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Cystic Fibrosis why we're here

British Thoracic Society

BIPRS

Peer review report

Birmingham Children's Hospital and shared care networks

10 July 2014

6. Appendices

1. Executive summary

1.1 Overview of the service

The South and Central West Midlands Paediatric Cystic Fibrosis (CF) Network is a large specialist clinical network comprising approx 300 children and teenagers with cystic fibrosis. Of these patients, 108 are cared for on a full-care basis by the Regional Centre (Birmingham Children's Hospital – BCH), and the other two-thirds on a shared care basis with six network clinics, four of which are large (33–45 patients) and two smaller (9–14 patients). The smallest (Hereford) also shares care with Cardiff for another eight patients. Service user feedback is generally excellent, particularly with regard to the dedicated, hard-working, experienced and caring staff across the entire network. Clinical outcomes, including UK CF Registry data, are generally excellent. Since the introduction of the new CF specialised services tariff in April 2013, there has been appropriate and much needed investment at Birmingham Children's Hospital to strengthen the CF multidisciplinary team (MDT). Overall the centre and network care is of good quality. The centre director and network clinicians are aware of the current areas of the service that require improvement.

1.2 Good practice examples

1. Hard-working, dedicated teams across entire network – greatly appreciated by patients and parents. Excellent expertise and knowledge. Well-established, experienced MDT at many sites. Generally excellent or good clinical outcomes on UK CF Registry across all sites.
2. Increased investment at some sites since 2008 peer review and to meet new CF service specification, most notably at BCH (net increase in 1.3 extra Band 6 nurses [including 0.3 whole time equivalent (WTE) at Band 8], 1 extra Band 7 physio, 1 extra dietitian, 0.5 extra consultant, 1 extra clinical fellow); Also increased physio time at Coventry, and increased physio and dietetic time at Heartlands.
3. Network board meetings; network manager appointed, Annual Clinical Network Meeting, with good clinician engagement across network including some network clinic consultants involved in BCH clinics. 24/7 CF consultant cover at BCH, including for network patients.

1.3 Key recommendations

1. Managers need to prioritise agreeing and signing off the service level agreements (SLAs) for network care. At the time of the peer review teleconferences, although some invoicing and temporary working agreements had occurred between Trusts, no SLAs had been signed, and for at least one network clinic the funding split between BCH and the network clinic had not been agreed. This is the single most important barrier standing in the way of improving effectiveness and quality of network care by the excellent clinical teams at BCH and at each network site. Commissioners may need to support/drive this process given the local difficulties. The split agreed between BCH and network sites needs to reflect how the network service should be (to allow investment in network MDT members), but with clear timelines for these network MDT staff to be appointed. The local specialised services commissioner suggested that all network SLAs be signed by the end of September 2014.
2. Joint network MDT clinics (comprising local CF MDT and centre CF MDT seeing patients jointly by discipline) need to be established at each network clinic site as an urgent priority. This will improve network function, clinical care and communication. A joined-up approach by centre and clinic teams will enhance professional development (particularly of clinic teams), and meet the current CF service specification. Dates for some sites to commence these in September/ October 2014 had been agreed, and dates for all network sites' joint MDT clinics need to be agreed by the end of March 2015. Network-wide guidelines need to be developed.

