%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	5 (10%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	1 (2%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	257
	4–7 years	40
	8–11 years	61
	12–15 years	104
	16+ years	83
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	22
	8–11 years	10
	12–15 years	0
	16+ years	7
Total number of IV days split by age group	0–3 years	257
	4–7 years	62
	8–11 years	71
	12–15 years	104
	16+ years	90

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=30) 22 (73%)
If not on DNase, % on hypertonic saline	2 (7%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	2 (4%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 9 (19%) without chronic PA

Patient survey

Southampton Children's Hospital

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	5	1	12	2
Female	3	3	11	2

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	13	11	4	3
Communication	13	12	7	2
Out-of-hours access	7	6	4	3
Homecare/community support	12	6	3	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	14	11	5	0
Waiting times	6	10	9	3
Cross-infection/segregation	14	11	4	1
Cleanliness	10	15	5	0
Annual review process	13	12	2	1
Transition	0	1	1	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	8	8	2	1
Cleanliness	8	5	8	1
Cross-infection/segregation	10	10	2	0
Food	2	8	8	1
Exercise	6	4	1	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	14	1	0	0
Availability of equipment	5	9	1	2
Car parking	0	13	2	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	16	12	3	0
Of the ward staff	8	8	4	2
Of the hospital	10	8	7	1

Comments about CF team/hospital

"As my daughter was only diagnosed two years ago it is new to us, but the team have been excellent and are always available for us."

"Community nurse very helpful in getting cough swabs back to hospital, always very helpful. Never been back into hospital for anything since first diagnosis and original intravenous antibiotics."

"Would like a 'forum' team or email for generic, non-urgent enquiries."

"Our experience with the CF team has been second to none and my only wish is that they were located on my doorstep!"

"The Monday to Friday support is very good but 'out of hours' not sure; would not know who to contact. When physically in hospital as an admission, again the weekends seem less organised."

"Very happy with everyone in the team and service we receive."

"At times it has been difficult to reach a member of the CF team and usually this is because of an emergency or urgent enquiry; this can be very distressing. On the whole I feel the care we receive to be very good and has a significant influence on the quality of life for the CF patient."

"The CF team are absolutely fantastic. My daughter feels safe and happy and I feel the same. The only request I have which has only just come to me – I have yet to mention it to the team – is more information for carers or advice on where to get information. I always feel the team go above and beyond for us and no matter what our queries are, we have always been more than satisfied with their advice and support."

"They are always available, professional, friendly and very helpful from day one of diagnosis until now."

"Excellent."

"Fantastic care given – mainly continuity of staff including physio, dietitian, nurse and consultants. CF specialist nurse always available for advice."

"Having experienced two other CF teams/ hospitals elsewhere in the UK, we are thoroughly delighted with the care our son receives and the professionalism and dedication of the staff."

"Excellent service all of the time."

"We moved care from Winchester to Southampton in January. The advice, treatment and care have been 100% better and we are extremely pleased that we made this decision to move to Southampton. All the CF team are understanding and I couldn't ask for a more dedicated team to look after and provide help for my daughter."

"Our CF team at Southampton is great with our son; always helpful and reassuring."

Patient/parent interviews

Patient interviews – Southampton Paediatric peer review, 5 November 2013

Patient one

The parents attended the interview. They have a daughter of four years old who has cystic fibrosis. The child has had many admissions to Southampton hospital for sickness, meningitis and a twisted bowel.

When the child was diagnosed, the surgeon informed the parents. There was good support with an overnight stay, showing how to treat the child. The nurse made a visit to their home and they were made to feel in control and never made to feel like a fool.

The CF nurse has always been their first port of call at the hospital.

They have no complaints about the service, although when there was an outbreak of swine flu, it was difficult to get a single cubicle for isolation in the ward. They had access to their own sink, but no toilet.

When the child had meningitis, she was on antibiotics within one hour and they believe this saved her.

Patient two

Parent to child aged two years and three months.

Diagnosed by heel prick testing. Excellent level of support, had a home visit for five hours. The parents will not be having any more children.

The child has only had one hospital visit and is keeping well. The parent is happy with the clinic and feels it is very well run. They were given their own room for the visit and feel they are in a safe environment.

Weight and measuring takes place in a communal area.

Communication between the ward and pharmacy is often poor. The child was not given food for three days; the mother had to provide this. The parent feels this problem was not resolved and the care issue could not be identified.

During the child's stay in hospital, the parent stayed on a Z bed for two weeks. Staff ensured the parent was comfortable, although she was not offered food.

Parent suggested a welcome pack could be given or that more information could be obtained from a specific website or forum.

The nurse Judi made them feel as if their child was the only child with CF. The whole team conducted the ward round together, ensuring consistent information was given. The parent never felt that they were wasting staff time; they are very friendly.

Concerns outside the service: GPs are problematic.

Parents' meetings during the day are helpful, even just to vent. It would be helpful to have these meetings in the evenings or at the weekend.

Access to unit is by phone only.

It would be helpful if the service had clinic-specific website/info, online contact/enquiries. Medical emergency is 'open access'.

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Southampton Children's 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	A large waiting area. Side rooms are numbered and, after reporting to reception on arrival, patients are sent to the room. Four patients per clinic. Patients are asked not to stay in the reception area.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Separate, large height and weight room.
Where are the lung function tests done for each visit?		There is a separate room. Physiotherapists and the respiratory technician carry this out. Individual filters are used and cleaned in between patients.
Are clinic rooms appropriately sized?	Yes	Sizes vary, but are appropriate; all are well equipped.
For annual review patients, are any distractions provided?	Yes	Books and cleanable toys; patients are also encouraged to bring own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		There is only one diabetic patient at the moment.
Transition patients – can they get tour of outpatients' facilities?	Yes	Comprehensive transition programme in place ('Ready, steady, go').
Transition/new patients – do they get information pack?	Yes	'Ready, steady, go' pack.

Additional comments:

- There is a young persons' clinic week held four times each year, aimed at 11 year olds and over. Charities are invited, eg the 'No Limits' charity comes along and talks about drug/alcohol awareness. There is a DJ playing music and a magician, who visits the children in their rooms and performs tricks. Sex education information is available.
- Lung function room: Testing is carried out by the physiotherapist and respiratory technician. Tests are started at the age of two-and-a-half to three years old to familiarise the patient with the equipment.
- If a patient were infected, they would be tested at the end of clinic.

- There is also a mobile lung function machine available for use.
- Small room: Limited for wheelchair use.
- Team room: For the team to keep notes and liaise with each other between patients, where any concerns can be raised.
- X-ray: For paediatrics only, a large waiting room. Decoration is very child-oriented. CF patients would not be sent together.
- Pharmacy: A very small room with seating for just six people, although CF patients do not sit and wait for prescriptions. There is a new outpatients' pharmacy on the ground floor, near the main entrance.

Environmental walkthrough: Ward

Ward name: Paediatric General Medical Unit

Microbiology status: general

		Hospital name	**Southampton Children's Hospital 53 patients/10 shared I.O.W**
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable for CF patients.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		10	Four allocated for CF patients, although could use others if required.
Do the en suites have:	**Toilets?**	No	Shared, although facility can be allocated for personal use.
	Wash basins?	Yes	All rooms have basins.
	Bath or shower?	No	Facility can be allocated.
Do CF patients have to share any bathroom facilities?		Yes	There are separate showers/bathrooms and toilets that can be allocated for CF patient use only.
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 service, not connected to patient link – most TVs have Freeview.
If no, are there any concessions for CF patients?			

	Yes/no/ number/ N/A	Notes/comments
Are there facilities to allow parents/ carers/partners to stay overnight?	Yes	Z beds are available for each room. There is also a parents' bathroom, kitchen and seating area.
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	There is a patient kitchen which has a microwave and fridge.
What facilities are provided for teenagers?		TV only. Can bring in own laptops and games. There can be a problem with the Wi-Fi connection.
Is there access to a gym or exercise equipment in the rooms?	Yes	There is a gym, and a programme prepared by the physiotherapist for each patient. This is carried out with the physiotherapist in a formal gym session.
What facilities are there to help with school and further studies?		There are laptops with internet access available for school work during their stay. The hospital teachers are in contact with the school. Hospital teachers give 1-2-1 time if required.
Is there a relatives' room?	Yes	Sitting/quiet room.
What internet access is there?	Wi-Fi	Although a connection is not guaranteed.
What facilities are there to enable students to continue to work and study?		Laptops are available. Hospital schooling starts from day one of stay. Ward G3 (orthopaedic ward): exams can only be taken in the school room. CF patients do not generally study here.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Can sterilise in the rooms, using Milton sterilising unit.
What facilities are provided for those with MRSA?		These patients are admitted to wards G3 and G4S – separate rooms.
What facilities are provided for those with B. cepacia?		Wards G3 and G4S – separate rooms.
What facilities are provided for those with other complex microbiology?		Wards G3 and G4S – separate rooms.
Are patient information leaflets readily available on ward?	No	Most leaflets are web-based and can be printed on demand. They can also be requested in person. staff give parents guidance on the required leaflets.

Additional comments

- Southampton: established clinic links. Networks working well with good involvement, good relationships and good communications with the MDT.
- There is a robust annual review process in place, which works well. The full team has regular formal meetings about each patient and the whole team is involved in the full care.
- The team is developing and can advise and work together to pinpoint key issues.
- Concerns about particular hospitals:
  - Smaller services rely on one individual (consultant) for outcomes/decisions. This will improve as the network progresses.
  - Creating interest for staff to join the team.
  - Time for shared care with clinics, six monthly visits to all clinics by full MDT.
  - Pre-clinic and post-clinic 'wash up' time for all team to recap and learn.

Wards

Paediatric Medical Unit (PMU)

- Rooms 1–5 have separate shower/bath/toilet facilities, with a separate entrance for patients. These can be allocated for CF patient use.
- Rooms 6–10 also have their own separate shower/bath/toilet facilities, as well as a separate entrance for patients.
- There is a good sized, fully equipped treatment room.
- Drug room: for stock and supplies, kept locked.
- Ward G3 orthopaedic ward: this ward is not generally used for CF patients, unless specialist surgery is required eg spinal.
- Assessment Unit G1: CF patients would not generally stay here, unless they were admitted out of hours via A&E or GP referral. There is always a CF consultant on call. There are four cubicles available.
- High Dependency Unit (HDU): This is a new unit which has two en suite side rooms.
- G4 Ward: A surgery ward with six side rooms; used only for complex surgery.
- John Atwell Day Unit: Newly refurbished. Very brightly decorated with large waiting area. This is used for emergency reviews, out-of-hours clinic, and out-of-hours annual review – glucose tolerance testing (only one CF patient at a time). Also has a fully equipped treatment room.

Physiotherapy

- Physiotherapy treatment is assessed for the individual patient and physiotherapy staff provide as many treatments as indicated. This may be twice or three times daily. One session may be led by the parents/patient if they are out of the hospital for part of the day.
- There is access to an outside play area, which is equipped with swings and a playground. This is at Burlesdon House, which delivers specialist care for long stay, psychological patients. The physiotherapist will take the child for exercise/play.
- Transition clinics are held bi-monthly and aimed at 15–16 year olds.
- Bi-medical Research Unit: patients have their bronchoscopy, the specimen is split for testing and also for research. Patients have been put forward for Kalydeco trials in the past.
- The MDT (physiotherapists, ventilation nurse) share an office, so key staff are always available. Consultant office is situated very close by. This is convenient for parents requiring advice.

Additional information

- A large hotel for parents is currently being built. This is funded by McDonald's and will be named the Ronald McDonald House. It will have 63 bedrooms and will be exclusively for use by the parents of patients.
- There are also plans for a new children's A&E. A new children's hospital is also at the planning stage. This will take 10 years to complete; all plans are on the website.

Environmental walkthrough: Other

	Hospital name	Southampton Children's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	There is a large multistorey car park. There can be a problem with parking depending on the time of day. Visitors can only purchase a two-weekly or monthly ticket (£30 monthly) if receiving benefits.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Ward clearly signposted.
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?		Staff will not send patients together. Appointments are booked in advance for radiology and DEXA scans.
Do patients have to wait at pharmacy for prescriptions?		No – staff take patient prescriptions to pharmacy for collection by patient on way out. Staff pick up inpatient prescriptions.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	In main reception; has own office area and leaflet stand. Leaflets are also available on demand.
Are there patient comment/ feedback boxes?	Yes	In wards. There are also friends and family feedback leaflets.

Poole General Hospital

Overview: Consultants

"Poole Hospital NHS Foundation Trust is a 621-bed acute general hospital, predominantly serving the 272,000 people living in Poole, East Dorset and Purbeck. There are around 5,000 deliveries per year."

35 children with CF (has had up to 50 in the past)

Local Consultants	Dr Ann Dewar (AD)	0.35 WTE	Recommended: 0.23 WTE
	Dr Stephen Wadams	0.2 WTE	Recommended: 0.14 WTE
UHS Consultant	Gary Connett	(Poole Hospital about one hour away from UHS)	

Monthly joint clinics (half day)

Generally the Consultant sees patients just once per year for their annual review, but may see the sicker ones more often. Other patients may be discussed.

Areas of good practice:

The service is almost completely consultant led and well organised. She is easily available for advice.

Full MDT (except social worker) available for clinic and inpatients. Established CFRD clinics four times per year.

Cross-infection control:

Some concerns raised about risks, including by the MDT, eg spirometry in one room in outpatients department; clinic not always organised by patients' microbiological status. Four patients with Cenocepacia, MRSA and NTM.

Admissions:

Four patients have regular IVs – two or three are for 'social' reasons, plus the one with Cenocepacia.

Usually have a patient in and relatively high number of IV days overall – likely reflects the complex infections above.

Two wards available, with en suite cubicles. Minimal use of home IVs.

Guidelines/protocols:

Mixture – from UHS and own. Based on the Cystic Fibrosis Trust's Standards of Care.

DEXA scans and liver USS scans not performed on all patients as recommended. Former should be done at UHS.

Newborn screened infants:

Good overall experience (two to three infants per year). Unclear if sweat testing ACB standards are met.

Transition:

Onsite adult CF clinic, keen to become independent CF centre – supported by UHS adult CF centre.

Transition pack and pathway from aged 14 onwards. Joint medical consultation with AD and consultant from Poole adult CF clinic about three times prior to transfer. Those in higher bands are seen also at UHS adult CF clinic.

MDT:

All MDT members meet high standards and are experienced – in fact they can find it difficult when less experienced staff come in from UHS. (However, if the UHS team don't attend this may lead to problems with succession planning and a decrease in available skills, although other physio support will be available).

Lack of social worker is biggest problem – MDT spends much time doing tasks that social worker could do more effectively.

Recommendations:

- Improvement in staffing where there are deficiencies according to the Cystic Fibrosis Trust's Standards of Care
- Biannual patient reviews by UHS with at least some contact with MDT.
- Review process for performing liver USS at Poole, and DEXA scans at UHS.
- Review clinic process to ensure optimal segregation.
- Clinic of this size needs regular input from specialist social worker, which would free up other members of the MDT to focus on their own specialty.
- Review areas of care reported as 'fair or poor' by the patient/parent survey.
- Review sweat testing for compliance with the Cystic Fibrosis Trust's Standards of Care.

Specialist nurse – Poole (35 patients)

- Advanced nurse practitioner (ANP) = 0.8 WTE (Band 7); Cystic Fibrosis Trust's Standards of Care recommend = approx. 1.0 WTE.
- Member of the CFNA; attends annual meetings
- Attends MDT meetings.
- Has attended national and international meetings.
- No involvement in studies at present.
- Community support worker (CSW) = 0.4 WTE (Band 4); supports both inpatients and outpatients.
- Both are involved in home/school visits; CSW is responsible for equipment/consumables, and performs sweat tests, although is not directly involved in newborn screening. Involved in educating nurses and medical staff. Some home IV involvement, but as patients are complex they tend to be admitted.

Areas of good practice:

- MDT going up to centre twice a year.
- Transition pathway less stressful after GCSEs.
- Dedicated use of mobile phone with teenage group.
- Good relationships with dietetics team.
- Clinics: age related, with patients in single rooms.
- Full MDT attends regular clinics.

Areas for improvement:

- Nurses to be involved in clinic planning to improve segregation.
- If increased nursing time secured, could improve provision of education.

Physiotherapist – Poole

Alice Lander 0.8 WTE; Cystic Fibrosis Trust's Standards of Care recommend approx. 1.0 WTE approx. (about to go on one year sabbatical, but other physio support available).

- Attends study days, eg Wessex meeting, Association of Chartered Physiotherapists in Cystic Fibrosis.
- Always attends two ward rounds per week after clinic and the Friday morning MDT meeting to discuss inpatients and all other patients.
- Always covers ward; Band 6 paediatric physiotherapist covers ward if Physio on annual leave or in clinic. No absence cover of clinic if on leave; would follow up with home visit if needed based on team feedback.
- Attended Prague & Brest European CF Conferences.
- Research/audit: Low priority, difficulty recruiting to Torpedo study. Service development: transition documentation in process. Case study at Wessex meeting. Valencia poster.
- Key life stages: newly diagnosed seen within one week. Transition: close links with adult CF physio. 14+ clinics: good process, seen with adult team. Group is well – not needed end-of-life care for seven years.

Areas of good practice:

Inpatient and outpatient work covered well, able to offer home and school visits as needed; musculoskeletal assessment, continence, exercise testing – poor patient uptake.

Areas for improvement:

Additional time to meet standards and allow involvement in research and audits. Provide cover for clinics if lead is absent.

Dietetics – Poole

- Band 7 funded = 0.35 WTE; Cystic Fibrosis Trust's Standards of Care recommend = 0.3 WTE.
- Over 25 years' CF experience; also performs dietetic CF annual reviews for Dorchester CF clinics (eight patients).
- Member of the UK Dietitians Cystic Fibrosis Interest Group; attends meetings and MDT Wessex meeting annually.
- Has also attended 2010 European CF meeting.

Areas of good practice:

- Excellent service provided to all CF patients, no concerns raised; even provides input on CF care to children in Albania.
- Does home/school visits and transition clinics.
- Meal provision in hospital excellent.

Areas for improvement:

- Increase collaboration with Southampton specialist centre (SOH); consider reviewing MOT service up until April 2013. All MOTs done by dietitian with 25 years' CF experience.
- Consider utilising skills between Southampton and Poole for shared care clinics.
- Provide continued opportunity for study leave.

Pharmacy

Please refer to Southampton Children's Hospital.

Psychology

0.1 WTE

Social work

Please refer to Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Poole General Hospital

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	**Red.** **Biannual reviews to be arranged by Southampton.**	**Red**	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	There are some deficiencies that will improve service when filled.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Green	

2.1 Multi-disciplinary care	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	Consultant seen at 90–100% of visits.
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	Specifics were not discussed.

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	Some discrepancy with what has been reported by local team.	Action point for review.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Levels sent to Southampton; levels rarely available before 48 hours.	Red	Plan to perform levels locally.

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%	Amber	Amber	Action point for review.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red. Test not performed locally.	Red	Action point for change – with UHS.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% 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	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Green	Amber	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Amber	
	% availability of clinical psychologist at clinic and for inpatients	100%	Green	Amber	
	% availability of social worker for at clinic	100%	Red	Red	No social worker – needs addressing.
	% availability of pharmacist at clinic and for inpatients	100%	Green	Amber	Not available for outpatients.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	Few patients do home IVs.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	Team available but not needed in last six years.

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0%	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	Two AIRS forms re. Tobramycin levels.	Red	Plan for levels to be performed locally.
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	Unclear	

Staffing levels (adult)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Poole General Hospital 35 patients
Consultant 1	0.5	1	1	0.35
Consultant 2	0.3	0.5	1	0.2
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	0.8
Physiotherapist	2	3	4	0.8
Physiotherapy assistant				0
Dietitian	0.5	1	1.5	0.35
Clinical psychologist	0.5	1	1.5	0.1
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.1
Clinicians' assistant				0
Secretary	0.5	1	2	0.2
Admin assistant				0
Database coordinator	0.4	0.8	1	
CF unit manager				0
Children's community support nurse				0.2

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Poole General Hospital	
Number of active patients registered (active being patients within the last two years)	34
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	33
Median age of active patients in years	9
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	1 (3%)
	4–7 years	11 (34%)
	8–11 years	7 (21%)
	12–15 years	12 (36%)
	16+ years	2 (6%)

Genetics	
Number of patients and % of unknown genetics	1 (3%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	2 (6%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	1 (17%)	3 (75%)
	12–15 years	4 (66%)	1 (25%)
	16+ years	1 (17%)	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	1
	4–7 years	11
	8–11 years	7
	12–15 years	12
	16+ years	2
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	0
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	1 (3%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (3%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	2 (6%)

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	4 (12%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	4 (12%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (3%) with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	34
	8–11 years	137
	12–15 years	98
	16+ years	14
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	20
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	34
	8–11 years	137
	12–15 years	118
	16+ years	14

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=24); 12 (50%)
If not on DNase, % on hypertonic saline	1 (2%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	1 (3%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 3 (9%) without chronic PA

Patient survey

Poole General Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	2	1	1	0
Cleanliness	1	2	1	0
Cross-infection/segregation	3	1	0	0
Food	0	1	2	1
Exercise	0	3	1	0

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Team are good, sometimes there is a lot of waiting around. Dr Wadhams is very thorough!"

"A really friendly supportive team at Poole – we are hugely grateful for them!"

"I can only judge Southampton on the care we receive at Poole as we never have any need to attend Southampton. The service we receive at Poole is excellent; we are kept well informed and have built up a very trusting relationship with Drs and support staff as well as ward staff. I cannot praise them enough for the care we receive both from Poole and Southampton at annual reviews."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital name	Poole 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 area equipped with toys, tables and chairs.
Do patients spend any time in waiting room?	No	Three patients are seen per clinic. Patients do not wait in the area – they are taken to the clinic room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In the main reception area. This is appropriate as patients do not meet due to staggered appointments.
Where are the lung function tests done for each visit?		In the testing room, which is cleaned between patients and left for 30 minutes.
Are clinic rooms appropriately sized?	Yes	All well equipped.
For annual review patients, are any distractions provided?	Yes	Cleanable toys available in rooms; patients can also bring own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	N/A	

Additional comments

- The walls are full of bright, child-oriented artwork and information boards.
- All patient notes are kept in the outpatient offices by the secretary. Each patient has a new style folder for their records, devised by the team.
- There is a CF support nurse who will attend clinic to organise patients and ensure that stocks are supplied in the rooms.
- Annual review patients are tested before their annual review appointment.

Environmental walkthrough: Ward

Ward name: Acrewood and Bearwood (and also Elm ward – admissions)

Microbiology status: general

		Hospital name	Poole General Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Both wards are suitable for CF patients.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		19	Spread over Bearwood and Acrewood Wards.
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)			Some rooms have lockable cupboards.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Patient line is free until 7pm. There is a machine to purchase top-up cards (£5 denominations) although patients can play DVDs on their laptops.
If no, are there any concessions for CF patients?		N/A	
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?		Open access	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Some rooms have fridges; CF patients have priority for using these. There is also a patient/ parent kitchen on each ward.
What facilities are provided for teenagers?			Teenagers' room, Xbox, table football, DVDs, TV.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is access to the main gym. Physiotherapists also take patients to the local park for exercise, where there are outdoor gym facilities. Equipment such as gym balls, trampette and step can be taken to rooms. There is also a mobile Wii unit that can be put in the rooms.
What facilities are there to help with school and further studies?		School room, which is run by Ofsted. There are two teachers available who liaise with schools. The teachers collect work for the students. The school room has four computers with internet access. The room is stocked with books and teachers will spend one-on-one time with the students.
Is there a relatives' room?		
What internet access is there?		Only for school use. Patients can bring in their own dongle.
What facilities are there to enable students to continue work and study?	See above	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Milton sterilisers are available on request, plus use of basin.
What facilities are provided for those with MRSA?		There aren't any. Would follow infection control procedures.
What facilities are provided for those with *B. cepacia*?		There aren't any. Would follow infection control procedures.
What facilities are provided for those with other complex microbiology?		There aren't any. Would follow infection control procedures.
Are patient information leaflets readily available on ward?	Yes	Notice boards in corridors. Leaflets provided on request due to updated information.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

- The unit was renovated about 16 years ago, redesigned with side rooms and suitable facilities. Entry to the unit is via a security entry door equipped with cameras. The team have fought for facilities and staffing. There is a good team spirit and always good cross-cover for leave.
- The dietitian has been there for 25 years, the lead consultant for 16 years, and the physiotherapist, who is leaving soon, for six years. The team is sorry to see her go and apprehensive about finding a suitable replacement.

- The CNS is an advanced nurse practitioner and an independent prescriber, which is of great use to the team. The CNS and the physiotherapist conduct home visits to families of newly diagnosed patients. They also visit schools to raise awareness.
- All clinics are led by the two consultants, who provide cross-cover for each other.
- The MDT meets every Friday, where all patients are discussed; minutes of these meetings are taken and saved for future reference for the whole team.
- The CNS has set up an email system for parent contact, which is now regularly used.
- The CNS has a good relationship with patients and has even given advice on sexual health and drugs; there is openness and trust. The psychologist also gives advice to the families.

Recommendations:

- The consultants and team feel that they would benefit from a social worker as an addition to the team; this would take some pressure off the nurse and psychologist. In the past they have had 50 patients, and they would be keen to increase their number of patients in the future.
- Bearwood Ward – 11 side rooms: has eight side rooms, including three side rooms in Owls, which is the teenage part of the ward.
- Notice boards on the walls in Owls feature information on sexual health and alcohol.
- Admissions Ward: patients can phone the nurse directly if out of hours. The ward is not generally used for CF patients, although it could be used at weekends if required.
- Play room: Well equipped with table and chairs for colouring, painting and baking. A gated area for toddlers is well equipped with toys. There are two play therapists available who will bring patients in to have their meals at the table if there are issues with eating.
- Acrewood Ward: HDU with one side room. If this were not available for CF, patients would be sent to Southampton; fortunately this has never happened.
- Parents' kitchen: facilities for use; fridge, microwave, toaster, ice machine and table and chairs.
- Sensory room: fully equipped for use.
- Children's physiotherapy department: outpatients are seen here to learn new physiotherapy techniques; inpatients have physiotherapy in their room.
- Gully's Place: this is a self-contained area where the family of newly diagnosed patients can stay; it can also be used for end-of-life care. Gully's place is funded by charity money. Community nurses and the CNS assist with the end-of-life care; the CNS is on call at these times.

	Hospital name	Poole General Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Two hours free parking for all. There are no general parking issues. Inpatients can get a form signed for the duration of the stay for concessions.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	General unit is signposted.
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, although patients do not go to the pharmacy – parents would pick up prescriptions during the appointment. Radiology – staggered appointments.
Do patients have to wait at pharmacy for prescriptions?	No	GP prescriptions are faxed through by 2pm and will be issued the same day, for parents to collect from GP.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	PALS board in outpatient reception. Large area in main reception named 'Patient Information Centre'. There is also a large CF board in the waiting room, with a list of all the leaflets available; these can be printed on request.
Are there patient comment/ feedback boxes?	Yes	On ward and in general main reception. Suggestion boxes are in the reception areas of both wards.

Queen Alexandra Hospital, Portsmouth

Overview – Consultant

27 patients with CF linked with UHS

Local Consultants	Dr Hannah Buckley	0.2 WTE	Recommended: 0.12 WTE
	Dr Sebastian Austin (started September 2013, allocated time for CF clinic)		Recommended: 0.12 WTE
UHS Consultant	Dr Hazel Evans		

This service has recently seen significant changes. It was an independent clinic, run jointly by Dr Buckley and a consultant who retired in December 2012. Integration in the UHS network service was implemented in 2013 as a result of the national tariff. Integration with UHS is seen as very positive by the local clinical team thanks to its support for managing complex patients and reviewing clinical practice; apparently patients have been less happy with the change, although give largely 'excellent' or 'good' feedback in questionnaires. There is a plan for joint monthly, half-day clinics.

MDT

- There is an established and effective MDT, however, dietetic time is inadequate.
- Physiotherapist has not been funded for CF work and even then has limited time available. Physio is community based but is released to cover the CF clinic in the hospital.
- Well-resourced CF nurse.

Cross-infection control

- Some concern raised by the MDT about block booking of clinics – Dr Buckley confirms the strategy: patients are booked for the first or second session of the clinic depending on their microbiology status. Pseudomonas naive patients are always seen in the first session. Patients are transferred straight to their clinic room as soon as they are booked in, and the MDT rotates round. Three patients are seen in each session, so six patients per clinic.

Admissions

- IV antibiotics are mostly given in hospital. Overall there is adequate physio provision from Band 6 job share post. There is only one physio-led session during weekdays for those attending school – unless children come back early from school, especially for physio. Dietetic review is available but provided according to a patient's nutritional status.

Newborn screening

- There is a newborn screening laboratory at Portsmouth and infants suspected to have CF are referred directly to Dr Buckley.

Transition

- Twice-yearly clinic with adult CF physician from UHS. Patients begin introduction to transition from age 14 and are seen in transition clinic at least once a year initially, and then twice in the run-up to moving to adult services. The adult team provides an information pack and arranges department visits. Adolescents are initially seen on their own in the paediatric clinic from age 14.

Recommendations

- Improve staffing levels, with designated funding, to meet standards.
- Review/increase inpatient physio and dietetic care needs.
- Improve training and skills update opportunities.

- Review clinic organisation to minimise cross-infection risk/reassure staff.
- Psychology and social work input required.
- Parent/patient survey.

Specialist nursing – QA

Queen Alexander Hospital Portsmouth – 27 patients

- 0.8 WTE Band 7 nurse, hospital based. Two link nurses, one hour a week admin. No cover when Band 7 nurse is on annual leave.
- Member of the CFNA and attends regular meetings; national/international
- Involved in newborn screening, education, nursery, schools/college visits, home IVs with teaching pack, providing Disability Living Allowance support, transition support. Year 6 sexual health visit.
- Shared care with Southampton.
- Good education plan linked in with mandatory training.
- End-of-life document in place.

Areas of good practice:

- Encouraging teenagers to take responsibility to phone in.
- Sexual health programme.
- Clinics three times a year for teenagers.

Areas for improvement:

- Review clinic process regularly to ensure minimal opportunities for cross-infection.
- Lack of physiotherapist/dietitian.
- Lack of administrative support.
- Support for social worker.
- Annual leave cover.

Physiotherapy – QA

Portsmouth – 27 patients

- No funding, physiotherapist Band 7 is community team lead 0.9 WTE, spends approx. 0.16 WTE on CF at moment.
- Wessex study day able to get to local annual meeting. Attended autogenic drainage course recently. Association of Chartered Physiotherapists in Cystic Fibrosis member, but meetings not attended for years. Study leave very difficult as CF forms only a small part of the role and allowed on five days per year.
- Daily ward round by duty consultant Band 6 attends MDT once week.
- Band 6 covers acute trust, rotating yearly. Band 7 attends fortnightly clinics in afternoon (six patients).
- Band 6 attended CF conference, funded by charitable funds.

- Audited exercise but was a few years ago.
- Diagnosis – weekly or fortnightly, but Band 6 covering acute trust will see. Transition physiotherapist (PT) not involved due to staffing, often held on physiotherapy day-off clinics. Transplant: one patient with close relationship with Great Ormond Street Hospital.

Areas of good practice:

Awareness of importance of inpatient and outpatient care with no resources offers some services to patients, with support of two clinics a month from Southampton PT.

Areas for improvement:

- Urgently requires funding, no inpatient lead, Band 6 rotates. No outpatient lead with funding to provide a service.
- No specific budget for equipment/adjuncts.
- Very limited opportunity for CF training.

Dietetics – QA

Portsmouth – 27 patients

- WTE – goodwill 0.2 WTE. Cystic Fibrosis Trust's Standards of Care recommend 0.18 WTE.
- Band 6 dietitian worked in CF for 10 years. Completed MSc module in CF in 2011 and is a member of the UK Dietitians Cystic Fibrosis Interest Group.
- Attends Wessex MDT meetings and pre and post-clinic meetings.
- MOT done by Southampton.
- No time to attend national meetings but attends local Wessex meeting twice a year.
- No time to do audits or research.

Areas of good practice:

- Attends clinics and reviews inpatients when available; has good knowledge
- Food service funded by local CF charity for children. Average BMI = 53rd centile.

Areas for improvement:

- Needs allocated CF funding or ring fencing current goodwill sessions.
- Continue to improve communication with Southampton.

Pharmacy

Please refer to information for Southampton Children's Hospital.

Psychology

Please refer to information for Southampton Children's Hospital.

Social work

Please refer to information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Queen Alexandra Hospital, Portsmouth

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Amber	Will be 100% following full integration with UHS.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	N/A. Started shared care April 2013.	Agree	Plan to achieve full compliance in place.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Not really	Increases needed.
	% of MDT who receive an annual appraisal	100%	Green	Unclear	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Unclear	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Amber	Local meeting attended, but physio and dietitian not able to attend other courses.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	N/A		
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Some	Amber	Needs addressing to ensure consistency.

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red n=2 patients seen in separate diabetes and CF clinic.	Red	Not unusual occurrence. Needs support from UHS.

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	Unclear	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% 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%	N/A. 100% of discharged patients received written discharge summaries within 10 days.	Green	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	No leave cover.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	Link nurses on wards but no leave cover for CF CNS.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	See physio info above.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Amber	During school weeks, patients reported to only see physio once.
	% availability of a CF specialist dietitian at clinic	100%	?	Amber	No leave cover.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red. 52% seen twice a week, further 24% once a week. 24% not seen but mostly only in for 1–2 days. Reviewed as required by dietitian.	Red	Patients seen according to need rather than routinely. No ring fenced time for CF so seen as part of general dietetic cover for the ward, but usually by CF dietician.
	% availability of clinical psychologist at clinic and for inpatients	100%	Patient referred to CAMHs as required.	Red	
	% availability of social worker for at clinic	100%	Red. No access to SW.	Red	
	% availability of pharmacist at clinic and for inpatients	100%	Green	Amber	Limited in clinic.

4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	Unclear – available if needed.	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	None	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	None	0	
5.3	User survey undertaken a minimum of every three years	100%	Red. Feedback via parents' evening.	Red	Last done in 2010.
5.4	Service level agreements in place for all	100%	Green	Unclear	

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Queen Alexandra Hospital, Portsmouth
Consultant 1	0.5	1	1	0.2
Consultant 2	0.3	0.5	1	0.12
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
Physiotherapist	2	3	4	0.16 goodwill, no ring-fenced funding.
Dietitian	0.5	1	1.5	0.15 goodwill, no ring-fenced funding.
Clinical psychologist	0.5	1	1.5	As required.
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.05
Secretary	0.5	1	2	0.05
Admin assistant				0.025
Database coordinator	0.4	0.8	1	
CF unit manager				0

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Queen Alexandra Hospital, Portsmouth	
Number of active patients registered (active being patients within the last two years)	0
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	24
Median age of active patients in years	11
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	4 (17%)
	4–7 years	4 (17%)
	8–11 years	5 (21%)
	12–15 years	7 (28%)
	16+ years	4 (17%)

Genetics	
Number of patients and % of unknown genetics	1 (4%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	1 (4%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	1 (8%)	1(8%)
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	4
	4–7 years	4
	8–11 years	5
	12–15 years	7
	16+ years	4
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	1
	16+ years	1

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (4%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	2 (8%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (2%) with PH; 1 (2%) without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	16
	4–7 years	77
	8–11 years	32
	12–15 years	27
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	12
	12–15 years	12
	16+ years	0
Total number of IV days split by age group	0–3 years	16
	4–7 years	77
	8–11 years	44
	12–15 years	39
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n=14 7 (50%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	2 (8%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (4%) with chronic PA; 7 (29%) without chronic PA

Patient survey

Queen Alexandra Hospital, Portsmouth

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	1	0	2	0
Female	3	0	2	0

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	2	0	1	0
Cleanliness	2	2	0	0
Cross-infection/segregation	2	2	0	0
Food	1	1	1	1
Exercise	1	1	1	1

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Feel comfortable and part of a family."

"We find the team at Queen Alexandra Hospital, Portsmouth friendly and supportive. Available when needed and always call back. We feel thankful to have a good team."

"QA team – fantastic! They need more support and money. QA hospital (Tony Blair's hospital owned by Carillion not NHS!) CF team get nothing from Carillion or the Cystic Fibrosis Trust as in help and support – it's shameful! Nebuliser parts are excellent."

"The personal touch; familiarisation with your child is the main attribute to our CF team. JW is our main communication, however when he's not there nothing happens!"

"Really happy with the overall care accorded to us from diagnosis to the awesome care and information given to us from the team at QA. I cannot fault anything – keep up the good work."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital name	Queen Alexandra Hospital, Portsmouth
	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	Two very large waiting areas for use.
Do patients spend any time in waiting room?	No	Only three patients per session, two sessions per clinic.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	There are two fully equipped height and weight rooms.
Where are the lung function tests done for each visit?		Separate department.
Are clinic rooms appropriately sized?	Yes	All clinic rooms are of a very high standard and fully equipped.
For annual review patients, are any distractions provided?	Yes	Many toys available.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Same facility. There are two patients, who are seen on separate days. The diabetes nurse is called in on clinic visits.
Transition patients – can they get tour of outpatients' facilities?		Yes, they can visit the adult department at SUHT whenever they feel ready to.
Transition/new patients – do they get information pack?		Transition clinic with Southampton, who provide the information pack. The patients are seen on their own from the age of 14.

Additional comments

- Cystic Fibrosis Kids of Portsmouth (CFK) charity. This charity has funded a scheme where all CF inpatients have unlimited access to food and drink in the hospital canteen. The patient receives a credit/photo card for personal use only. They can obtain food vouchers from staff on the ward for use in the canteen, and this is charged to CFK.
- Patients can also obtain two £5 McDonalds vouchers for use during their stay.
- A Blockbuster card for free DVD rental is also available. The CFK also funded the gym equipment.
- There are TV and game station packages that can be brought into cubicles.

- Certificates and gift boxes available for younger patients – for bravery.
- Young person freedom card – with permission from parents/carers for boundaries, patients can go to areas such as the canteen/shops alone.
- Meals are served at 7.30am, 12.30pm and 5.30pm. Cystic fibrosis patients can order two portions. The food is served up from the trolley on delivery. Patients can also bring in their own food.

Environmental walkthrough: Ward

Ward name: Starfish (Medical) Ward, plus see comments box for Shipwreck (Surgical) ward

		Hospital name	Queen Alexandra Hospital, Portsmouth
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable ward.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		12	Eight are en suite. All CF patients would be given en suite cubicles. Four baby cubicles are available (not en suite).
Do the en suites have:	**Toilets?**	8	
	Wash basins?	12	
	Bath or shower?	8	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward)		Yes	Teenagers are given lockable pods.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free until 7pm, until 9pm on discretion. Portable DVD and games stations available.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull-down beds available in all cubicles. Separate parents' bathroom.