3. The annual review process at BCH is highly valued but feedback from parents and clinicians suggests it needs to be better resourced, with more consultant and administrative time in particular. This will allow a more detailed, specific strategic review of progress and planning for the year ahead/future aspirations/transition/education/career discussions (for some patients, this requires one hour of consultant contact time, and one hour consultant admin time). Routine psychology review at annual review is recommended. Admin/secretarial resource needs to be assessed as both patients and network teams suggest that annual review reports take over eight weeks to be sent and communication could be improved (ensure letters are copied to families). At the time of review, extra admin time had been allocated and the situation was reportedly improving.
4. Newborn screened patients: The screening lab is at BCH and results come through as appropriate to the CF centre team at BCH. For all areas, except New Cross Wolverhampton and Coventry, the BCH centre team would see newly diagnosed babies from across the region at BCH for first visits, and many of these children continue with BCH full care, as families generally prefer continuity with the team they meet first. This may not be the best model of care for these babies. If network clinic sites meet the National service specification, then there is no reason why in time the network clinic MDTs should not see these newly diagnosed patients in their catchment area for initial and on-going visits, and that these patients should not be seen at least twice a year by the BCH MDT. Otherwise network clinics may diminish and become unsustainable, ultimately reducing patient choice/local access. This is particularly the case for Heart of England, City and Sandwell, Worcester, and Hereford Trusts. To achieve this, network clinic MDTs must be established; network guidelines for newborn screened patients must be agreed (West Midlands guidelines already exist), network clinics need cover for holidays, and network dietitians in particular need appropriate expertise.
5. Transition to adult services: The quality of this process is patchy across the network, mainly due to severe pressure on adult services. The local specialised services commissioner will discuss this with providers of adult CF services and support the development of an additional adult centre (proposals include New Cross and Coventry).
6. Facilities for inpatients at BCH: While outpatient facilities are appropriate and clean, this is not the case for inpatient facilities. The patient feedback contained in this report (Appendices 4 and 5) as well as the pre-announced environmental walkthrough (Appendix 6) raise serious concerns regarding cleanliness and hygiene, particularly of the inpatient bathrooms. In addition, ward 7 can have four to five CF inpatients at a time. There is currently only one side room with en suite bathroom; hence the other patients will need to use shared bathroom with other CF patients. This does not meet pages 9, 13, and 15 of the national CF service specification with regard to the provision of side-rooms with en suite bathroom facilities. Ward 7 requires the provision of at least two more side rooms with en suite facilities to meet this service specification requirement. It is not acceptable for the current cohort of patients to wait eight years (probably longer) for the new hospital building to be completed. Recent national infection control guidance regarding Mycobacterium abscessus in CF patients makes this even more of an urgent priority. The BCH Trust has acknowledged these issues and approved an outline business case for improved facilities and improved hygiene/cleanliness (see details later in report).
7. Succession planning for senior network clinic clinicians approaching retirement (New Cross and Coventry) should be prioritised.
8. An audit urgently needs to be performed of chronic Pseudomonas infection rates at Coventry and Heart of England Trust, as 2012 CF UK Registry data suggests rates of 27% and 31% at these two sites respectively, whereas the national average is 12.5%. Initial discussion suggested this may have been due to misclassification at data entry stage. An initial audit conducted by the time of the final report (Sept 2014) suggests that actual chronic Pseudomonas rates at Coventry based on 2013 Registry data are closer to 5% (which is excellent), but rates at Heart of England remain cause for concern and an appropriate action plan has been instituted (see page 97).

1.4 Areas for further consideration

1. Psychology needs to be more proactive and preventative rather than fire-fighting reactive – the new resource should help embed this in the routine.
2. Royal Worcester Hospital Network Clinic has no cystic fibrosis nurse specialist (CFNS) (needs approx 0.8), no CF physio (needs approx 0.8), no CF dietitian (needs approx 0.2), and as such does not meet the national service specification. This Trust needs to address this as an urgent priority.
3. In addition to BCH, inpatient facilities for CF patients at City and Sandwell and Heart of England Trusts do not meet pages 9, 13, and 15 of the national CF service specification with regard to the provision of side rooms with en suite bathroom facilities. This is an important infection control priority for CF inpatients and is a major concern in the service user survey for these sites.
4. The Coventry CFNS role (highlighted as a great strength of the service by service user evaluation and colleagues) is currently provided by excellent staff in Community Services and its future is uncertain under new funding arrangements. Therefore, a suitable solution must be found to continue to meet service specification. In addition, Coventry requires 4 Programmed Activities (PA) total consultant time for CF given the size of the clinic (currently 2.5).
5. New Cross Wolverhampton did not see any significant increase in CF MDT staff time despite the recommendations in the 2008 peer review. The team is regarded as outstanding by their service users but is overstretched, and there is no clear succession plan for the senior consultant who is approaching retirement. Given the size of the clinic, this site urgently needs a total of four PA consultant dedicated to CF (currently 1 PA), ideally split between two consultants to provide more cover, and one additional whole time equivalent (WTE) physio and 0.4 WTE dietitian.