	Yes/no/ number/N/A	Notes/comments
Visiting hours – are there allowances for CF patients' families outside of normal hours?	Yes	Open access
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?	Yes	There is a fridge and microwaves in the parents' kitchen.
What facilities are provided for teenagers?		TV, Wi-Fi, DVD, games.
Is there access to a gym or exercise equipment in the rooms?	Yes	Very well-equipped gym, with bike, cross trainer, step, trampoline and Wii Fit – access via physiotherapist arrangement. Can provide equipment in cubicles.
What facilities are there to help with school and further studies?		Patients can take taxi to school and have treatment around schooling. Hospital teachers will support child in their cubicle doing school work if they are unable to go to school.
Is there a relatives' room?	Yes	Fully equipped with sofa and seating area, washer/dryer, fridge, microwave, dishwasher and table/chairs.
What internet access is there?	None	Only patient's own 3G access.
What facilities are there to enable students to continue work and study?		School teachers liaise with the schools and are there for student support.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sterile filters on taps in all cubicles, where nebuliser parts can be washed and hung up to dry in a net bag by window.
What facilities are provided for those with MRSA?		Patients would be segregated in own cubicles.
What facilities are provided for those with *B. cepacia*?		None. Risk assessment if occurred. Patients would be segregated in own cubicles.
What facilities are provided for those with other complex microbiology?		None. Risk assessment if occurred. Patients would be segregated in own cubicles.
Are patient information leaflets readily available on ward?	Yes	In patient education room.
Transition patients – can they get tour of ward facilities?	Yes	They can go on a tour of adult inpatient facilities at SUHT when they feel ready to.

Additional comments

- Shipwreck Ward – surgical ward for planned admissions: six cubicles, all en suite. Same facilities as Starfish Ward.
- Children's assessment unit: three cubicles (all en suite), four trolley spaces, large waiting area for out of hours and GP referral, although not usually used for CF patients.

- The paediatric unit is a very impressive, spacious and modern inpatient/outpatient unit, which has been open for approximately five years. Entry to the unit is via a security desk and locked door. There are two very spacious, brightly coloured waiting areas, fully equipped with toys, colouring equipment and children's tables and chairs. The second waiting area is for diabetes and ophthalmology.
- There is a separate waiting area for those aged 12 and over, equipped with a TV, board games and reading material.
- All cubicles and rooms are modern and fully equipped to a very high standard. Cubicles are deep cleaned when patients are discharged.
- Physiotherapist: patients receive two daily sessions, am/pm. At weekends, patients receive daily physiotherapy as required, at least one physio-led session at weekends and second session available if child is in hospital in the afternoon. There is always physiotherapy support available.
- Dietitian with CF interest is available when required.
- Separate storage room for nebulisers and parts.
- The unit has its own phlebotomy room and service.
- There is a fully-equipped spirometry room.
- Inhaler techniques are taught and patient information is stored in the patient education room.
- The parents' bedroom is not generally used by CF parents; they use the pull-down beds in cubicles if they are staying over.
- Outside play area is spacious with cushioned flooring, bikes and cars.
- The team is in the process of introducing a notice board to each cubicle wall. This will act as a timetable/diary, using velcro pictures to display the treatments booked and received, on which day and at what time. This will enable both parents and children to understand the schedule.

	Hospital name	Queen Alexandra Hospital, Portsmouth
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Large car park, costs £1.80 per hour. Disabled parking. There are no issues with parking facilities. Inpatients are subsidised for overnight stays. Refunds are available from the Cystic Fibrosis Kids of Portsmouth charity.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Paediatric unit is signposted.
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	Ward-based pharmacist; staff collect the outpatient prescriptions. DEXA scan would never occur as patients booked one at a time. Ultra sound and X-ray – very large waiting area for paediatric use only; patients would not be sent together.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Extremely large area in main hospital reception.
Are there patient comment/ feedback boxes?	Yes	Monthly surveys are conducted.

Basingstoke and North Hampshire Hospital

Overview – Consultant

18 patients with cystic fibrosis shared with UHS (two others shared with RBH and one with GOSH).

Local Consultant	Dr Priya Ilangovan	0.2 WTE	Recommended: 0.2 WTE
	Dr S Jog	0.05 WTE	
UHS Consultant	Gary Connett		

The local team is well established, experienced and very committed, providing a comprehensive service for their patients, and is responsive to feedback. The service linked with UHS in 2013, following implementation of the CF tariff, having previously run as an independent unit. The local team appears to have taken a positive and constructive approach to this joint working model. Only one joint clinic had been held prior to the peer review, and the plan is for four to five full-day clinics per year.

Hampshire Hospitals NHS Foundation Trust

Basingstoke and Winchester hospitals were part of a recent amalgamation, which has included their respective CF services. The two hospitals are 15 miles apart. There are integrated community and hospital services, and there is general paediatric dietetic and physio input from Basingstoke to Winchester on most days. The paediatrician for the Winchester patients is reported to be retiring in 2014, and there are plans to manage the two groups of patients together (18+8). This development is a positive step in providing a comprehensive CF service, with good MDT cross-cover, between two pre-existing local network clinics.

Local clinics

The CF service is consultant-led with very positive feedback in the parent questionnaire. The two consultants work on an annualised rota, and are able to set clinic dates one year ahead and patients are allocated to specific clinics. The whole MDT sits in the same room with each child and family for a 45-minute appointment – a practice introduced following discussion with parents.

Monthly team meeting. Cystic Fibrosis Trust's Standards of Care for performance of liver USS and DEXA scans are not currently being met.

MDT

Generally well resourced, and appreciated by parents, although apparently has a regular turnover of physiotherapists and the dietitian was on maternity leave at the time of review. Adequate physio support for inpatients is not available according to risk matrix.

Previously had dedicated psychologist; now only service is available through Child & Adolescent Mental Health Service. Social worker support available as linked with Winchester.

Infection control

Some (potential) overlap in clinics reported. Same room used for lung function. Two en suite cubicles available.

Good microbiology support, with samples sent to Colindale when needed. There is a discrepancy (1 vs 3) in the number of patients with chronic PA on Port CF and unclear if any/all are on chronic nebulised antibiotics. This may just be a clerical error.

Admissions

Most patients have infrequent courses of IVs and, when they do, they tend to have the whole course in hospital – with the team utilising the time to provide education and revision of management plans. A few older patients start IVs in hospital and do the rest at home. Physiotherapy input is not quite adequate enough, ie not enough sessions at weekend.

A detailed care and nutrition plan is issued to each child on admission, which helps the child and family know what to expect.

Transition

Largely to adult CF service at UHS, although some concern that the service is too big as there are delays in getting IV antibiotics. Some patients are starting to go to Frimley Park.

Recommendations

- Formalise time spent on cystic fibrosis and fund staffing according to the Cystic Fibrosis Trust's Standards of Care.
- Ensure careful forward planning of CF services across hospital sites – eg admissions to only one site; this will enable concentration of experienced staff there, particularly to ensure seven-day physio access.
- Review clinic planning to minimise cross-infection risk – patients can still overlap, even though they attend one at a time.
- Provide nurse and dietitian with opportunities to attend educational meetings, eg special interest groups.

Specialist nurse – Basingstoke

Basingstoke and North Hampshire Hospital – 24 patients (18 Basingstoke and 6 Winchester)

- Nurse is Band 6, 0.5 WTE, community based, has done the Bristol course.
- Not a member of the CFNA (have forwarded details), therefore has not attended meetings, but has attended other CF meetings.
- Involved in inpatient/outpatient care, own documentation. Winchester has ready-made service, newborn screening, education, nursery school visits.
- Not yet been to Southampton MDT; Frimley Park is closer and easier to travel to.
- DLA by CF nurse, some input from Southampton's social worker.
- Port CF registry data sent to Southampton for inputting.
- End-of-life document.

Areas of good practice:

- Nurse has a general case load so a lot of goodwill.
- Good inpatient facilities.
- Good links with professionals.

Areas for improvement:

- Block clinics – potential risk of cross infection.
- More nurse time for CF.
- Social worker time.

Physiotherapy – Basingstoke

Basingstoke and Winchester – 23 patients

- Basingstoke and Winchester have 15 and eight patients respectively. Winchester's Band 7 physiotherapist works 1 WTE, without funding. Spends approx. 30–40% of time on CF. Service merged approx. two years ago.
- Attends Wessex winter club yearly. Has attended Royal College of London meeting. Member of Association of Chartered Physiotherapists in Cystic Fibrosis. Did not attend national study day. Attends Southampton MDT evening lectures.
- Basingstoke: attends MDT meetings/ward round; ward physiotherapist Band 5 or Band 7 cover. Winchester: cannot attend these meetings – no cover.
- Attended 2012 & Dublin European CF Conferences – study leave and funding not an issue.
- Involved in audit of ward physiotherapy 18 months ago, clinic service for physiotherapy.
- Adolescent clinic with approx. four patients.

Areas of good practice:

- Offers a service to inpatients and outpatients split over two sites and also another satellite at Alton.
- Able to do exercise testing, attends clinics.
- Basingstoke patients seen twice daily for airway clearance; once daily gym for inpatients.

Areas for improvement:

- Urgently requires funding for Winchester and Basingstoke. Winchester inpatients covered by adult physiotherapists.
- Gym facilities ad hoc.

Dietetics – Basingstoke

Basingstoke – 15 patients (covers 8 patients at Winchester)

- Funded 0.2 WTE; Cystic Fibrosis Trust's Standards of Care recommend 0.17 WTE.
- Band 7 – worked in CF for three years.
- Member of the UK Dietitians Cystic Fibrosis Interest Group – has not yet been to a meeting.
- No concerns with care cover when on annual leave.
- Good catering facilities.
- No involvement with research or audit, but would like to do some joint work with Southampton.
- Beginning to develop good relationships with Southampton dietitians, as only recently started coming to clinics in April 2013.

Areas for improvement:

- Develop more shared care working with Southampton, as was previously a stand-alone hospital providing all MOTs.
- If funding available, do MSc in CF.
- Attend a meeting of the UK Dietitians Cystic Fibrosis Interest Group.
- Discuss using CF time in MOT clinics, as there may be different way of utilising time, audits, etc.
- Consider cover for all local care for Winchester CF patients, as the dietitians have been one department since April.

Pharmacy

Please refer to information for Southampton Children's Hospital.

Psychology

Please refer to information for Southampton Children's Hospital.

Social work

Please refer to information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Basingstoke and North Hampshire 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%	Red since April 2013.	Red	Only had one joint clinic so far; should meet standards in time.
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	Amber	Again, will improve.

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Red	Amber	New joint clinics just being set up.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Not really	Unfunded MDT time; inadequate IP physio.
	% of MDT who receive an annual appraisal	100%	Green	Unclear	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Unclear	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Amber	Nurse and dietitian appear not to have attended meetings.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red There are local arrangements.	Red	Needs to be addressed with new UHS arrangements.
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Green	Unified policies.

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red. **Discussed locally with endocrinologist and diabetologist.**	Red	Link with UHS service.

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	Possible that both rooms may be in use – but generally try to ensure CF patients are priority.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Unclear	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red. Sent to Southampton – takes 48 hours to get results.	Red	Needs addressing.

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. All aged >10 have had yearly ultrasound.	Red	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red. Some in pipeline 2/6 in last year.	Red	Should be done at UHS.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% 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	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	Adequate cover for leave?
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	Leave cover?
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	Leave cover?
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Amber	Conflicting information about this – some say not seeing physio at weekend.
	% availability of a CF specialist dietitian at clinic	100%	Green	Amber	Leave cover?
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Amber	Leave cover?
	% availability of clinical psychologist at clinic and for inpatients	100%	Red. Available if needed.	Red	Input needed.
	% availability of social worker for at clinic	100%	Green	Amber	Leave cover?
	% availability of pharmacist at clinic and for inpatients	100%	Green	Amber	Available in clinic.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Unclear	Most have IVs in hospital.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Basingstoke & North Hampshire Hospital
Consultant 1	0.5	1	1	2 PA
Consultant 2	0.3	0.5	1	0.5 PA
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	0.4 WTE (shared time with Winchester hospital).
Dietitian	0.5	1	1.5	0.4 WTE (shared time with Winchester hospital).
Clinical psychologist	0.5	1	1.5	As needed.
Social worker	0.5	1	1	As needed.
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	
Play therapist				0.4 WTE

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Basingstoke and North Hampshire Hospital	
Number of active patients registered (active being patients within the last two years)	15
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	14
Median age of active patients in years	7
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	2 (14%)
	4–7 years	7 (50%)
	8–11 years	0
	12–15 years	3 (16%)
	16+ years	2 (14%)

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	0

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	1 (20%)	1 (11%)
	8–11 years	0	0
	12–15 years	0	1 (1%)
	16+ years	1 (20%)	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	2
	4–7 years	7
	8–11 years	0
	12–15 years	3
	16+ years	2
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	1 (7%)
	12–15 years	2 (14%)
	16+ years	0

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (7%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	1 (7%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	16
	4–7 years	77
	8–11 years	32
	12–15 years	27
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	12
	12–15 years	12
	16+ years	0
Total number of IV days split by age group	0–3 years	16
	4–7 years	77
	8–11 years	44
	12–15 years	39
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n=8 0
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	1 (7%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	0
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (7%) with chronic PA; 3 (21%) without chronic PA

Patient survey

Basingstoke and North Hampshire Hospital

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	11	1	0	0
Communication	11	1	0	0
Out-of-hours access	11	0	1	0
Homecare/community support	11	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	11	1	0	0
Waiting times	6	5	0	0
Cross-infection/segregation	9	1	1	0
Cleanliness	10	2	0	0
Annual review process	10	1	0	0
Transition	2	0	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	8	3	0	0
Cleanliness	8	3	0	0
Cross-infection/segregation	8	1	0	0
Food	4	4	1	1
Exercise	9	0	0	0

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	4	0	0	0
Availability of equipment	9	1	0	0
Car parking	7	2	1	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	10	1	0	0
Of the ward staff	10	1	0	0
Of the hospital	10	1	0	0

Comments about CF team/hospital

"Excellent. Can't fault; follow all guidelines from Cystic Fibrosis Trust."

"Basingstoke are really good at everything they do, especially the CF team."

"Very happy with ongoing care, no problems identified."

"The hospital is always very accommodating to all our needs."

"Generally Basingstoke is good. I brought my daughter here as it is closer to my house than Southampton. I have had many differences with the CF consultant at Basingstoke but she has listened to my opinions and taken note. Other than when my daughter was in as a baby for two operations, I have never seen the CF team at Southampton. When my daughter was admitted at the start of May 2013 and I asked to speak/see Dr Connett, all I got was a phone call. Some of the staff on ward were very good/kind but one or two of the others were ignorant and rude."

"Fantastic supportive team."

"Outstanding levels of service and care. Should be used as an example to other trusts of how it can work and should."

"Cystic Fibrosis team at Basingstoke have been so important in us coming to terms with our son's illness and helping deliver the care his condition requires and keeping us up to date with current developments and improvements in care/plans/treatment."

"Everyone at Basingstoke are polite, professional, caring and efficient."

"We have always received the best standard of care and attention at Basingstoke hospital. The CF team are all aware of patient history, as are all the nursing team on the ward."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital name	Basingstoke and North Hampshire 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. Patients are checked in and sent directly to either the clinic room, height and weight room, or lung function room.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Separate room for this.
Where are the lung function tests done for each visit?		Separate testing room.
Are clinic rooms appropriately sized?	Yes	Fully equipped.
For annual review patients, are any distractions provided?	Yes	iPads, toys, play therapist available.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Seen at clinic.	
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	The consultant and nurse travel to Southampton to meet parents of newly diagnosed patients on the ward. They will even visit the family at home. There is an information pack available with photos of the team, their names and contact details.

Additional comments

- All clinics are booked one year in advance. Patient appointments are staggered and allocated 45 minutes per session, although can overrun. The team does as much as it can in order to avoid patients meeting unexpectedly.
- After each clinic visit, a clinic pro-forma is sent to update the GP, detailing drugs prescribed, school information and diet information.
- For annual reviews, testing such as bloods is carried out prior to appointment.
- In the reception area there is a step-by-step guide, with pictures, explaining the clinic visit system.

- The dietitian has put together a high-calorie recipe book for patients named 'Yummy Yum Food Fun'. All the recipes have been collected from patients/parents and staff, and contributors are named in the book. Printing of the book was funded by 'Anna's Challenge' charity.

Environmental walkthrough: Ward

Ward name: G2

Microbiology status: General

		Hospital name	Basingstoke and North Hampshire Hospital – 18 patients
		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 are required)		Yes	
Number of side rooms?		10 in total	Two en suites, which are given to CF patients as priority.
Do the en suites have:	**Toilets?**	Yes	Other side rooms can have facilities dedicated to CF patients if needed.
	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 bed for adults? (Include in notes policy of ward)		Yes	All rooms have lockable lockers.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Freeview TV for CF patients. Other patients have free 'Patient line' until 9pm.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	All rooms have pull-down beds.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Small fridges in rooms available for CF use. Fridge/microwave for use in parents' kitchen.
What facilities are provided for teenagers?			Teenage room ('Skeats Lounge') equipped with sink, TV, music, play station and Xbox, DVDs and videos.

	Yes/no/ number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Access to well-equipped gym run by physiotherapy team and dedicated time given; well equipped with large and small exercise bikes, Xbox connect and Wii Fit – fitness games (dance, football, Olympics), two therapy beds, trampettes, exercise balls. Awaiting delivery of treadmill (donated). Equipment can be put in side rooms for use.
What facilities are there to help with school and further studies?		Timetabled school work in daily care plan. Parents and nurse liaise with the school and parents collect work. On occasion the teachers will visit the patients.
Is there a relatives' room?	Yes	Sofa in quiet room. Free tea and coffee facility available from the parent kitchen.
What internet access is there?	None	Patients can bring in own dongle.
What facilities are there to enable students to continue work and study?	Hospital laptop available for use with own internet facility.	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Milton tank and basins in side rooms.
What facilities are provided for those with MRSA?		Would follow policy – have none.
What facilities are provided for those with *B. cepacia*?		Would follow policy – have none.
What facilities are provided for those with other complex microbiology?		Would follow policy – have none.
Are patient information leaflets readily available on ward?	Yes	Abundance of noticeboards and leaflets displayed; also can be printed off from CF website on request.
Transition patients – can they get tour of ward facilities?		Encourage patients to visit adult centres. Hold a six-monthly transition clinic.

Additional comments

- The children's unit is located on the fifth floor and accessed via lifts. There is a security door on entry. Brightly coloured murals on all walls, Disney characters, and very child-oriented.
- On admission patients/parents are given a patient ward pack with a detailed care plan, a nutrition care plan for keeping an eating record, a daily programme, a check list of treatment being given and guidance for parents on what to expect.