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

2.1 Models of care

Summary

Overall the model of care is excellent for full-care patients at BCH, which meets all the key requirements to provide CF centre care (although adequate inpatient rooms are limited). The establishment of a network management board is an excellent idea and will hopefully support and drive improved network care. For the care of network patients, joint network MDT clinics must be urgently established to meet standards of care. Service level agreements must be agreed. In addition, some of the network clinics need urgent investment in CF MDT in order to meet the CF shared care network clinic specification (most notably Redditch and Worcester).

Audit and outcomes (from section 2.1 UK CF Standards of Care 2011):

- Are all patients seen at least once a year by a team from the specialist CF centre for annual review?
- Are all patients seen at least twice a year by the full specialist centre MDT?
- Are service level agreements in place for all network CF clinics?

Audit and outcomes (from section 2.3 UK CF Standards of Care 2011):

- Is there a multidisciplinary team of trained and experienced CF specialist health professionals in the network CF clinic?
- Is there evidence that the staff maintain their CPD relevant to CF?
- Is there a standard operating procedure for the delivery of care by the network CF clinic agreed with the specialist CF centre?
- Does the network CF clinic send respiratory samples to a microbiology laboratory fulfilling the 2010 CF Trust laboratory standards for processing microbiological samples?

2.2 Multidisciplinary care

Summary

- Excellent or good at most sites. Redditch and Worcester are very deficient in MDT which must be urgently addressed if CF care is to continue at this network site. New Cross MDT requires additional resource.
- Joint clinics with paediatric diabetes for patients with cystic fibrosis related diabetes (CFRD) are recommended to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)'. There are already six joint CF/CFRD clinics per year, but these cater primarily for BCH patients.
- CF nurse specialists need to attend centre and network MDT clinics.
- CF psychology involvement/support needs to be more integrated and normalised (eg at annual review) and psychology support is needed for network patients. CF social work support has been very deficient – a recent appointee addresses this but will need appropriate supervision and training including Assessed and Supported Year in Employment (ASYE) programme over the next two years.

2.3 Principles of care

Summary

- Generally good/excellent infection control precautions.
- Outpatient clinics run with single room per patient. Inpatient facilities for CF patients at BCH, City and Sandwell, and Heart of England Trusts do not meet pages 9, 13, and 15 of the National CF Service Specification with regard to the provision of side rooms with en suite bathroom facilities. This is an important infection control priority for CF inpatients and is a major concern in the service user survey for these sites.
- Management of respiratory and nutritional aspects of CF as well as complications all appropriate.
- Appropriate access to therapies.

2.4 Delivery of care

Summary

- Generally good or excellent outpatient facilities.
- Inpatient facilities at some sites do not meet UK CF Service Specification; this must be addressed. Availability of advice good during office hours, could be improved for parents out of hours, according to parent feedback shown later in this report.
- Good access to home IVs (certainly for centre patients).
- Referral for transplantation occurs appropriately.
- Transition process to adult services is patchy across the network. This requires both adequate adult CF service provision and agreed network guidelines.
- Timely and adequate written communication has been poor due to administrative and secretarial pressures at BCH, but an additional 0.6 WTE Band 4 medical secretary has now been appointed.

2.5 Commissioning

Summary

- Birmingham Children's Hospital has a well-established paediatric cystic fibrosis service with an emerging network providing a range of shared care services for babies and young people with cystic fibrosis. There are many strengths to the service, including a keen awareness of their strengths and weaknesses and a programme of work in train to address identified issues, which will hopefully be bolstered by the peer review process.
- The network has moved forwards with a number of key appointments, including a network manager and clinical fellow post, which should help to ensure the future sustainability of paediatric CF services. There has been progress in addressing administrative delays, including ensuring that families receive copies of doctors' letters and plans for better communication between the centre and shared care providers.
- The main focus for development over the coming months relates to the need to agree SLAs with all the shared care providers, to ensure that there is a sure footing for moving forward with staffing, the delivery of the service specification and standards of care across the network.