- All patient notes are kept on the children's unit.
- The MDT has a monthly meeting where there is an agenda, issues and all patients are discussed. Minutes are taken and are available for providing updated information to the team.
- There are plans for a new build in the future; the consultant has relayed requirements necessary for the new paediatric unit.
- The consultant has worked here for 18 years and the nurse for 13 years. The team is dedicated and very proud of the service they deliver, and also of their team.
- Sensory room: Well equipped for patient use when accompanied by trained nurses and play specialists.
- 'Skeats Lounge' (teenage room): This is dedicated to a patient who passed away, and was funded by the parents in her memory. The equipment supplied is what the patient suggested was required for teenagers.
- Teenage bays (one each for boys and girls): Four beds in each. One teenage patient prefers to be here to interact with other children. Only one CF patient would be permitted to stay here at any one time. This child is issued with a dedicated wet room/toilet facility.
- HDU: One side room fully equipped.
- Day assessment unit: Two side rooms, which would be used for CF patients. Patients have open access 24/7.
- Assessment room: Newly refurbished with walls and ceiling covered in a sea-life mural. The mural (funded by 'Anna's Challenge' charity) is used as a distraction for ports procedures and treatments, after which the patient would be transferred back to one of the side rooms. This room also houses the new pod for sending the prescription to pharmacy and for delivery of drugs. There is also a fully equipped triage area with all HDU facilities and a parent room.
- Outside the gym is a noticeboard. This is regularly updated by the nurses and physiotherapists with new topics. At the moment, the focus is on keeping fit and basic health rules. A variety of gym equipment has been funded by the 'Anna's Challenge' charity.
- The team feels there is a need for an information pack on the adult centres (Frimley and Southampton).

	Hospital name	Basingstoke and North Hampshire Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	All CF patients complete a form, signed by the consultant; this offers free parking for six months, for up to two cars, and can be continually extended.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Unit is signposted.
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?		Prescriptions are sent via the Pod system, or parents collect them during the appointment. The nurse will also deliver if visiting. DEXA/ radiology – these are by appointment only.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	There are many noticeboards throughout the children's unit.
Are there patient comment/ feedback boxes?	Yes	They also have their own iPad-based patient satisfaction survey; the iPad rotates throughout the hospital departments on a monthly basis.

Dorset County Hospital

Overview – Consultants

"DCH is the main provider of acute hospital services to a population of around 210,000 living within Weymouth and Portland, West Dorset, North Dorset and Purbeck. It has around 2,300 deliveries per year."

Eight children with CF linked with UHS

Local consultant Dr Rollo Clifford – 0.1 WTE Recommended: 0.05 WTE
Consultant has been in post for 20 years. No cover provided for leave.

UHS consultant Gary Connett

Full-day joint clinics held twice per year (reduced from three per year as patient numbers decreased)

- Risk matrix indicates that no child sees the MDT from UHS at least twice a year – if so, this is a serious deficiency.
- The local consultant presented a somewhat negative view of the service that they were able to provide. He was not aware of financial details of the locally applied tariff, nor has he seen any evidence of benefit to his service.

Local clinics

- Dietitian only available about two-thirds of the time; CNS not always present.
- No segregation of patients.
- Conflicting information about whether there are none or three patients with CFRD.

MDT

- Experienced team but limited time and mostly unfunded – most arrangements are informal. Lead physio is community based.
- Nurse has to do any administration as there is no clerical support available in the paediatric department.

Areas of good practice:

- Clinic letters produced immediately by consultant using electronic database system.

Admissions

Overall the consultant considers inpatient management to be adequate but recognises that limited and inexperienced physiotherapy input is a concern. Only 20 inpatient days in 2012 (Port CF), so ward experience of CF patients is going to be low since three siblings with NTM left the clinic.

Guidelines/protocols

- Uses the UHS text book, which is due to be updated.
- DEXA scans and liver US scans not performed on all patients as recommended.
- CFRD screening currently only comprises HbA1c testing.

Transition

- Routinely referred to regional adult CF clinic based in Poole.
- Outreach from adult services – for joint clinics.

Newborn screening

- No positive newborn screened infants in previous five years.
- Unclear who performs sweat test, and whether they have adequate experience. Sweat samples sent to UHS for processing.

Infection control

- This did not seem to be a high priority as the consultant didn't seem to believe that there was much potential for cross infection. Patients aren't allocated individual rooms in clinic, but rotate around the MDT rooms. Lung function tests are done in one room.
- Have two patients with chronic PA; three siblings with non-tuberculous mycobacterium recently moved from Dorchester to Salisbury.
- Considers that they have a really good, CF-specific microbiology service.
- En suite cubicles on ward.

Recommendations:

It is unlikely that there will be a significant increase in patient numbers in the future, which poses a challenge to bringing staffing standards up to recommended levels in a way that will be sustainable. As a minimum:

- All children should be seen at least twice a year by the UHS MDT.
- Increase physio and dietetic time to meet the Cystic Fibrosis Trust's Standards of Care, 2011.
- Implement infection-control measures in outpatient clinics.

Specialist nurse – Dorset

Dorset County Hospital – 7 patients

- 0.1 WTE (Community Nurse) Cystic Fibrosis Trust's Standards of Care recommend 0.2 WTE.
- Recently became a member of the CFNA. Due to poor staffing levels, was unable to attend networking day.
- CF nurse sees patients on a daily basis when inpatient. There is a link nurse who has completed the Bristol course.
- Attends local cystic fibrosis meetings.
- Involved in drug trials.
- Not involved in newborn screening, transition – traffic light system, home IVs on ad-hoc basis.

Areas of good practice:

- A lot of goodwill – committed to the service, supporting DLA forms.
- Own documentation.

Areas for improvement:

- Full MDT to attend clinics.
- Social worker/support.
- Link nurse should become CF support nurse.

Physiotherapy – Dorset

Dorchester – eight patients

- Band 8a physiotherapist – 70% clinical, funded for three hours a month – unprotected.
- Covers clinics, case conferences, visits, outpatient appointments for exercise testing.
- Band 6/7 cover wards. No physiotherapist available on Sundays, so parents do treatment.
- Attends Wessex Study Day and Royal College of London meeting – study leave not an issue, paediatric funding okay.
- Attends ward round; all children discussed at the end of each clinic.
- Band 7 will cover clinics in Band 8a's absence. Children's centre based on hospital site.
- Attends European/International Cystic Fibrosis Conferences: Band 8a physiotherapist attended European Cystic Fibrosis Conference in Hamburg.
- Not involved in any audit/research.
- One new baby diagnosed in past five years; would be able to see within a week.

Areas of good practice:

Cover provided to clinics with very limited funding; one day, alternate months – eight patients per clinic. One member of staff in clinic. Children 8+ years get exercise testing two afternoons a year. Only two children have regular IVs three monthly, always as inpatients, receiving airway clearance twice daily.

Areas for improvement:

- Funding for physiotherapy time.
- Budget for physiotherapy adjuncts.

Dietetics – Dorset

Dorchester – eight patients

- Dietitian Band 6/7 – goodwill 0.025 WTE – not funded; Cystic Fibrosis Trust's Standards of Care recommend 0.05 WTE.
- Attended European Cystic Fibrosis Conferences in Prague and Dublin, Wessex MDT meetings.

Areas of good practice:

- CF trained with 20 years' experience.
- Has done school visits.

Concerns from dietitian:

- Not properly funded, finds it difficult to cover workload. MOTs are all day with Southampton, and she has other commitments in the afternoon, so cannot be there for the whole day.
- Unhappy to cover without full funding, feels patients not getting regular, consistent care by a dietitian.

Areas for improvement:

- Fund local dietitian.
- Continue training and improving shared care with Southampton.

Pharmacy

Please refer to information for Southampton Children's Hospital.

Psychology

Please refer to information for Southampton Children's Hospital.

Social work

Please refer to information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Dorset County Hospital

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Red	Red	Unclear why, when only eight patients and two joint clinics per year.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	N: We do not do all we would like to do.	No	
	% of MDT who receive an annual appraisal	100%	Green	Unclear	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Unclear	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red. Relates to centre.	Red	
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Unclear	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red. No such clinic – but no patients with diabetes.	Inadequate CFRD screening (HbA1c only).	

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. Numbers too small.	Red	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red. Not yet available for Tobramycin.	Red	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Red	OGTTs not done.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Red. 3/7 not – 1 DNA.	Red	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red. Last male transferred two years ago.	Red	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red.	Red	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	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	Amber. 90% on risk matrix.	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber. Again, 90% on risk matrix.	Leave cover?
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	Leave cover?
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Red	No full cover at weekends.
	% availability of a CF specialist dietitian at clinic	100%	Amber	Red. 70% on risk matrix.	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red. Ad hoc.	
	% availability of clinical psychologist at clinic and for inpatients	100%	Red	Red	
	% availability of social worker for at clinic	100%	Red	Red	
	% availability of pharmacist at clinic and for inpatients	100%	Green	Amber	Seems unlikely in clinic.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	N/A	Matrix says none doing home IVs.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	Not needed.

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	None	None	
5.2	Number of clinical incidents reported within the past 12 months	<1%	None	None	
5.3	User survey undertaken a minimum of every three years	100%	Green	Unclear	
5.4	Service level agreements in place for all	100%	Green	Unclear	

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Dorset County Hospital
Consultant 1	0.5	1	1	0.1 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	0.1 WTE
Physiotherapist	2	3	4	0.025
Dietitian	0.5	1	1.5	0.025
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.01
Secretary	0.5	1	2	0.01
Database coordinator	0.4	0.8	1	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Dorset County Hospital	
Number of active patients registered (active being patients within the last two years)	8
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	6
Median age of active patients in years	11
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	0
	4–7 years	2 (33%)
	8–11 years	1 (17%)
	12–15 years	3 (50%)
	16+ years	0

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	0

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	1 (33%)	1 (33%)
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	0
	4–7 years	2
	8–11 years	1
	12–15 years	3
	16+ years	0
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	1
	16+ years	0

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	20
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	20
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n=6 2 (33%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	1 (17%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 1 (17%) without chronic PA

Patient survey

Dorset County Hospital

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	0	0	0	1
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	1	0	0	0
Homecare/community support	0	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	1	0	0	0
Waiting times	1	0	0	0
Cross-infection/segregation	0	1	0	0
Cleanliness	0	1	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	0	0	0
Cleanliness	1	0	0	0
Cross-infection/segregation	0	1	0	0
Food	0	1	0	0
Exercise	0	0	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	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	1	0	0	0
Of the hospital	1	0	0	0

Comments about CF team/hospital

"West Dorset is a great hospital; we are very blessed! All the CF team are lovely and we try not to pester them too much!! Friendly bunch – God bless them all! Thank you."

	Hospital name	Dorset County Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	No more than eight patients ever per clinic. There is little overlap, however, it is a possibility they may wait for a short time for a room to become available.
Do patients spend any time in waiting room?	Yes, possibly on rare occasions.	Patients are currently taken into a room as soon as they are free. However, patients rotate rooms to visit staff rather than staff moving and patients remaining in their own room for the visit.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height/weight room in outpatient clinic. None of the clinic rooms currently have their own height/weight facilities, therefore, there is the possibility of cross-infection risk in some clinics where all are utilising the same room.
Where are the lung function tests done for each visit?		In physiotherapy clinic room. The CF unit only has one spirometry unit available. However, all patients have single-use, disposable equipment.
Are clinic rooms appropriately sized?	Yes	Good size.
For annual review patients, are any distractions provided?	Yes	Toys provided. Children bring in their own toys, mobiles and distractions.
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?		Three patients, seen in outpatient clinic by diabetolologist (not a joint clinic, however, it runs at the same time as the CF clinic).
Transition patients – can they get tour of outpatients' facilities?	No	Can be offered as required; happens as and when, rather than as part of a process.
Transition/new patients – do they get an information pack?	Yes	Leaflet about the CF team and Cystic Fibrosis Trust leaflets available, as required.

Additional comments

- The age range of the eight8 patients attending this clinic is one to 17 years.
- Two are chronically colonised with Pseudomonas aeruginosaPA; two are undergoing eradication. There are no patients with MRSA, Burkholderia cepacia or Mycobacterium abcessus. The main issue here appears to be a lack of time for CF, particularly ring fenced, designated time for CF. There is no psychology or social work input locally. There is some small psychology input from Southampton. It is recognised this is an area where Dorset patients are not receiving the same standard of care as in Southampton.

- There is also a shortage of dietetic, physiotherapy and nursing time for CF. Most arrangements are informal and this should be addressed with allocated, funded time in job plans for all team members.

Environmental walkthrough: Ward

Ward name: Kingfisher

Microbiology status: all

		Hospital name	Dorset County 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 en suite cubicles suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Nine rooms, eight en suite side rooms.
Number of side rooms?		Nine	
Do the en suites have:	**Toilets?**	Yes	Except room 5.
	Wash basins?	Yes	
	Bath or shower?	Yes	Except room 5.
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bed 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 of charge.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	The rooms have camp beds and there is a parents' room available.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	Open access. No restrictions for primary relatives.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	There is a fridge and a microwave in the main kitchen for use by parents.
What facilities are provided for teenagers?			Adolescent room for use with family and friends. No two CF patients use it at any given time. There is a suggestion that this room may be removed in the refurbishment. However, it is important that it remains.

	Yes/no/ number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	Physiotherapy equipment is available in another area in the children's unit for use with the physiotherapist, although this is rarely used by CF patients due to a lack of physiotherapy time. No portable equipment is currently utilised on ward, such as bikes or gym balls.
What facilities are there to help with school and further studies?		Teacher and school room. Can also bring in own laptops, study in room or school room with desks.
Is there a relatives' room?	Yes	Parents' room on ward.
What internet access is there?		Wi-Fi available.
What facilities are there to enable students to continue work and study?		School room with desks. Teacher liaises with school. Patients can also use their own laptops in their rooms.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Parents/patients can wash, clean and air dry in their own bowl in the sink in the room, or air dry on table top.
What facilities are provided for those with MRSA?		Isolation side room segregation on same ward (0 patients at present).
What facilities are provided for those with *B. cepacia*?		Isolation side room segregation on same ward (no patients at present).
What facilities are provided for those with other complex microbiology?		Isolation side room segregation on same ward (no patients at present).
Are patient information leaflets readily available on ward?	No	Distributed by nurse as required. None seen on ward or in outpatient area.
Transition patients – can they get tour of ward facilities?	Yes	New patients get tour of ward and outpatients as and when required, however, it is not a formal process.

Additional comments

- Very clean and tidy ward area with panoramic views of local area from side rooms. Artwork and colour on walls creates a pleasant, child-friendly atmosphere.

	Hospital name	Dorset County Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	CF inpatients/parents get free parking. Outpatients pay £1.60 for one hour, £2.10 for two hours and £4.20 for up to four hours. Over four hours costs £6.50. If receiving benefits, patients are eligible for complete refunds.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Maps and signage are clear, however, there are no CF signs as they are not a dedicated CF ward or outpatients' department. Staff are very helpful in directing visitors.
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	Good sized waiting areas with only small chance of patients meeting, due to only eight patients attending in total. Nurse currently either delivers drugs to patients home, or collects from pharmacy.
Do patients have to wait at pharmacy for prescriptions?	No	Very short waiting times, however occasionally up to 20–30 minutes.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	No	No posters or signs seen on ward or in outpatients' department.
Are there patient comment/ feedback boxes?	No	Have tried questionnaire in past, with poor feedback. Patients tend to ring or speak to staff with concerns or complaints.

Additional comments

- Clean and bright areas. The hospital looks new, with decent waiting areas; surprisingly, it is 10 years old. There is colour and artwork in all areas and corridors.
- Outdoor seating and pleasant walkways can be enjoyed when the weather's nice.
- Parking was easy on walkthrough day. Although there appears to be no concession for outpatients, the charges are relatively low compared to some other CF centres.

Salisbury Foundation Trust

Overview – Consultants

20 CF patients linked with UHS

Local consultants	Dr Tracey Farnon	0.2 WTE	Recommended:	0.13 WTE
	Dr Robert Scott-Jupp	0.2 WTE	Recommended:	0.08 WTE
UHS consultant	Julian Legg			

Both local consultants are very experienced in managing children with CF, however, they have no formal recognition of CF workload – the WTE mentioned above are what they actually do, rather than in the job plan. Overall the team is extremely committed and has high expectations of themselves to provide excellent care. Most, if not all of the team, is providing much of the CF care outside their job plans. They feel well supported by UHS.

Recently received transfer of three siblings who are quite unwell, resulting in significant increase in workload – inpatient days have doubled. One patient on transplant list. There's also a large local population of military families who tend to be relocated regularly. Reasons for overall high patient banding will therefore be multifactorial, rather than reflecting suboptimal local care.

MDT

- Experienced CF physiotherapist – no formal funding (and suffered banding wise with agenda for change implementation).
- No funding for CF nurse, who is community based.
- Minimal dietetic input due to funding being about 25% of what it should be.
- Pharmacist attends significant proportion of clinics (as well as providing full ward cover) – but again no formal time in job plan for this.
- Despite this, the MDT manages to achieve very good attendance at study days and other training opportunities.

Infection control

- Plenty of clinic rooms available. Spirometry performed in each clinic room. Most cubicles are en suite.
- Three patients with NTM and one with B cenocepacia.
- Concerns from team, and shared by lab, about meeting relevant standards for microbiological testing (further info from microbiologist mentioned but not seen by peer review team).

Admissions

- Most IV courses are done in hospital. No weekend physio cover – would have to transfer to UHS if 'unstable'.
- Weekday treatment is variable due to children being off the ward in school or at home between IV doses - presumably there is a clear plan in place to ensure children aren't missing a lot of formal physio in this way.
- Admission summary and plan for treatment.

Newborn screening

- Had experience with managing four infants, one of whom admitted for failure to thrive.
- Some difficulty getting health visitor to do home visit(s).

Transition

- Outreach from UHS adult team to meet teenagers; interested local respiratory physician.
- Complicated patients seen at UHS adult centre.

Recommendations

- This is a very viable service but has a heavy case load of sick patients. The team needs urgent recognition of, and funding for, the time required for CF work from consultants and MDT.
- Review patient bandings and associated tariff to ensure appropriate income is in place – the three with NTM, one with B cepacia, are not in Port CF data, which may well pull down banding/tariff.
- In particular, increase physiotherapy cover for admissions and also dietetic input.
- Ensure that measures in place to optimise inpatient physio, ie so that patients don't miss too many sessions by being off the ward.
- Continue to ensure robust measures in place to minimise cross infection, particularly with recent evidence of transmissibility of NTM.
- Microbiology service review – with support from UHS lab.
- Psychological input required, particularly in light of peripatetic military families.
- Continued/improved support for team to attend relevant courses/conferences/meetings.

Specialist nursing – Salisbury

Salisbury District Hospital – 18 patients

- CF nurse is member of the CFNA – attends meetings.
- Attends MDT meetings.
- Community-based Band 6 less than 0.6 WTE – but this is not all CF time as the post holder has other responsibilities as well, cross cover with community team.
- Attend CF meetings and study days when they can.
- Involved in clinics – cough/sputum samples, spirometry, newborn screening, home IVs, port flushes.
- Nursery/school visits – education/transition at 16 years; preparation starts at 14 years.
- Just increased clinics with Southampton.
- Involved in creation of end-of-life document.

Areas of good practice:

- Good links with professionals; a lot of goodwill.
- Improving segregation of clinics.

Areas for improvement:

- DLA currently completed by CF team – requires social worker input.
- Secretarial input.
- Education.
- Port CF data collection.
- More home visit support.

Physiotherapy – Salisbury

Salisbury – 19 patients

Some patients complex and sick, one patient on transplant list. Band 6 working at Band 7 level. No funding or CF covers: clinics, inpatients, outpatients, visits.

- Recently attended Airway Clearance Technique (ACT) course; funding and leave supported by line manager, but no separate funding provided for ACPCF. Attends ACPCF meeting on alternate years.
- Attends local meetings, when able.
- No cover for annual leave and, if changing clinic day, is unable to work around it due to other commitments.
- No cover for clinics – Band 5, Band 6 paediatric physiotherapists see inpatients.
- Last attended clinic eight years ago – funding issues.
- Not as a regular. Most recent questionnaire re: cleaning of and use of nebulisers to identify any issues.
- Diagnosis – introduced at first appointment with medic.

Areas of good practice:

- Can offer twice daily airway clearance to inpatients on weekdays, and clinics twice a month for over half a day, with six patients per clinic.
- A Band 6 with occasional musculoskeletal (MSK) input from MSK colleagues.
- Providing the best service possible with no funding.

Areas for improvement:

- Physiotherapy urgently needs funding.
- Weekends: no cover, nor evening cover.
- For acute unwell patients, weekday evening treatment has been arranged as an overtime payment.
- For weekend treatment, patients should be transferred to Southampton, but beds not often available.

Dietetics – Salisbury

Salisbury – 19 patients

- Band 6 dietitian, 0.03 WTE funded = 4 hours a month
  Cystic Fibrosis Trust's Standards of Care recommend 0.13 WTE.
- Has worked in CF for one year.
- Attended Wessex CF Club Study Day for AHPs; attended training with centre dietitian.
- Average BMI = 44th centile.

Areas of concern:

- Not properly funded; only one session per month – need 1.3 sessions per week.
- Dietitian very keen to increase training in CF.
- Finding it very difficult to cover, pulled between workload. Only covers one clinic a month, inpatient care very poor.
- Catering facilities very poor.
- Difficult to get catering to provide high energy meals and snacks.

Areas for improvement:

- Lack of inpatient cover for patients and no cover when on annual leave. Concern because more children coming in for IVs.
- Increase funding for local dietitian.
- Become a member of the UK Dietitians Cystic Fibrosis Interest Group.
- Look at how inpatient catering at Swindon can be improved, and liaise with Southampton centre for support with catering issues.
- Southampton to look at providing cover for local dietitian for annual leave and clinics.

Pharmacy

Please refer to the information for Southampton Children's Hospital.

Psychology

Please refer to the information for Southampton Children's Hospital.

Social work

Please refer to the information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Salisbury Foundation NHS Trust

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	See UHS entry.
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	No	Staff do their best, but standards not met and high banded caseload.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red. Not specialist centre.	Red	
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green. Advised by centre.	Green	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Red	Red	Further information not available from local team.
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	Consultant-led service.
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Unclear	

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	Unclear	…but concerns about micro service exist, so how accurate is micro status?
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Red No 1st isolates.	Not red! Had no new PA.	Part of TORPEDO-CF study, so would attempt eradication of PA if found.
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	Tobra levels done in house; Amikacin sent to Bristol.

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Amber	Most other centres haven't achieved this, as performed at UHS.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	Consultant-led service.
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	Unclear where delay is.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Red	Red	Electronic discharge summaries can be adequate – suggest reviewing whether relevant info is included.

4.2 Inpatients/ outpatients	% 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	Amber	No cross-cover for CF physio.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Red	No weekend cover and not seen twice daily during week, for various reasons.
	% availability of a CF specialist dietitian at clinic	100%	Green	Red	Limited availability, no cross-cover.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	Limited availability, no cross-cover.
	% availability of clinical psychologist at clinic and for inpatients	100%	Red	Red	No local support available.
	% availability of social worker for at clinic	100%	Red	Red	No local support available.
	% availability of pharmacist at clinic and for inpatients	100%	Green	Amber	Attends clinic when she can.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	Only one patient does home IVs.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Red	Green Not really non-compliant as don't have any palliative patients	No palliative patients, but those on transplant list have access to Naomi House Hospice.

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	3	Green	All complaints from one parent – complex situation. Appears to have been handled appropriately.
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Red	Red	One apparently underway.
5.4	Service level agreements in place for all	100%	Red	Red	Still under negotiation.

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Salisbury Foundation NHS Trust
Consultant 1	0.5	1	1	0.2 WTE
Consultant 2	0.3	0.5	1	0.2 WTE
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.3 WTE
Physiotherapist	2	3	4	0.5 WTE
Dietitian	0.5	1	1.5	0.04 WTE
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	0.1 WTE
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Salisbury District Hospital	
Number of active patients registered (active being patients within the last two years)	19
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	17
Median age of active patients in years	10
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	3 (18%)
	4–7 years	3 (18%)
	8–11 years	4 (23%)
	12–15 years	7 (41%)
	16+ years	0

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	2 (12%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	1
	12–15 years	2 (40%)	4 (36%)
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	3
	4–7 years	3
	8–11 years	4
	12–15 years	7
	16+ years	0
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	1
	16+ years	0

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	3
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0 – apparently one patient on transplant list.
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	36
	12–15 years	209
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	36
	12–15 years	209
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n=14 10 (71%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	2 (29%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	2 (12%) with chronic PA; 4 (24%) without chronic PA

No patient surveys returned.

	Hospital name	Salisbury District 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	After checking in, the patient is taken immediately to either the clinic room or the height/weight room.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Separate room equipped for this testing.
Where are the lung function tests done for each visit?		In clinic rooms, all rooms are equipped for testing.
Are clinic rooms appropriately sized?	Yes	There are 10 rooms of which four are for CF use.
For annual review patients, are any distractions provided?	Yes	CF toy box. Colouring equipment, DS games, or can bring own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	Diabetes patients are seen during clinic.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	CF pack from consultant.

Additional comments

- There is a large modern, child-oriented waiting area, with ship-styled seating, fish tank and toys, although CF patients would never be waiting there.
- Outside there is a large play area. The play therapist can be called to take care of and play with siblings here during patient appointments.
- Prior to the clinic, the team meets for an update in a side room to discuss the six patients to be seen that day.

Environmental walkthrough: Ward

Ward name: Sarum

Microbiology status: All general paediatric

		Hospital name	Salisbury District 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 are required)		Yes	
Number of side rooms?		10 (five for CF patients).	Five of the 10 rooms have en suite facility; CF patients would only be admitted to the en suite cubicles.
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 bed for adults? (Include in notes policy of ward)		Yes	Locker facility in cubicle.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	'Patient line' free TV until 7.30pm, after which DVDs are available. TVs are switched off during school time. Older patients can go to the teenage bay for after-hours TV.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull-down bed in cubicle for one parent to stay.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open access.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Parents' kitchen is equipped with microwave, fridge, and hot water facility. Ward kitchen is also available for use.
What facilities are provided for teenagers?			Teenage bay – equipped with TV, DVD, games, trampette and table football game.

	Yes/no/ number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Gym near outpatients, equipped with treadmill/trampette – sessions are with physiotherapist. Also a larger physio room with equipment for younger patients (see comments).
What facilities are there to help with school and further studies?		Have teacher who liaises with the patient's school. Hospital use of newly purchased laptops, or can bring in own laptop.
Is there a relatives' room?	Yes	
What internet access is there?	None	Can bring in own access facility.
What facilities are there to enable students to continue work and study?		Teaching room. Laptop use. Teacher liaison (as above).
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Room for cleaning. Can also be cleaned in cubicles.
What facilities are provided for those with MRSA?		Follow own cubicle segregation policy. Only had one patient this year.
What facilities are provided for those with *B. cepacia*?		Follow own cubicle segregation policy.
What facilities are provided for those with other complex microbiology?		Follow own cubicle segregation policy.
Are patient information leaflets readily available on ward?	Yes	Have own computer-based information on ward – ISID, also hard copy available.
Transition patients – can they get tour of ward facilities?	Yes	New patients.

Additional comments

- The paediatric unit is situated in a newly built part of the hospital, built two years ago. The outpatients' department is on the ground floor and the ward is situated directly above.
- Ward reception area: Open 8am–8pm
- Assessment room: Used for long lines and portacath access.
- There is a separate room off the ward; this can be used for parents of newly diagnosed or long journeys. There is a separate toilet and shower facility, a quiet area and kitchen/sitting room, fully equipped with microwave, fridge, hot water facility and TV. There are plans to purchase a combination oven in the near future.
- In larger physiotherapy room for younger patients, there is Omi Beam – a projector beaming moving images such as bubbles, bugs etc. onto the floor. When the child treads on a bubble, it will burst. When the child steps on an insect, it will move away – to prompt the child to work harder to catch it and squash it. This promotes fun exercise for young children with different levels of ability.
- The teaching room can also be used as a dining room by patients, so that they can have a meal away from their cubicles.

- Patients who live locally are encouraged to go home for an evening meal if well enough. A snack box is stored in the kitchen.
- In the past the physiotherapist has taken patients to the staff leisure centre to use the pool.
- The team has a 'CF patient admission checklist'. This is designed for use when the team changes shift. The checklist contains all patient information, plus details of investigations on and during admission.

Home leave arrangements

- A summary of IV access, any sedation used, sputum culture results, antibiotics administered.
- Spirometry and weight measured on admission and discharge, and any new problems identified during admission.

Environmental walkthrough: Other

	Hospital name	Salisbury District Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Most patients have disabled badges, and therefore have free parking. Parking for up to one hour costs £1.60. Two hours = £2.50, three hours = £3.20, four hour = £4.20 , five hours = £5.30. Five to 24 hours = £6.30. Parent parking can be arranged for £8 for two weeks. This is arranged, on admission, via the ward staff.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	General unit is signposted.
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 has a large waiting area, although CF patients never have to wait in these areas. Visits to radiology are by arrangement only, so patients do not meet.
Do patients have to wait at pharmacy for prescriptions?	No	Staff will collect prescriptions.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	'Customer Care Service'. Also, leaflets are available on ward.
Are there patient comment/ feedback boxes?	Yes	On admission, parents are given a survey to complete and return on discharge.

Great Western Hospital, Swindon

Overview – Consultants

"The Great Western Hospitals NHS Foundation Trust provides acute hospital services (at Great Western Hospital), community health and maternity services across Wiltshire, parts of Bath and North East Somerset. As a result of the merger (with Wiltshire Community Health Services), it has become one of the largest maternity providers in the country, responsible for the delivery of over 9,000 babies a year."

24 CF patients linked with UHS

Local consultants	Dr Paul O'Keeffe 0.075 WTE	Recommended: 0.16 WTE
	Second consultant recently withdrawn	Recommended: 0.1 WTE
UHS consultant	Julian Legg	

Joint clinics every two months – almost full day

Longstanding relationship with UHS, although nearer Bristol (location of nearest PICU and takes non-CF respiratory cases) and Oxford. UHS performs bronchoscopies but Ports and PEGs may be done at Oxford.

Increase in UHS MDT visits since 2013 to meet standards of care; at least two patient contacts within centre team.

Eight patients with FEV1 <85% predicted – but no further info on how low lung function is. One recent transplant (now in adult care). Five patients with CFRD. Overall number of deliveries indicates regular new diagnoses likely.

Local clinics

- A keen, proactive, consultant-led service, despite inadequate allocated time for CF overall.
- Monthly clinics; doctor also sees a lot of out-of-clinic reviews (MDT may not attend).
- No dietetic input; limited physio input. CFRD linked with local diabetes team.
- Quite variable patient feedback.

MDT

- Severely under resourced.
- Physiotherapist community based; minimal funding (five hours per month; Cystic Fibrosis Trust's Standards of Care recommend 0.64 WTE). Second physio doing CF MSc module, who could be appointed if funding available.
- Currently an inexperienced dietitian who has no allocated funding, sees patients infrequently (Cystic Fibrosis Trust's Standards of Care recommend 0.16 WTE).
- Other community nursing team provides support in Louise Gilbert's absence.

Infection control

- Clinics currently done in an area with only two rooms, so very difficult to segregate patients (and inefficient if all MDT present).
- No specific isolation of those with/without PA. Child with B cepacia is seen in separate clinic.

- Due to move to an area with four available rooms. En suite side rooms on ward.
- Micro lab standards not met previously but being addressed.

Admissions

- High number of IV days via Port CF data.
- Adult physiotherapists provide majority of care, with one person actively developing their CF skills.
- Port CF data indicates 170 inpatient days, ie significant activity, although this may decrease following transition of 17-year-old patient post-transplant to adult services.
- All admitted CF patients are seen by dietician on ward. No dietetic input.

Newborn screened infants

- Portsmouth is screening lab for GWH. Positive results communicated directly to Dr O'Keeffe and specifically discussed. It is unclear if sweat test standards are met. If insufficient sweat collected then required to go to Oxford.

Transition

- Generally to adult CF service at Bristol. Some receive adult shared care with adult physician at Swindon.

Recommendations

- Urgent service development with formal recognition and funding of required physiotherapy and dietetic time – requires input to Swindon management to ensure tariff is available for CF service, via service level agreement.
- Audit 'out-of-clinic reviews' to determine whether extra clinic(s) per month would be more efficient.
- Nominate second consultant as local back-up in Dr O'Keefe's absence.
- Ensure early clinic move to ensure segregation by microbiological status in all clinics.
- Ensure optimal management of those with CFRD – link with UHS CFRD team.
- Review whether local sweat testing meeting ACB standards.
- Perform liver USS and DEXA scans as recommended in national standards.
- Consider focusing all (routine) surgery, sweat tests, etc at UHS to ensure consistent input.
- Implement further parent survey/focus group to discuss concerns and as strong voice of support to trust management for improvements.

Specialist nursing – Swindon

- Great Western Hospital Swindon – 24 patients.
- Community-based nurse. No allocated time for CF work.
- Member of the CFNA, attends meetings – local and national/international.
- New build: excellent facilities.
- Band 6 non-prescriber (easy access to medical team).
- Involved in outpatient support, home IV teaching pack/support, and consumables/equipment. Also involved in care plans/school visits, newborn screening/ transition – 'Ready, steady, go' (number of patients go to Bristol adults as it's closer), and DLA support.

- Excellent relationships with other professionals, eg diabetic team.
- Attends Southampton MDT six-monthly meeting.

Areas of good practice:

- Excellent working relationships with professionals.
- Excellent inpatient facilities supported by play specialists.
- Supports the clinics.

Areas for improvement:

- Outpatients needs to be more concrete – insufficient rooms and time.
- Social worker involvement for DLA support.
- Secretarial input.
- Needs designated CF time and psychology input.

Physiotherapy – Swindon

Swindon – 24 patients

- Band 8a physiotherapist who is community based and funded to attend only 12 clinics per year.
- Wessex meeting once a year, Band 6 attends, local study leave and funding not an issue.
- Member of ACPCF. Hasn't attended National Study Day.
- Meets monthly – MDT trying to move to pre-clinic as physiotherapist not able to attend easily.
- Band 6 can cover but not funded. Still not able to cover all MOT and routine clinics.
- No funding for attending European/International Cystic Fibrosis Conferences – cannot justify for number of patients.
- No transition clinic. Report written. At diagnosis home visits for new referrals ad hoc. Monthly visit but sometimes with consultant general paediatric clinic, not CF clinic, so patient not always seen.

Areas of good practice

- Able to attend most routine clinics with very limited resources.

Areas for improvement

- Need funding to support service, ie inpatients, additional outpatient clinic, home visits etc. Band 6 acute that shadows clinic cover for two sessions of 1.5 hours per week – link between hospital and community.
- Training and education in CF needs to be addressed.

Dietetics – Swindon

Swindon – 24 patients

- Band 6 dietitian – no dedicated time to cystic fibrosis. Cystic Fibrosis Trust's Standards of Care recommend 0.18 WTE
- Has done training in CF module.
- Not a member of the UK Dietitians Cystic Fibrosis Interest Group, therefore no ongoing training in CF care due to no funding.

Areas of concern

- Very little time for CF patient care. No cover if on annual leave and very little cover for patients. Clinic cover = very few.
- MOT done by Southampton twice a year, but feels dietetic care is very patchy for 24 patients as there is no dedicated time and there is even less time since the MOT clinics.

Areas for improvement

- Fund CF dietetic time.
- Increase input from Southampton until local dietitian care is funded.

Pharmacy

Please refer to information for Southampton Children's Hospital.

Psychology

Please refer to information for Southampton Children's Hospital.

Social work

Please refer to information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Great Western Hospital, Swindon

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%	Red	Unclear	UHS should be doing this.
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Red. Shared care since 2013.	Amber	Increased visits by UHS MDT – increased in 2013 to meet Cystic Fibrosis Trust's Standards of Care.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	N. Service is safe but not effective.	Agree	
	% of MDT who receive an annual appraisal	100%	Green	Unclear	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Red. Not known.	Red	Needs addressing – especially to ensure CF education.
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	Only consultant attended European Cystic Fibrosis Conference recently.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red	Red	
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Green	

2.1 Multi-disciplinary care	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	Only consultant in clinic.
	% 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%	Red	Red – no segregation for PA.	Only local clinics, which are due to move to day assessment area where joint clinics held and four rooms are available.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Red	Red	No data on numbers given.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red	Red	No data on numbers given.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	No data on numbers given.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	Assuming no admissions when Dr O'Keefe on leave.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	Leave cover?
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	Leave cover? Community based.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	Leave cover?
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Care largely provided by adult team. Is CF seen as priority?
	% availability of a CF specialist dietitian at clinic	100%	Red	Red	Cover for leave?
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red. Not a specialist dietitian	Red	Cover for leave?
	% availability of clinical psychologist at clinic and for inpatients	100%	Red. Service available.	Red	
	% availability of social worker for at clinic	100%	Red	Red	
	% availability of pharmacist at clinic and for inpatients	100%	Red. Pharmacist does not attend clinic.	Red	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	Few patients do home IVs.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0%	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0%	0	
5.3	User survey undertaken a minimum of every three years	100%	Green	Unclear	
5.4	Service level agreements in place for all	100%	Green	Red	Tariff not given to MDT.

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Great Western Hospital, Swindon
Consultant 1	0.5	1	1	0.075 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	30 hours a week
Physiotherapist	2	3	4	0.04 WTE
Dietitian	0.5	1	1.5	0
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	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Great Western Hospital, Swindon	
Number of active patients registered (active being patients within the last two years)	19
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	19
Median age of active patients in years	10
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	3 (16%)
	4–7 years	4 (21%)
	8–11 years	4 (21%)
	12–15 years	5 (26%)
	16+ years	3 (16%)

Genetics	
Number of patients and % of unknown genetics	2 (11%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	2 (11%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	1 (11%)
	12–15 years	3 (30%)	2 (22%)
	16+ years	2 (20%)	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	3
	4–7 years	4
	8–11 years	4
	12–15 years	5
	16+ years	3
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	1
	8–11 years	1
	12–15 years	1
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	1 (5%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	0
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	5 (16%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH; 1 without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	1
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	15
	8–11 years	0
	12–15 years	49
	16+ years	109
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	66
	16+ years	36
Total number of IV days split by age group	0–3 years	0
	4–7 years	15
	8–11 years	0
	12–15 years	115
	16+ years	145

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n=12 8 (67%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	3 (16%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (67%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 2 without chronic PA

Patient survey

Great Western Hospital, Swindon

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	0	0	1	0
Cleanliness	0	0	0	1
Cross-infection/segregation	0	0	0	1
Food	0	0	0	1
Exercise	0	0	0	1

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"New to Great Western Hospital (GWH), but disappointed at lack of interest of infection control/ segregation at clinics."

"Our local CF team/hospital are excellent; easily accessible. I believe our specialist nurse team to be under-resourced as we rarely see our nurse. We do however know how to contact her as needed. We have annual review by Southampton team, no concerns and have good, supportive visiting team."

"Don't always get a reply straight away by email, but otherwise fairly good! Don't use Southampton often enough."