Other areas for future focus include:

- Succession planning across the network – lead consultants in two of the key shared care centres are working towards retirement.
- Patient pathways – as networked care develops there may be a move from newly diagnosed patients being managed at BCH to shared care from the outset.
- Patients' environments within BCH create significant challenges as there is little space to provide attractive en suite rooms for patients, although infection control outcomes are good.
- Ensuring effective transition to adult services, recognising the pressures currently facing the adult centre within the area.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	108

			Male	Female
FEV_1	Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
		4–7 years	0	1 (7%)
		8–11 years	0	5 (31%)
		12–15 years	0	5 (31%)
		16+ years	0	5 (31%)

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	n=4; 3 (75%)

***Pseudomonas aeruginosa* (PA) Chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	8 (7%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	8 (100%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	2 (3%)
	Number and % of patients on chronic macrolide without chronic PA infection	17 (16%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- Excellent, experienced consultant team with 24/7 cover, including weekend ward rounds and telephone advice for entire network. Consultant staffing levels seem appropriate. Competently lead experienced and excellent MDT with good continued professional development (CPD) attendance, very appreciated by service users. Good clinical outcomes.
- Good, up-to-date BCH CF guidelines.
- Recent investment in staff, including network manager and clinical fellow, to allow joint MDT network clinics to commence – hopefully this September. Excellent network board and clinical network meetings established. Good to do joint clinics with some of the network clinic consultants at BCH. Clinical fellow position will be excellent for training future potential network clinic consultants.
- Annual review with BCH MDT team has room for improvement, regarding sufficient consultant time (not sure this is factored into business plan, probably one hour contact, one hour admin per network patient) involved for all network patients (BCH patients generally have nurse-led MDT annual review). Annual review letters need to come out more promptly and have more future planning, including educational/career/transition discussions as appropriate.
- All BCH consultants involved in CF care need to continue to have their CPD supported and to attend appropriate CPD, eg European CF Conference, North American Cystic Fibrosis Conference, and to lead the appropriate national and international profile of this large, expert and influential service.

4.2 Specialist nursing

The CF nursing service currently has 4.5 WTE, which meets the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

The CF nursing service plays a pivotal role in the CF team, providing easy access to the CF team for patients and families. All nurses are based at Birmingham Children's Hospital (BCH) and cover inpatient and community services. All nurses are members of the Cystic Fibrosis Nursing Association (CFNA) and attend national and international conferences. Leave is covered within the team. Nurses are involved with audit and research. The nurses attend ward meetings and outreach clinics, which are under review. The nurses play a leading role in transition to adult care, newborn screening, end-of-life care with help from palliative care, and children referred for transplantation. The Band 8 leadership role has been fully supported by the BCH management team and, although this is a new team, good succession planning has enabled the new members to be supported in their roles.

Areas of good practice:

- Nurses are very experienced and motivated. They show excellent communication skills with children, families and the shared care centres.
- The Band 7 and 8 CF CNSs are non-medical prescribers, which enables them to be independent nurse practitioners, running nurse-led clinics.
- Newborn screened baby clinics.

Areas for improvement:

- Attendance at CF clinics. This is under review with new members of staff.
- There is no current formalised annual review. Nurses could use this time for education and planning and support.
- CF nursing time may be pulled to other areas that have not got specific funding streams.

Recommendations:

- A formalised annual review.
- Attendance at clinic both at BCH and shared care centres.

4.3 Physiotherapy

- The lead physiotherapists fulfil the required criteria for a 'specialist CF physiotherapist' and have the opportunity to attend local MDT network meetings, Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) study days and international CF conferences.
- The senior staff are experienced, motivated and enthusiastic.
- There is involvement in audit, service improvement and CPD.
- There have been recent increases in staffing, at several levels, some of whom are yet to start.
- The physiotherapy team is developing the service as the new members become established and has plans to develop shared care guidelines and protocols and also to increase education and support across the network. They have representation on the more recently created Oversight Network Panel and will therefore be able to contribute to the development of the CF service to the patients within the network.
- The WTE now stands at 3.3, which is adequate for centre patients and providing a service to the network.

Areas of good practice:

- Outpatient clinics physiotherapy provision allows an average of 80% of patients to be seen by the physiotherapist. There is backfill from senior staff for annual leave.
- Inpatient physiotherapy provision meets the required standards of the ACPCF. The team attends ward rounds and MDT meetings and there are very good inpatient exercise facilities.
- The staff are able to undertake community visits where necessary, and provide a good service for newly diagnosed families and for young adolescents transitioning to adult services.