"Limited exposure except for annual blood test and couple of visits – long waiting time. The (GWH) team are very supportive. Help and information by Dr P O'Keefe and Louise Gilbert are excellent."

"Although professional I do not believe anyone considers emotional impact on child/family. Fed up also of promises of physio aids and never getting them. This is both Swindon and Southampton."

	Hospital name	Great Western Hospital, Swindon
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	No more than eight patients per clinic. Usually no more than two attend at one time. Little overlap, however it is a possibility. The plan is to shortly move all monthly clinics to the day assessment area, where MOT clinics currently take place jointly with Southampton. This will further minimise risk, as patients can be shown into an en suite room (four available) for the duration of all outpatient clinics.
Do patients spend any time in waiting room?	Yes, possibly on rare occasions.	At present patients are taken into rooms as soon as they are free. Soon all clinic patients will attend day assessment unit. See above.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Height/weight room in outpatient clinic and an open area in day assessment unit. Each clinic room does not at present have its own height/weight facilities, therefore there is the possibility of cross-infection risk in some clinics, with up to eight children utilising the same room or area.
Where are the lung function tests done for each visit?		In laboratory or in clinic room, usually performed by consultant. The CF unit only has one spirometry unit available, however, all patients have single-use disposable equipment.
Are clinic rooms appropriately sized?	Yes	Two in outpatient clinic. Four rooms, fully equipped in day assessment unit.
For annual review patients, are any distractions provided?	Yes	No toys available due to cross-infection concerns. Patients bring own toys, mobiles and distractions.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Three patients. Seen in outpatient clinic by diabetologist (not a joint clinic, however it runs at same time as CF clinic).
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	N/A	

Environmental walkthrough: Ward

Ward name: Children's unit

Microbiology status: All

		Hospital Name	Great Western Hospital, Swindon
		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 en suite cubicles, suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	26 beds, 12 en suite side rooms.
Number of side rooms?		12	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Shower.
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward)		No	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	The rooms have chairs and camp beds are available.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open access. No restrictions to primary relatives.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	There are fridges in rooms and a microwave can be utilised by parents in parents' room.
What facilities are provided for teenagers?			Adolescent room for use with family and friends. No two CF patients use it at any given time.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	Physiotherapy gym is available in another area with the physiotherapist. No portable equipment utilised for rooms (bike, weights, gym balls).
What facilities are there to help with school and further studies?	None	Two teachers and play assistants. Can also bring in own laptops, study in room or school room, with desks and PCs available.
Is there a relatives' room?	Yes	Parents' room on ward is equipped and comfortable.
What internet access is there?		In school room or via dongle in own room. Wi-Fi not available.
What facilities are there to enable students to continue work and study?		School room: Two teachers liaise with school and keep up to date on work to be studied. Patients can use their own laptops/dongles in their rooms. Teachers liaise with other agencies such as the youth engagement worker to offer bespoke packages. Possibility of investing in virtual learning and upgrading of IT equipment was discussed, as it appeared very dated. Discussed the importance of virtual learning and patients meeting online to help prevent cross infection.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Parents can wash, clean and air dry neb. parts in their own bowl in the sink in their room, or air dry on table top.
What facilities are provided for those with MRSA?		Side room segregation on same ward (one patient at present).
What facilities are provided for those with *B. cepacia*?		Side room segregation on same ward (one patient at present).
What facilities are provided for those with other complex microbiology?		Side room segregation on same ward (one patient at present).
Are patient information leaflets readily available on ward?	No	Distributed by nurse as appropriate. None seen on ward.
Transition patients – can they get tour of ward facilities?	Yes	New patients get tour of ward and outpatients.

Additional comments

- Very clean and tidy, spacious ward area with great panoramic views of local area from many side rooms. Artwork and colour on walls throughout gives a pleasant, child-friendly appearance and warm atmosphere.

Environmental walkthrough: Other

	Hospital name	Great Western Hospital, Swindon
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Large car park. CF patients get ticket from ward clerk when inpatient, for reduced cost of £1 per day. Outpatients pay £1 for one hour, £2 for two hours and three pounds for three hours parking. There is also a drop-off point directly outside the main entrance. If receiving benefits, may be able to get full reimbursement with a letter from the nurse.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes/No	Signage to children's unit is clear, however, there are no CF signs as it is not a dedicated CF ward or 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?	Yes	Large or reasonable sized waiting areas with only small chance of patients meeting due to maximum eight patients at any given clinic; patients separated by time. At present nurses either deliver drugs to patient's home or they are collected from local pharmacy; minimal risks. A new Boots chemist is opening shortly, where patients may have more chance of meeting. The potential increased risk of cross-infection should be investigated further.
Do patients have to wait at pharmacy for prescriptions?	No	Occasionally very short waiting times for some, as community CF nurse delivers to home, or parents collect from local chemist.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Large sign near main entrance.
Are there patient comment/ feedback boxes?	No	Snapshots in clinic and the new 'Fabio the Frog' system, which allows parents and patients to feedback anonymously in clinics. At present this is generic and not CF specific. However, it is possible to design CF specific questions in future.

Royal Hampshire County Hospital, Winchester

Overview – Consultants

Part of Hampshire Hospitals NHS Foundation Trust (HHNFT).

"HHNFT serves a population of approximately 600,000 across Hampshire and parts of west Berkshire. Hospitals in Winchester, Basingstoke and Andover were amalgamated in 2012."

10 children linked with UHS (one has alternate appointments at UHS)

Local consultants	Dr Keith Foote 0.1 WTE. (Trained in Leeds CF Centre as registrar with Dr J Littlewood)	Recommended: 0.07 WTE
	Dr Struthers	0.01 WTE for CF (has provided cover)
UHS consultant	Dr Connett	Three joint clinics per year (was four)

Long-established clinic, but there has been a decline recently in both patient numbers and provision of local MDT care. Many staffing and clinical standards are not being met. Dr Foote believes that the recent merger with Basingstoke has/will have a positive effect on CF care, due to integration of the MDTs and more specialist physio/dietitian input.

Four patients (40%) have FEV1 <85%. There are two patients with chronic PA and one each MRSA and NTM respectively. Relatively high IV antibiotic usage. Only 10% of patients reported (on risk matrix) seeing UHS MDT at least twice per year. No patients had liver USS, DEXA or fertility discussion (if needed) recently.

Local clinics

Appointments are largely ad hoc within other clinics; MDT tries to attend clinic, but often unable to. Have not met the Cystic Fibrosis Trust's Standards of Care for review in clinic by any of MDT nor inpatient physio and dietetic review.

MDT

Local MDT is very limited in time and CF experience. Recent changes (link with Basingstoke) have led to availability of input from Basingstoke MDT on most weekdays.

Infection control

- Patients not specifically segregated, and are often seen ad hoc within other paediatric clinics.
- One small room used for spirometry. One patient each with MRSA and NTM – although they weren't identified on the walkthrough as needing particular facilities. Only one en suite cubicle.

Admissions

Inpatients treated by adult physiotherapists – unclear what level of service they receive.

Newborn screening

- No patients under the age of three. No specific information received, but unlikely to receive appropriate input from Winchester MDT due to their general lack of experience. Sweat testing meets ACB standards.

Transition

Mainly UHS – adult consultant visits for two joint clinics with patients. One lived in Andover and went to Frimley Park.

Recommendations

- Arrange closer and more regular links/clinics with experienced MDT – either at Basingstoke or UHS (depending on where family lives/chooses).
- Consider whether inpatients should be cared for on a single site, as it's likely to be difficult to achieve adequate inpatient standards of care in Winchester for this relatively small group of patients.
- Review infection-control standards.
- Ensure liver USS, DEXA, etc. recommendations are met.

Specialist nursing – Winchester (6 patients)

- CNS Band 8c clinical services manager.
- Member of CFNA; attends CFNA meetings and local/national meetings.
- Not nurse prescriber.
- Newborn screening predominantly performed in Bristol, then picked up with Liz (sweat test done in Taunton).
- IVs generally done in hospital. There is community support for those that go home.
- End-of-life document in place.
- Amalgamating with Basingstoke.

Areas of good practice:

- Excellent support.
- Transition: 'Ready, steady, go' programme and use of local document.
- Growers and non-growers clinics.
- Good documentation.

Areas for improvement:

Social worker DLA support with community nurses.

Physiotherapy – Winchester

Basingstoke & Winchester – 23 patients

Basingstoke and Winchester have 23 patients. No funding. Physiotherapist spends approx. 30–40% of time on CF. Services merged approx. two years ago.

- Attends Wessex winter club yearly. Has attended Royal College of London meeting. ACPCF member. Did not attend National Study Day. Attends Southampton MDT evening lectures.
- Basingstoke: attends MDT meetings/ward round; ward physiotherapist Band 5 or Band 7 cover. Winchester: cannot attend these meetings as no cover.
- Attended 2012 & Dublin European Cystic Fibrosis Conferences – study leave and funding not an issue.
- Involved in audit of ward physiotherapy 18 months ago, clinic service for physiotherapy.
- Adolescent clinic has approx. four patients.

Areas of good practice

- Basingstoke physio offers a service to inpatients and outpatients split over two sites, and also another satellite at Alton.
- Able to do exercise testing; attends clinics.
- Basingstoke: patients seen twice daily for airway clearance; once daily gym for inpatients.

Areas for improvement

- Urgently requires funding for Winchester and Basingstoke.
- Winchester inpatients covered by adult physiotherapists.
- Gym facilities are used ad hoc.

Dietetics – Winchester

Winchester – 8 patients = 0.5 WTE

- Local dietitian funded by Basingstoke is new to paediatrics and CF covered by Basingstoke CF dietitians.
- Inpatients covered by Basingstoke dietitians.
- Catering good, no concerns.

Areas for improvement

- Consider having the eight patients looked after by Basingstoke dietitian and MOT with UHS.
- Give training to new dietitian for cover arrangements and inpatient care.

Pharmacy

Please refer to information for Southampton Children's Hospital.

Psychology

Please refer to information for Southampton Children's Hospital.

Social work

Please refer to information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Royal Hampshire County Hospital Winchester

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Red.	Red	Needs addressing as relatively poorly patient population.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	No	See above.
	% of MDT who receive an annual appraisal	100%	Green	Unclear	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Unclear	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Most	Amber	Should be all.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Unclear	
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Unclear	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	
	% 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	Red	There should be a plan in place.

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. Always available 50% en suite.	Amber	Only one en suite cubicle so presumably can't guarantee availability.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Red	Clinics not segregated.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green. No cases in 12 months.	N/A	No cases.
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red. Gentamicin levels in 24 hours. Tobramycin levels take longer.	Red	UHS issue.

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Unclear	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Red	Red	No reason given.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red	Red	No reason given.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	No reason given.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Unknown	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Red	Red	No reason given; can lead to suboptimal care from GP and UHS if info not received.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green. Typed summary given on discharge.	Green	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Amber	Amber	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Unclear	Unlikely if patients attend ad-hoc local clinics.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Unclear	Seen mainly by adults' physio.
	% availability of a CF specialist dietitian at clinic	100%	Green	Unclear	Unlikely if patients attend ad hoc local clinics.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	
	% availability of clinical psychologist at clinic and for inpatients	100%	Green. Available.	Red	Only available by prearrangement.
	% availability of social worker for at clinic	100%	Green. Available.	Red	Only available by prearrangement.
	% availability of pharmacist at clinic and for inpatients	100%	Green. Available.	Red	Only available by prearrangement.
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Unclear	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Unclear	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Royal Hampshire County Hospital, Winchester
Consultant 1	0.5	1	1	1 PA
Consultant 2	0.3	0.5	1	0.1 PA
Consultant 3			0.5	General paeds consultants give support.
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	0.5 PA
Specialist nurse	2	3	4	0.1 WTE
Physiotherapist	2	3	4	0.2 WTE
Dietitian	0.5	1	1.5	
Clinical psychologist	0.5	1	1.5	As necessary.
Social worker	0.5	1	1	Access as needed.
Pharmacist	0.5	1	1	Available as needed.
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Royal Hampshire County Hospital	
Number of active patients registered (active being patients within the last two years)	10
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	10
Median age of active patients in years	12
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	0
	4–7 years	2 (20%)
	8–11 years	2 (20%)
	12–15 years	6 (60%)
	16+ years	0

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	1 (10%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	1 (17%)
	12–15 years	1 (25%)	2 (33%)
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	0
	4–7 years	2
	8–11 years	2
	12–15 years	6
	16+ years	0
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	2
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (10%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	1 (10%)

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (10%) with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	14
	8–11 years	0
	12–15 years	55
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	98
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	14
	8–11 years	0
	12–15 years	0
	16+ years	153

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n=9 3(33%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	2 (20%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (10%) with chronic PA; 1 (10%) without chronic PA

Patient survey

Royal Hampshire County Hospital, Winchester

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	2	2	1	0
Cleanliness	0	5	0	0
Cross-infection/segregation	1	3	1	0
Food	0	1	3	1
Exercise	1	0	2	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	0	3	0	1
Availability of equipment	0	5	0	0
Car parking	0	0	0	5

How would you rate the overall care?

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

Comments about CF team/hospital

"Winchester – regularly cannot contact correct person – other staff aren't very knowledgeable about CF (eg antibiotics). Dietary advice is poor and minimal. Dr K Foote and Bev Murray (community nurse) are very good, when available. Physio good too (from Basingstoke)."

"Sometimes I don't hear sputum sample results and am not sure if this is because they are fine or they haven't been checked on the system? Discharge from ward can be very slow. Overall though very happy with support."

"Because Winchester is a smaller hospital, everyone knows you and you don't just feel like a number. It helps us parents too!"

"Parking is really hard at Winchester, resulting in lateness. Big problems getting CVAs and meds from pharmacy, mainly resulting in us waiting around for hours sometimes. We are asked to vacate the bed as it is needed, which means we are just pushed from pillar to post, which we find the whole thing annoying as this is planned well in advance."

"Winchester hospital food could be more varied. Car park needs to be bigger!"

	Hospital name	Royal Hampshire County Hospital, Winchester
	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	If there were to be more than one CF patient at a time, they would be sent to separate waiting areas.
Do patients spend any time in waiting room?	Yes	If not taken immediately to waiting room, they would be put in separate waiting area, although this is highly unlikely due to low CF patient numbers.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Yes, within the unit.
Where are the lung function tests done for each visit?		There is a separate lung function testing room. There are plans for this to be refurbished; start at five years old. Room is cleaned after use.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Toys and games available. All testing takes place prior to annual review, ensuring shorter waiting time.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Liaised with CCN.
Transition patients – can they get tour of outpatients' facilities?	Yes	CCN supports.
Transition/new patients – do they get information pack?	N/A	Responsibility of specialist centre.

Additional comments

- The unit uses laptops, websites and DVDs for all information. They do not have hard copy leaflets on display as they have previously found that leaflets become outdated. They are also not permitted to photocopy leaflets, so they guide the parents to the appropriate information as and when required.

Environmental walkthrough: Ward

Ward name: North Brook

Microbiology status: General (nine patients with cystic fibrosis)

		Hospital name	Royal Hampshire County Hospital, Winchester
		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 are required)		Yes	
Number of side rooms?		7	One cubicle has en suite facilities. Two acute cubicles for closer observation
Do the en suites have:	**Toilets?**	1	
	Wash basins?	7	
	Bath or shower?	1	
Do CF patients have to share any bathroom facilities?		No	A bathroom would be designated for personal use if required.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward)		Yes	A locker in the cubicles; there are plans to update these.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Four of the cubicles have TV; there are plans to buy further equipment for all cubicles. Free TV service available 08:00–21:00. Have use of DVD/Xbox from 21:00. Patient link also available.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	One parents' room with two single beds, TV. Z beds are available in the cubicles. Separate parent toilet/shower facility.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Close relatives have open hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Fridges in cubicles. Access to parents' kitchen – use of microwave/fridge, tea and coffee facilities, which are supplied on a donation basis.
What facilities are provided for teenagers?			TV area with bean bag seating. DVD, iPad, Xbox and age appropriate games.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapist operates a timetable system for patients.
What facilities are there to help with school and further studies?		Use of a laptop. They are in the process of setting up Wi-Fi access. Students can then access school website via portal.
Is there a relatives' room?	Yes	
What internet access is there?	None	In the process of arranging this.
What facilities are there to enable students to continue work and study?		iPad and laptop use. Parents are responsible for arranging school work.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sterilisers are used in the milk kitchen.
What facilities are provided for those with MRSA?	N/A	Would adhere to Trust policy and segregate patient in own cubicle.
What facilities are provided for those with *B. cepacia*?	N/A	Would adhere to Trust policy and segregate patient in own cubicle.
What facilities are provided for those with other complex microbiology?	N/A	Would adhere to Trust policy and segregate patient in own cubicle.
Are patient information leaflets readily available on ward?	Yes	Leaflets are not displayed as they have found that they become outdated. Parents are guided by staff on where to find information online.
Transition patients – can they get tour of ward facilities?	Yes	Supported by the CCN.

Additional comments

- The paediatric unit houses the inpatient ward and outpatient clinic. The reception area is newly refurbished and brightly decorated to a high standard. The receptionist is aware of the CF patients. There is an office behind reception which contains all of the patient notes, for quick referral. Staff are very enthusiastic for future refurbishments to take place.
- 'Sophie's Place': Assessment centre – three beds, seating for six, good size, child-friendly area with toys. Not generally for CF patients. Five clinic rooms – three working rooms currently, with two in the process of being refurbished. Patient artwork on the walls in the clinic rooms.
- Annual reviews: They will see three patients for annual review. The physiotherapy report will have been completed in advance of the appointment and the dietitian will see the patient on the day. The appointment times are staggered. In the event of patients meeting, they would be escorted to another waiting area. After annual review, the whole team has a 'wash-up' session.
- Treatment room: Fully equipped, with plans for refurbishment.
- Play room: Large, very bright, newly decorated. Play therapists available.

- The CNS visits the schools to raise awareness of CF and also to give training to teachers on physiotherapy and nebuliser use.
- There is Charity Fund access. This helps to fund training for team and conference attendance. For patient/parents, there is respite, equipment (eg sterilisers). The charity is funded by parent donations.

Environmental walkthrough: Other

	Hospital name	Royal Hampshire County Hospital, Winchester
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Inpatients are charged £1.50 per night; the car owner would give car registration plate details. Disabled parking available. There is a park-and-ride facility available. Parking can be limited due to appointment timings.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Ward is signposted.
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	Due to small patient numbers, it is highly unlikely that CF patients will mix.
Do patients have to wait at pharmacy for prescriptions?	No	Patients do not go to pharmacy; CCN team will call pharmacy and also collect prescriptions. These can also be arranged by CCN for collection via GP.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Large display at main reception.
Are there patient comment/ feedback boxes?	Yes	Also have a rotating iPad feedback scheme throughout the hospital. The parent completes 'live' feedback during the visit.

Yeovil District Hospital

Overview – Consultants

"Yeovil District Hospital serves a population of around 185,000 people, primarily in south Somerset, North and West Dorset and parts of Mendip. It has almost 2,000 deliveries per year."

Nine patients with cystic fibrosis are linked with UHS. One other patient is not linked with UHS.

Local consultant	Dr Chris Zaborowski	0.1 WTE for CF. Recommended: 0.1WTE. No cover.
UHS consultant	Gary Connett	Two joint clinics per year

Dr Zaborowski has been in post since 2010 and is a very enthusiastic and committed clinician. He cares for a small and healthy group of children with cystic fibrosis – and consequently the service is in receipt of a relatively low tariff.