Areas for improvement:

- Annual physiotherapy reviews are now reinstated and BCH plans to complete these with their own patients and also for those patients from the smaller clinics. The team is confident that staffing levels will be able accommodate this. It is important, however, within this scenario that the format of reviews is standardised throughout the network and that the larger clinics do their own.
- The team is also confident that they have the resources to accommodate the proposed introduction of MDT network visits, and that this will contribute to the education and support to the network.

Recommendations:

- Funding for physiotherapy adjuncts has historically come from the physiotherapy budget; however, as this aspect is included within the tariff, this should change to be funded directly from the CF budget. There also needs to be standardised funding for adjuncts across the network and for this to come from the network clinics, because when funding and staffing is finally established, the money should be in the budgets to accommodate this.
- The nebuliser service is managed by nursing staff at present; however, it is a desire of the physiotherapy team and a recommendation that this should be jointly managed by nurses and physiotherapists to facilitate the dissemination of knowledge.

4.4 Dietetics

The CF nutrition service at BCH was 1.1 WTE, but a further 1.0 WTE post has just been recruited to meet the Cystic Fibrosis Trust's Standards of Care for dietetic staffing. The service demonstrates an expert knowledge of nutrition, and the dietitians are members of the UK Dietitians Cystic Fibrosis Interest Group and regularly attend European and American CF conferences, and relevant UK CF meetings. The nutrition service is involved in the audit of nutritional matters and plans to increase participation in this area now that staffing levels are fully met. Cover is always available for IPs, provided by a Band 6 dietitian. A dietitian always attends the weekly CF multidisciplinary meetings.

Historically, due to inadequate dietetic funding, the service has been unable to regularly attend CF ward rounds and there has been no dietetic cover for outpatients during leave periods. The service has been unable to provide a structured dietetic annual review assessment or attend network shared care clinics and transition clinics. The recent increase in staffing levels will allow these issues to be remedied.

Areas of good practice:

- Expert clinical knowledge within the nutrition team.
- Clear dietetic protocols and guidelines based on current evidence.
- Excellent team working within dietetics and the wider MDT.

Areas for improvement:

- Increase research and audit participation.
- Improve dietetic transition process.

Recommendations:

- Introduce structured dietetic annual review assessments.
- Ensure attendance at joint network clinics and development of resources and guidelines for use across the network.
- Ensure participation in CF wards rounds and provision of cover for outpatients during leave.

4.5 Pharmacy

Number of patients: 108 full care, 192 shared care
Pharmacist time dedicated to CF: 1 WTE
Cystic Fibrosis Trust's Standards of Care: 1.36 WTE

Position of 1 WTE Band 8a highly specialist pharmacist recently funded and pharmacist will start full time in the position in September. The post holder is highly motivated and has already improved the pharmacy service provision and is an active member of the UK Cystic Fibrosis Pharmacist Group.

- Able to attend relevant UK CF specialist interest group meetings annually.
- Attends weekly inpatient MDT meeting, does not attend ward rounds or outpatient MDT meeting.
- Ward cover available in absence, junior rotational pharmacist.
- Attends the European Cystic Fibrosis Society conference.
- Audits done on Tobramycin levels, Ivacaftor use and Flucloxacillin prophylactic doses.
- No particular involvement in key life stages for those with cystic fibrosis.

Areas of good practice:

- Good inpatient service provision, very good relationship with the CF team, very appreciative of the pharmacist input.
- Recent increase in staffing allows for gaps in service provision to be addressed. The post holder is very committed and has many good ideas about how to improve the service, many of which have already been implemented.

Areas for improvement:

- Given the number of patients, the service may require further resources to be able to repatriate all patients on high-cost inhaled drugs as per NHS England guidelines and better enable the role as planned.
- Pharmacist currently doesn't participate in outreach clinics. Given that the shared care unit pharmacists do not provide outpatient clinic service to annual review clinics; this represents a gap in service provision.