MDT

The patients are served by a committed MDT. They have little time formally allocated for cystic fibrosis. This puts the service at great risk in the future, as any new/replacement staff may be unable to provide the same level of input. The arrival of any patients who are less well could also challenge the service. There is excellent outpatient physio, but it is based in Taunton (one hour drive away) and they may only see a few patients in a clinic. Experienced dietitian recently left and local outpatient dietetic support now comes from Dorchester. One patient has CFRD and is managed locally.

Infection control/microbiology

- Aim for segregation, but some concerns reported by local team. En suite cubicle available.
- Samples are sent to Taunton/Bristol, where they are processed according to recommended standards.
- Low prevalence of chronic infections.

Admissions

- Few inpatient episodes – again commendable, but could limit experience of ward and MDT staff in managing exacerbations.
- Inpatients seen by adult physios (only once per day?) and different dietitian – potential for different advice than given by outpatient team.

Newborn screening/sweat tests

- Notifications come from Bristol Regional Paediatric CF Centre, with sweat test performed by a technician who travels from Taunton.
- Would expect ≤1 NBS/year, so experience of whole team in managing such infants will be limited; they do not appear to have had any NBS diagnoses in the last couple of years.

Transition

- UHS adult CF consultant does outreach to meet patients.

Recommendations

- It is essential that the CF service at Yeovil continues to receive the strong support of their hospital trust in order to sustain the very valuable work that they do. In particular, a commitment is needed from trust managers to ensure the MDT have adequate allocated time for CF in their job plans and there is long term security of these posts.

- Identify a local consultant to cover for Dr Zaborowski when on leave, and clinical review is needed.
- Maximise the number of patients available for routine review by the physiotherapist, who is based in Taunton.
- Explore options for extending the Yeovil dietetic services to provide consistent inpatient and outpatient services.
- Continue to ensure good infection control measures are in place.
- Consider joint management of infants diagnosed through newborn screening with the specialist centre, in view of their much greater experience in working with families at this very challenging and unpredictable time.

Specialist nursing – Yeovil

Yeovil District Hospital 9 + 1

- Specialist nurse, Band 6 is a member of CFNA, attends local and national meetings.
- Newborn screening predominantly done in Bristol, then picked up with Liz (sweat test done in Taunton), 'Ready, steady, go' transition document, home IVs. Education in nursery, schools and university, DLA support, community visits. Consumables – charity donations.
- TORPEDO-CF study – no patients enrolled.
- Inputs into MDT.

Areas of good practice

- Excellent support.
- Great support from Southampton and patients are very happy with Southampton.
- Good support from Taunton.

Areas for improvement

- Secretarial support.
- Block bookings – potential risk of cross infection.

Physiotherapy – Yeovil

Yeovil – 10 patients

- Band 7 community clinical lead for whole county.
- No funding; works approx. 0.2 WTE, covering clinics and visits.
- Attends South West physiotherapist meeting once or twice a year, organised by Bristol. Attends ACPCF meeting alternate years. Masters funded by the ACPCF; has genuine interest in CF and developing services.
- Attends MDT meeting before each clinic.
- All patients seen at each clinic now, unless ad-hoc clinic added.
- If physiotherapist on annual leave, there is no cover. Band 6 training to pick up community work, but will continue to cover clinics. Not able to book hospital space, so patients only seen in community.
- Attended European Cystic Fibrosis Conference in Dublin, funding for all is not available; study leave not an issue.

- Diagnosis: Able to see weekly if needed. No end-of-life care needed as yet. No transition process – only had one recently and he just left – not sure where to; just completed a transfer document.

Areas of good practice

- Interested in developing service for patients.
- Outpatients: provides cover as able with no funding.
- Good relationship with Southampton.
- Ran study day following completion of Masters.
- Community B6 attends clinic to shadow/supervision.
- List of competencies undertaken.

Areas for improvement

- Urgent funding required.
- 1+ hour's travel as base is in Taunton; only a few hours spent in clinic – difficult to justify attendance at times.
- Inpatients: Unclear separate service, adult respiratory team, low priority probably as cover ITU, poor feedback from hospital team?
- Once daily airway clearance provided, unlikely that exercise is available.
- Children seen every six to eight weeks, clinic is ad hoc and sporadic. Can have one a week for three weeks then nothing for three or four weeks.
- Only two patients seen at each clinic due to availability of hospital rooms – only one room allocated; patients given appointment one after the other.

Dietetics – Yeovil

Yeovil – nine patients

- Local cover good, with no funding – Cystic Fibrosis Trust's Standards of Care recommend 0.05 WTE.
- Band 6/7 dietitian (from Dorchester!); CF trained experience 20 years – attended European Cystic Fibrosis Conference in Dublin and Wessex MDT meetings.
- Band 7 dietitian covers ward.
- No dedicated time recently funded; paediatric time funded by Yeovil hospital, not specifically allocated to CF but includes cover for CF clinic with an MDT.
- MOTs covered by Southampton. Inpatient stay covered by local dietitian.

Areas for improvement

- Fund routine CF care.
- Ensure patients receive consistent care as there are two local dietitians and Southampton all involved with nine patients.
- Improve training /liaison with Southampton.

Pharmacy

Please refer to information for Southampton Children's Hospital.

Psychology

Please refer to information for Southampton Children's Hospital.

Social work

Please refer to information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Yeovil District Hospital

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	No	
	% of MDT who receive an annual appraisal	100%	Green	Unclear	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Unclear	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red	Red	Need to come from UHS.
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Red	Red	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	This needs to be clarified as sent away.
	% 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	Unclear	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Ad-hoc appointments	Often only two patients in local clinic.
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	Done in-house?

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Unclear	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Amber	Not if Dr Zaborowski is on leave.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	Only if specified clinic?
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Unclear	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Amber	Amber	In part because they are often ad-hoc clinics and there is no cover for leave.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Suspect not, as adult physios.	This needs to be clarified.
	% availability of a CF specialist dietitian at clinic	100%	Green	Unclear	Travels from Dorchester.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Green	Different dietitian.
	% availability of clinical psychologist at clinic and for inpatients	100%	Red	Red	
	% availability of social worker for at clinic	100%	Red	Red	
	% availability of pharmacist at clinic and for inpatients	100%	Red. Inpatient daily 0% clinic.	Red	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Unclear	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

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

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Yeovil District Hospital 9 patients
Consultant 1	0.5	1	1	One clinic a week.
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	37.5 hours a week covering general paediatrics and CF patients.
Physiotherapist	2	3	4	Two days a week.
Dietitian	0.5	1	1.5	One clinic a week.
Clinical psychologist	0.5	1	1.5	One clinic a week for general paediatrics, including cystic fibrosis.
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Yeovil District Hospital	
Number of active patients registered (active being patients within the last two years)	7
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	8
Median age of active patients in years	8
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	3 (37.5%)
	4–7 years	1 (12.5%)
	8–11 years	2 (25%)
	12–15 years	2 (25%)
	16+ years	0

Genetics	
Number of patients and % of unknown genetics	2 (25%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	0

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	0	0
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	3
	4–7 years	1
	8–11 years	2
	12–15 years	2
	16+ years	0
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	1 (12.5%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=5) 2 (40%)
If not on DNase, % on hypertonic saline	2 (40%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	0
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0

Patient survey

Yeovil District Hospital

	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	0	0
Communication	1	0	0	0
Out-of-hours access	0	0	0	0
Homecare/community support	1	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	1	0	0	0
Waiting times	1	0	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	1	0	0	0
Cleanliness	0	1	0	0
Cross-infection/segregation	0	1	0	0
Food	0	0	1	0
Exercise	0	0	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	1
Car parking	1	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	1	0	0
Of the hospital	0	1	0	0

Comments about CF team/hospital

"CF team are fantastic – no problem/question is ever too small and our CF nurse is brilliant with the girls and will visit us anytime we need her. CF consultant is very thorough and the girls adore him. Physio – not seen as often as we would like/should."

	Hospital name	Yeovil District 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	CF patient appointments are staggered.
Do patients spend any time in waiting room?	Yes	There would never be more than one CF patient at any one time.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	A separate area is curtained off.
Where are the lung function tests done for each visit?		A mobile machine is used in the clinic room.
Are clinic rooms appropriately sized?	Yes	Well equipped.
For annual review patients, are any distractions provided?	Yes	Annual review patients remain in the room and the team rotates. Rooms are equipped with toys and the play assistant can supply colouring/craft materials.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Separate clinic run by Southampton.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	CF starter pack. Works closely with Southampton.

Additional comments

- There are general leaflet boards in the reception area and others are available on request. Toys are available in the waiting area.
- Treatment room – fully equipped.

Environmental walkthrough: ward

Ward name: Dillington

Microbiology status: General

		Hospital name	Yeovil District 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 are required)		Yes	
Number of side rooms?		8	One room is usually used for oncology patients, although this could be available for CF care.
Do the en suites have:	**Toilets?**	Yes	Two of the rooms have a door that adjoins a bathroom and can be locked off for individual use.
	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 bed 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 service and two Starlight mobile units with games.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull-down beds in rooms. Families can stay overnight at Convemore House, opposite the hospital.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Access by arrangement to the ward kitchen, which has a microwave and fridges and free tea/coffee available.
What facilities are provided for teenagers?			iPad and DS for use, Wi-Fi is available for all to use. Patients can also bring in their own IT equipment.

	Yes/no/ number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Two gyms. Patients have physiotherapy twice daily. Well-equipped gym facilities: trampettes, exercise balls, rowing machines, cross trainers, bikes, treadmills and three therapy tables.
What facilities are there to help with school and further studies?		School room with a computer and Wi-Fi. A qualified teacher and classroom assistants attend every weekday 9am–1pm. The teachers liaise with the schools for school work and the patients can take exams. Well equipped with books.
Is there a relatives' room?	No	Due to limited space, this is not available; the team would like to have this facility, space permitting. There is access to a room on HDU.
What internet access is there?	Free Wi-Fi.	This is available to all. Every patient is given a password.
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	Basin as well as steriliser available for own use.
What facilities are provided for those with MRSA?		Segregation in own room – would follow policy.
What facilities are provided for those with *B. cepacia*?		Segregation in own room – would follow policy.
What facilities are provided for those with other complex microbiology?		Segregation in own room – would follow policy.
Are patient information leaflets readily available on ward?	Yes	In outpatient reception and also on request.
Transition patients – can they get tour of ward facilities?	N/A	New patients would be given a tour. Transitioning patients would have a visit to Southampton arranged and the consultant from the Southampton adult service would come to meet them.

Additional comments

- The main entrance to the hospital is situated on level 3. The paediatric ward and outpatients is on level 10, via lifts. There is security door access (with camera) to the ward. The patients age range from three months to 16 years in age.
- The MDT meets weekly before clinic, all patients are discussed and minutes are taken for an updated record. All patient notes are kept at the outpatient reception. There is continuous cross-cover for the CNS; staff work together very closely. The consultant stated that space is an issue at the moment.

- The consultant has relayed his keenness for an adult service at Yeovil.
- The team are actively seeking patients for the Torpedo trial.
- Family rooms are available to stay in, in a separate building named ‘Convemore House’, opposite the hospital. This also houses doctors, nurses and offices. The parents can be issued with a phone for contact.
- Rainbow room: For palliative care. This could also be used for CF patients. It contains a sofa bed facility with en suite. TV, music, fridge, games and DVD.
- Treatment room: Brightly decorated for distraction, and toys available.
- There are two extensive menus to order from, which are rotated weekly. There are snacks available from the kitchen (eg toast) and supplements. The dietitian can arrange for patients to have extra food, free of charge from the canteen.
- Patients can phone the ward directly at any time and be admitted when required.

	Hospital name	Yeovil District Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	On admission, an 'exit pass' can be issued for free parking for the duration of the appointment/visit. There are some spaces in the road outside the hospital, offering two hours free parking. Car park charges: Up to 30 minutes = £1; up to one hour = £2; up to two hours = £4; up to five hours = £7; over five hours = £12. The team says that they have not had any complaints from patients concerning parking. However, on leaving the hospital. I noticed that cars were queuing down the road, one in, one out. The taxi driver informed me that parking was an issue if visiting.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To ward and outpatients on level 10.
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: Seen by appointment. Seating for seven. Ultrasound: Seen by appointment. Seating for 10 and toy area. Pharmacy: Seating for eight.
Do patients have to wait at pharmacy for prescriptions?	No	The community nurse delivers the prescriptions or they are issued by the GP. Inpatients: Pharmacy calls for collection of prescriptions, usually by staff or parents.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	There is a large office at main reception.
Are there patient comment/ feedback boxes?	No	The hospital conducts its own survey by iPad; this rotates around the hospital.

St Mary's Hospital, Isle of Wight

Overview – Consultants

Isle of Wight NHS Trust is the only integrated acute, community, mental health and ambulance health care provider in England and provides a full range of health services to an isolated offshore population of 140,000.

Around 1,300 deliveries per year.

10 cystic fibrosis patients are linked with UHS.

Local consultant Dr Sian Butterworth 0.1 WTE. Recommended: 0.1 WTE (consultants total) (Dr Butterworth is part time, with no cover)

UHS consultant Julian Legg Four joint clinics per year (just over half a day each)

The population of the Isle of Wight is reported to be of generally low social status, with complex circumstances. Patients/families are said to be extremely reluctant to leave the island for any reason. Dr Butterworth endeavours to provide good care to children with cystic fibrosis, but is hindered and greatly frustrated by lack of resources – in particular adequate specialist CF physio and dietetic input.

Patient numbers are small, but a significant proportion have poor nutrition, low lung function and chronic infection with Pseudomonas aeruginosa, MRSA and NTM. There are four poorly teenagers – which are the group that are often hardest to manage effectively. Overall standards of care for children with CF are not being met, but there is generally good feedback from patients in survey.

MDT

- The small size of the clinic makes it hard to achieve seven-day, adequate CF experienced physio/dietitian presence for the tariff available.
- There is minimal physio input – community physios are not respiratory trained and aren't willing to see children with CF.
- Inpatient physio and dietitian do not have formal CF training.
- Good community nursing team, which largely holds the service together.

Cross infection/microbiology

- Three clinic rooms available. Don't have own (portable) spirometer – patients tested in adult respiratory unit.
- Some respiratory samples "sent away", with notable delay in receiving results.
- Only two cubicles, one is en suite – not always available/priority for CF patients. A risk if more than one patient in at a time.

Admissions

Children are treated by adult respiratory physios, largely only seen once daily.

Newborn screening/sweat testing

- One diagnosis through newborn screening predicted every two years – so local MDT team will be inexperienced in managing such young infants.
- Sweat test meets ACB standards.

Transition

To UHS, however many young people don't attend clinic there and "drop out" of care. Adult consultant from UHS does not currently do joint clinics and paediatric team keeps seeing patients in late teens.

Recommendations

- Urgently engage with the hospital trust to release tariff to fund appropriate care and meet SLA.
- Meet with physio/dietetic managers to find innovative way of improving CF care to inpatients and outpatients.
- Secure funding for physiotherapy – eg to part support a new community post with respiratory/ CF training.
- Meet with parents and individual teens, along with support from CF Trust and local agencies, to assess their barriers to visiting UHS – and ways to overcome them, eg funding of travel.
- Hold joint clinics with UHS adult team on island.

Specialist nurse – Isle of Wight

St Mary's Isle of Wight – nine patients

- Member of CFNA; attends regular meetings.
- Community-based ex link with charge nurse (no CF time allocated); excellent support from community and link nurses. Also excellent support from medical team.
- Band 6 nurse provides cover.
- Not attended any national/international meetings.
- Not involved in any trials.
- Inpatient facilities shared with oncology; single room with teenage room/en suite.
- Home IV support, no homecare service.

Areas of good practice

- A lot of good with care pathway from inpatient to outpatient.
- Patient support group.
- Family meetings planned.
- Just set up psychology service.
- Full MDT attends clinics.

Areas for improvement

- Social worker needed (nurse currently completes the DLA form).
- Would like mobile phone for more contact with the patients.
- Secretarial support (not CF funded; currently has one day).
- Block clinics, although cleaned, still risk of cross-infection.

Physiotherapy – Isle of Wight

Isle of Wight – nine patients

- Physiotherapist works 0.87 WTE but without funding. CF sometimes works in own time.
- Uses The Chartered Society of Physiotherapy website and follows discussions etc. Doesn't attend ACPCF meetings.

- Departmental membership now lapsed; will look into it.
- Started monthly meetings recently, has been able to attend two. Parents invited to get their views.
- No cover for routine clinics. Southampton comes to do MOT clinics four times a year. Unsure of when clinics are held – tend to be ad hoc and cannot always attend due to other commitments. Mainly attended by nurse and doctor mainly.
- One children's ward, previously covered by orthopaedic adult physiotherapist and now adult respiratory physiotherapist. Adult Band 5/6physiotherapist, very little training – only has info passed on word of mouth. only usually one patient on ward. Non-tuberculous mycobacterium patients are not allowed out of their rooms, in line with infection control.
- No new diagnoses recently, but feels could cover if required.

Areas for improvement

- Urgent funding required.
- Training required.
- Support to wards and clinics.

Dietetics – Isle of Wight

Isle of Wight – nine patients

- Dietitian has no funding, spends 0.025 WTE on CF; Cystic Fibrosis Trust's Standards of Care recommend 0.06 WTE.
- Has worked in CF for eight years.
- Membership of the UK Dietitians Cystic Fibrosis Interest Group has lapsed.
- Attends monthly MDT meetings, sees all outpatients and inpatients as needed.
- Has cover when on annual leave.
- No concerns about hospital catering.
- BMI – 50th centile.
- CF patients all seen within MDT. Cover is provided at the expense of other paediatric workload, so no concerns about cover. CF trained, but would like more regular CF training.

Areas of good practice

- Good liaison with Southampton, which covers all MOTs.

Areas for improvement

- Secure funded CF time.
- Secure time for training.

Pharmacy

Please refer to the information for Southampton Children's Hospital.

Psychology

Please refer to the information for Southampton Children's Hospital.

Social work

Please refer to the information for Southampton Children's Hospital.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

St Mary's Hospital Isle of Wight

1 Models of care

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	No	Poor physio cover and limited dietetic cover.
	% of MDT who receive an annual appraisal	100%	Amber	Amber	Significant concern if true.
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Unclear	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Uncler	
	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 cystic fibrosis care?	100%	Green	Green	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	
	% 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	Unclear	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission	100%	Green	Amber	Only two cubicles, one is en suite.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Unclear	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Red	Unclear	Were there no patients, or did they not attempt eradication?
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red. Sent to Southampton and take three to four days.	Red	Significant issue.

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Unclear	
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	Unclear	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Unclear	These are done at UHS, so presumably patients travel?

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Amber	No cover for consultant leave.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	Leave cover?
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Unclear	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Amber	Amber	Limited local input.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red. Seen once daily, given various exercises for second session.	Red	
	% availability of a CF specialist dietitian at clinic	100%	Green	Amber	Leave cover?
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Unclear	
	% availability of clinical psychologist at clinic and for inpatients	100%	Amber. No access to psychologist during clinic. Refer to YMCA if needed.	Amber	Would they be able to provide the sort of interventions needed?
	% availability of social worker for at clinic and for inpatients	100%	Green	Amber	Children's disability and social work team. In clinic?
	% availability of pharmacist at clinic and for inpatients	100%	Green	Amber	I suspect not available in clinic.

4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Unclear	Most managed in hospital.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

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

Staffing levels (paediatric)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	St Mary's Hospital, Isle of Wight
Consultant 1	0.5	1	1	0.1 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	7.5 hours per week + ad hoc nurse
Physiotherapist	2	3	4	0
Dietitian	0.5	1	1.5	
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	Ad hoc, according to clinical need.
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – St Mary's Hospital, Isle of Wight	
Number of active patients registered (active being patients within the last two years)	10
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	9
Median age of active patients in years	13
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	1 (11%)
	4–7 years	1 (11%)
	8–11 years	1 (11%)
	12–15 years	3 (33%)
	16+ years	3 (33%)

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	2 (22%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	1 (25%)	1 (20%)
	16+ years	1 (25%)	1 (20%)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	1
	4–7 years	1
	8–11 years	1
	12–15 years	3
	16+ years	3
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	1

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	4
	12–15 years	62
	16+ years	4
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	10
	12–15 years	5
	16+ years	24
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	14
	12–15 years	67
	16+ years	28

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=4) 3 (75%)
If not on DNase, % on hypertonic saline	1 (25%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	1 (11%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (11%) with chronic PA; 0 without chronic PA

Patient survey

St Mary's Hospital, Isle of Wight

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

How would you rate your CF team?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	2	0	0	0
Cleanliness	1	1	0	0
Cross-infection/segregation	1	1	0	0
Food	0	2	0	0
Exercise	0	1	0	0

How would you rate the following?

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

Comments about CF team/hospital

"CF team at Southampton and St Mary's are excellent. Diligent, attentive, friendly, informed and on the ball."

"CF team in Southampton and St Mary's are great. I know I can phone the ward at any time day or night, and they will know who I am straight away and help with any problems. The car park at St Mary's is way too small; not enough disabled spaces."

"The CF team on the Isle of Wight are a real support to families like us. Our child is always treated with respect and great care. We really do need a children's physiotherapist on the island though, as inpatient support is there but not at home!"

Outpatients/CF clinic

	Hospital name	St Mary's Hospital, Isle of Wight
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	Yes	The waiting room has a large waiting area, although CF patients do not wait there. Patients go directly to the clinic room and appointments are staggered, so they would not meet.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes, appropriate.	In the large reception area.
Where are the lung function tests done for each visit?		The spirometry room in the respiratory unit. Funding has been requested to purchase their own equipment, as theirs is broken and has not yet been replaced.
Are clinic rooms appropriately sized?	Yes	All clinic rooms are of a good size and well equipped.
For annual review patients, are any distractions provided?	Yes	There are toys available and a play therapist and they can bring their own toys/electronic games.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		This is a joint clinic; the diabetic nurse will come along to the clinic room.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	

Additional comments

- The outpatient reception and waiting area is a large area containing 10 seats, a children's table and chairs with toys and games available for use. The décor is very bright and child-oriented, with many pieces of art on the walls as well as pictures patients have drawn at the reception counter.
- There is an information point at reception, featuring a stand with many general leaflets available
- The team will see two or three patients per clinic, and these are seen at staggered times so that they do not come into contact with one another.
- There are two patients with Mycobacterium abcessus who will be seen at the end of clinic. During the annual review, the team go to the clinic rooms, where the patients will be waiting.

Environmental walkthrough: Ward

Ward name: Children's

Microbiology status: General

		Hospital name	St Mary's Hospital, Isle of Wight
		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 are required)		Yes	The rooms are of a good size.
Number of side rooms?		2	
Do the en suites have:	**Toilets?**	Yes	One cubicle has an en suite; the other has its own dedicated wet room/bathroom room just outside the cubicle. Both facilities are of a good standard.
	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 bed for adults? (Include in notes policy of ward)		No	Paediatrics.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	TV until 9.30pm. There are two TVs on wheels, which are free for use. There is a facility for purchasing a top-up card for extended use to the 'Patient line' TV, although this is not required as there is always a TV available.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Z beds available.
Visiting hours – are there allowances for CF patients' families out of normal hours?			Open hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Both inpatients'/ward kitchen. The ward kitchen has two hobs, a toaster and hot water; all cupboards are clearly labelled with contents.

	Yes/no/ number/N/A	Notes/comments
What facilities are provided for teenagers?		Teenage lounge – TV, Xbox, DVD's, exercise bike and sofa seating.
Is there access to a gym or exercise equipment in the rooms?	Yes	With the physio. There is also the exercise bike, which can be put in the cubicle, and a trampette.
What facilities are there to help with school and further studies?		There is access to a teacher for a long-stay patient. There is also support for the children to attend school during day time.
Is there a relatives' room?	Yes	Parent's room: situated away from the ward. Well equipped with TV, music, microwave, fridge, sink, toaster, hot water facility, sofa seating and coffee table.
What internet access is there?	None	
What facilities are there to enable students to continue work and study?		Teacher support, and patients can bring in own laptops and own Wi-Fi.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Basin in cubicles.
What facilities are provided for those with MRSA?		Own cubicle and follow guidelines.
What facilities are provided for those with *B. cepacia*?		Own cubicle and follow guidelines.
What facilities are provided for those with other complex microbiology?		Own cubicle and follow guidelines.
Are patient information leaflets readily available on ward?	Yes	As there is such a wide range of information online, this information can be printed off, as and when required.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

- The building was refurbished about 10 years ago. The entrance to the Children's ward, day ward and outpatients is clearly visible at The North Building. The ward entrance is adjacent to the building's main entrance. The outpatient clinic is next door to the wards, and there is a secure entrance to the ward.
- The community nurse and consultant are always available at the end of a phone for patients when required.
- Home IVs are supported by the team. There is a teaching package for parents and teenage patients.
- Patients range from one aged four years old to six teenage patients.
- Children's day ward: This is used for bloods. Only one CF patient is permitted here at a time.

- From the outside play area, through a gate and down some stairs is a private garden. This is a tranquil, and sunny, pebbled area with two sets of tables and chairs with parasols, and nicely kept flower beds with colourful sunflowers. This is generally a very well kept area which the staff are proud of. This garden has been funded and donated by the parents of a deceased patient, in his memory. There is a shed painted as a traditional station ticket office with the child's name on the station signage.
- High dependency unit: Attached to the ward, although rarely used by CF patients.

Environmental walkthrough: Other

	Hospital name	St Mary's Hospital, Isle of Wight
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	There is a parking area directly outside the paediatrics unit; they have never had an issue with parking. There are two designated parking bays for paediatrics.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Very clear 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?		No DEXA scanning. Patients would never meet at radiology or the pharmacy as there are so few CF patients and their appointments are always staggered.
Do patients have to wait at pharmacy for prescriptions?	No	The community nurse will deliver prescriptions.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Available in the outpatient clinic/ward and day ward. Specific information is available on request via the internet and CF website.
Are there patient comment/ feedback boxes?	Yes	In reception.

Jersey General Hospital

Overview – Consultant

Jersey is independent of the UK and EU with its own government ('States of Jersey') and laws. It is not part of the NHS and patients with CF are therefore not funded through the CF tariff. There are formal links with the Jersey health service and UHS for a number of specialities. Population is around 100,000, with 1,000 deliveries per year.

Dr Connett does a combined respiratory and CF clinic two or three times per year, but UHS MDT does not attend. There are five children with CF – four are cared for by one paediatrician, the fifth by a second consultant. There are also some adults with CF on the island.

A family of three siblings chooses not to engage with the service offered by UHS. Dr Connett sees the others, and they also attend UHS twice yearly. Only two children have data entered on Port CF – one has poor nutritional status and relatively low lung function. The children are seen separately in general paediatric clinics. A local CF trained physiotherapist sees them regularly. Some dietetic input is available.

Inpatient services are adequate but could be much better.

Expensive therapies such as DNase are available.

Overall multidisciplinary care is patchy, and it is hard to envisage improving this for such small numbers.

Feedback from one parent was fairly negative.

Any input from UHS MDT would need to be funded by the Jersey Health Service – but would be beneficial to staff and children.

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Jersey General Hospital	
Number of active patients registered (active being patients within the last two years)	5
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	2
Median age of active patients in years	11.5
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	0
	4–7 years	0
	8–11 years	1 (50%)
	12–15 years	1 (50%)
	16+ years	0

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	1

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	1 (50%)
	12–15 years	0	0
	16+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	1
	16+ years	0
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	42
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	42
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=2) 2 (100%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	0
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 chronic PA; 1 (50%) without chronic PA

Patient survey

Jersey General Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Good when we get to see the team from Southampton – poor otherwise locally, with the exception of our current physiotherapist."

	Hospital name	Jersey 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	CF patients do not wait, they are taken directly to the clinic room and appointments are staggered.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In the nursing side room.
Where are the lung function tests done for each visit?		Side room.
Are clinic rooms appropriately sized?	No	The rooms are various sizes; the consultant feels that they are inadequately furnished and equipped.
For annual review patients, are any distractions provided?	Yes	Toys available; patients can also bring own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Separate clinic – do not have any CF related diabetes.
Transition patients – can they get tour of outpatients' facilities?	Yes	For new patients.
Transition/new patients – do they get information pack?		They use the Southampton information pack.

Additional comments

- The clinic is shared with the maternity clinic; the consultant and team are unhappy with having to share these clinics and feel this is not appropriate. This means that assessments have to be carried out on the ward. The team is looking forward to the new build in 2017, which will give it its own clinic facilities.

Environmental walkthrough: Ward

Ward name: Robin

Microbiology status: General

		Hospital name	Jersey 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. However, the consultant expressed concern that overall the general facilities are inadequate and unsatisfactory.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		5	Five rooms can be available, only one has en suite facilities.
Do the en suites have:	**Toilets?**	1 of 5	
	Wash basins?	5	
	Bath or shower?	1 of 5	
Do CF patients have to share any bathroom facilities?		No	This could occur, but is unlikely due to the low number of CF patients.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward)		N/A	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	There are pull-down beds in the side rooms and also a parents' room.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open hours for parents.	Other visitors are limited for cross-infection purposes.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	There are both in the parents' kitchen.
What facilities are provided for teenagers?			A dedicated teenage room, equipped with couch, TV and games.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	
What facilities are there to help with school and further studies?		The play therapist liaises with the school and arranges the work.
Is there a relatives' room?	Yes	Parents' room.
What internet access is there?	No	Can bring in own facility.
What facilities are there to enable students to continue work and study?		Patients would bring in own laptop and Wi-Fi.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Usually carried out by the nurses. There is use of the basin.
What facilities are provided for those with MRSA?		Own side room policy.
What facilities are provided for those with *B. cepacia*?		Own side room policy.
What facilities are provided for those with other complex microbiology?		Own side room policy.
Are patient information leaflets readily available on ward?	Yes	Noticeboards feature lots of general information, also leaflets are available to be printed on request – following Southampton's procedures.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

- Robin Ward signage from the ground floor directs you to the second floor via a lift. Patients are then directed along a corridor and onto another lift, where they are directed to the fourth floor. Patients have found this confusing; but unfortunately there is no other direct route to the ward.
- There are plans for a new build to be completed by 2017; this will house the paediatric ward, maternity and outpatient departments. The team feels that the facilities at the moment are not appropriate, are dated and that the outpatient arrangement is inconvenient. Entry to the ward is via a security door.
- Kitchen: For preparation of paediatric meals.
- Patient facilities: One bathroom, one shower and two toilets. Two treatment rooms.
- Isolation cubicle: Contains a pull-down bed and good en suite facilities and could be used if required by CF, MRSA, *B. cepacia* or other microbiology.
- Parents' room: Small room, however, it is equipped with a pull-down bed, tea and coffee making facility, toaster, microwave and fridge.

Environmental walkthrough: Other

	Hospital name	Jersey General Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	Patients have to rely on the town centre public car parks as the hospital is situated in the centre of town and does not have its own parking facilities.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	The signage is clear, although there is no direct route to the ward. Some patients have found this confusing.
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 12 seats. Parents collect the prescriptions. There is adequate seating (10 seats) in radiology, although patients are given staggered appointment slots and – due to the low number of patients, they do not meet.
Do patients have to wait at pharmacy for prescriptions?	No	Parents collect from pharmacy and on discharge prescriptions are delivered to the ward. Outpatients collect prescriptions from their GPs.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	No	There are some leaflets displayed in the main area.
Are there patient comment/ feedback boxes?	No	The hospital conducts its own surveys periodically. Recent 'picker' surveys showed excellent results (97% and 99% satisfaction) and these are displayed on a ward noticeboard.

Overview – Consultants

Like Jersey, Guernsey is outside the UK, NHS and CF tariff. Children with cystic fibrosis are cared for by a paediatrician with respiratory training, who in turn visits UHS every month. The patients also attend UHS twice yearly.

There is no local CF-trained MDT, but input from respiratory physiotherapist and dietitian is available.

Patients have not received liver USS or DEXA in line with the recommendations of the Cystic Fibrosis Trust's Standards of Care.

Patients admitted infrequently – cubicles available.

Any input from UHS MDT would need to be funded by the Guernsey Health Service. This would be beneficial to both staff and children.

Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'
Report and actual compliance below follows a Red, Amber and Green (RAG) rating defined as the following:

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

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

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

Hospital name

Princess Elizabeth 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	Is the annual review done at UHS? Unclear.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	This is assuming they do see the UHS MDT when they visit Southampton twice yearly.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Unclear	Don't really have enough info, but probably not.
	% of MDT who receive an annual appraisal	100%	Red. No local MDT.	Red	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Red. No local MDT.	Red	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Red. Individual professionals attend CF meeting in keeping with their role and appraisal needs.	Red	Not sure which meetings they get to from Guernsey.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red. Not aware of these.	Red	This needs input from UHS.
	Are there local operational guidelines/ policies for cystic fibrosis care?	100%	Green	Unclear	Don't have enough info.

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	If they say so – don't have enough info.
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red. No local MDT.	Red	So who would manage them?

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	Too few to cohort; seen ad hoc.	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	No evidence either way.

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	Why not when they attend UHS?
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A	Unclear	Is it on their list of things to do for boys?
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red. Not available for children.	Red	Why not when they attend UHS?

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Amber	This is a concern, especially if admissions are relatively rare.	
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	Unclear	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Unclear	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Red. Limited CNS provision for all services.	Red	How 'CF specialist' are they if don't see UHS MDT?
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Red	Red	How 'CF specialist' are they if don't see UHS MDT?
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Red. Seen at separate visit.	Red	How 'CF specialist' are they if don't see UHS MDT?
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Red	How 'CF specialist' are they if don't see UHS MDT?
	% availability of a CF specialist dietitian at clinic	100%	Red. Seen separately.	Red	How 'CF specialist' are they if don't see UHS MDT?
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Amber	How 'CF specialist' are they if don't see UHS MDT?
	% availability of clinical psychologist at clinic and for inpatients	100%	Red. Seen separately.	Red	
	% availability of social worker for at clinic and for inpatients	100%	Red. Very limited availability.	Red	
	% availability of pharmacist at clinic and for inpatients	100%	Red. In hospital only.	Red	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	Home IVs not done.	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	Is there a service available if needed?	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	Unclear	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Unclear	
5.3	User survey undertaken a minimum of every three years	100%	Red. None undertaken – difficult with so few patients.	Unclear	

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2012	
Demographics of centre – Princess Elizabeth Hospital, Guernsey	
Number of active patients registered (active being patients within the last two years)	4
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	4
Median age of active patients in years	10.5
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	0
	4–7 years	0
	8–11 years	2 (50%)
	12–15 years	1 (25%)
	16+ years	1 (25%)

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	0

FEV_1 (ref: 1.14 Annual Data Report 2012)			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	0	0
	16+ years	0	1 (33%)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	0
	4–7 years	0
	8–11 years	2
	12–15 years	1
	16+ years	1
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	42
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=2) 2 (100%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	0
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 1 (50%) without chronic PA

No patient surveys returned.

	Hospital name	Princess Elizabeth Hospital, Guernsey
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Patients are seen at the beginning and end of clinic; they are taken straight to the clinic room.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		All clinic rooms are equipped for this.
Where are the lung function tests done for each visit?		A mobile unit can be wheeled to the rooms.
Are clinic rooms appropriately sized?	Yes	Well equipped, bright, modern and a good size. The rooms are carpeted, therefore cough swabs/bloods and sputum samples taken in the nurses/treatment room, which has hard flooring, for easy cleaning after use.
For annual review patients, are any distractions provided?	Yes	Toys are available for use.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Diabetic clinic.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	Southampton information pack. Tour available.

Additional comments

- Specialist health services: Outpatients is situated in a separate location, approximately five minutes' drive from the main hospital.
- The building is very modern and impressive, with a high glass roof, and is very spacious. There is free parking for all visitors and a vast amount of seating in the waiting area, with toys for general use.
- The age of the four patients ranges from eight to 17 years.

Environmental walkthrough: ward

Ward name: Frossard

Microbiology status: General

		Hospital name	Princess Elizabeth Hospital, Guernsey
		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 are required)		Yes	
Number of side rooms?		5	Three for CF and two for neonatal use. All rooms have double doors for infection control.
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 bed for adults? (Include in notes policy of ward)		N/A	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Z beds in the side rooms.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	No microwave. There is a fridge in the parents'/ward kitchen.
What facilities are provided for teenagers?			Teenagers' room with seating, TV, DVD, iPad and games. Two of the side rooms have doors giving access to the teenagers' room.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Exercise ball and cycle can be put in rooms. Physiotherapists take patients for hydrotherapy. In the physio department there is a treadmill, cycle, weights, and spirometer and exercise balls. Inpatients see the physiotherapist two to three times daily.
What facilities are there to help with school and further studies?		Supply teachers would be brought in for long-stay patients, otherwise the parents would liaise with the school.
Is there a relatives' room?	No	Access to kitchen, which is well equipped with two hobs, a toaster, tea and coffee/cold drink making facility and water machine.
What internet access is there?	Yes	Wi-Fi.
What facilities are there to enable students to continue work and study?		Parent liaison.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Basin in room.
What facilities are provided for those with MRSA?		Separate side room.
What facilities are provided for those with *B. cepacia*?		Separate side room.
What facilities are provided for those with other complex microbiology?		Separate side room.
Are patient information leaflets readily available on ward?	Yes	General leaflets, mostly downloaded from website on request.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

- Entry to the ward is via intercom at the nurse's station.
- The décor is bright; the staff are awaiting delivery of stickers for wall decoration.
- There is a main menu and also an extra menu available for additional food.
- High calorie drinks can be arranged for collection from pharmacy by the dietitian.
- High dependency unit could be used for CF patients, if required.

	Hospital name	Princess Elizabeth Hospital, Guernsey
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	All free.	There are no parking issues; the hospital offers free parking for everyone.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Clear signage to the ward on level 3.
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?		Staff bring up prescriptions to inpatients. Outpatients use outside pharmacies. Patients are called down individually to radiology (eight seats in waiting area).
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?		They have their own 'health promotion' kiosk and leaflet boards. Information is available as and when required, and is printed out from the website, in line with Southampton's procedures.
Are there patient comment/ feedback boxes?	No	A survey is given to parents/patients on admission for completion – the results are sent directly to the CEO.

Appendix 7

Panel members

Dr Hilary Wyatt*	Consultant	King's College Hospital
Sue Bell	Dietitian	University Hospital of North Staffordshire, Paediatrics
Dr Samantha Phillips	Psychologist	University Hospital Bristol
Nanna Christiansen	Pharmacist	The Royal London (Barts Health)
Zoe Rushton	Physiotherapist	University Hospital of North Staffordshire
Siobhan Davies	Nurse Specialist	University Hospital of North Staffordshire
Michelle West	Commissioner	Leicestershire and Lincolnshire
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust

*Panel Lead

cysticfibrosis.org.uk