Recommendations:

- Review the staffing resource, particularly in light of the repatriation of high-cost inhaled medication, homecare service provision and plans to develop independent prescriber role.
- Review how shared care annual review clinics receive pharmacy cover.
- Continue to improve pharmacy network connections.
- Establish how all elements of the specialist pharmacist role are covered during periods of absence.

4.6 Psychology

In December 2013, BCH instituted the Choice and Partnership Approach (CAPA) model, also known as the 'single point of access', as a means of allocating mental health services to referred patients across the hospital. CAPA is in the early stages of development and there have been a number of job freezes which have made it challenging to determine whether or not it is a positive move for CF patients, their families and carers. I have outlined below the opportunities and the constraints that this system offers. There does appear to be some ambivalence, particularly from the CF lead clinician, as to the 'fit' for the paediatric CF service.

Furthermore, there currently seems to be a disparity between the accessibility to mental health services offered to CF patients, their families and carers at BCH, and those under the care of the six other CF shared care centres.

My report is made with consideration to the above.

Choice and Partnership Approach (CAPA)

This system was established in 2011 for use by Community Mental Health Teams (adults) and Child and Family Mental Health Services (CAMHs). CAPA is a way for mental health services to effectively manage the demand and capacity of referrals it receives. It also facilitates the sharing of expertise among mental health clinicians and decision making on mental health treatment choices in collaboration with children and young people and their families, based on many options that present in any clinical intervention. This system has also been adopted by Exeter and Glasgow paediatric services.

BCH adopted CAPA on 1 December 2013 as a means of allocating a mental health service (including clinical psychology but also family therapy, psychiatric liaison and other therapies) to all referred mental health paediatric patients (including those with CF) and their families.

My summary of the opportunities and constraints of the CAPA system is as follows:

Opportunities *

i. Equitable (all paediatric patients are offered service irrespective of physical and/or mental health diagnosis).

ii. Timely (response time from referral to offering patient an appointment is relatively fast).

iii. The 'right' service and the 'right' response is given to each referred child/young person and their family.

iv. Good for professional and personal development of (mental health) staff members.

v. More opportunities to offer services such as group working across (physical illness) specialties (great potential for children/young people with CF due to cross-infection concerns within the CF population).

Constraints**

i. It is a reactive not proactive/preventative service (ie waits for a problem to be identified and a referral made to mental health services, rather than offering advice and consultation to prevent a possible problem occurring in the first place).

ii. Those families who are more articulate and who are able to advocate a mental health service for themselves are more likely to gain access to and receive the 'right' (their preferred) mental health service.

iii. The Cystic Fibrosis Trust's Standards of Care identify services offered to CF patients and their families and carers which do not fall under the CAPA model, eg annual assessments, meeting families of newborn screened babies, transition, end-of-life care/consideration of lung transplantation, etc.

iv. CAPA appears not to develop the 'consultation' potential offered by a CF clinical psychologist who attends ward rounds/CF outpatient meetings, etc.

v. A clinical psychologist is viewed as an integral part of the CF MDT with a view to informing themselves about and understanding each individual patient and their family (and what CF means to that family). In the event that a challenge occurs requiring the input of a clinical psychologist, this can be perceived by the family as an ordinary process rather than a more formal mental health referral, and may therefore promote engagement with therapy among families who would otherwise be difficult to engage.

vi. The development of expertise and knowledge in working with the CF population is valued by the children/young people and their families. Such expertise and knowledge would be difficult to attain if there is no dedicated CF mental health professional.

vii. The Cystic Fibrosis Trust's Standards of Care recommend the allocation of 1.5–2.0 WTE clinical psychology, funded directly via the tariff system for CF patients at South and Central West Midland Paediatric Cystic Fibrosis Service. It is not clear whether this funding would directly benefit the CF patients and their families or whether the finances would 'go into a pot' for all paediatric services (ie there is a possibility the paediatric CF service could either benefit or lose out via the CAPA system).

viii. Although not impossible, it is difficult to envisage how the tasks of audit, research, teaching and training specific to CF fits with CAPA.

* For reference: http://www.capa.co.uk/

** For reference: 'Guiding Principles on how to manage relevant psychological aspects within a CF team: interdisciplinary approaches', Journal of Cystic Fibrosis, Vol 10 Suppl 2(2011) S45-S52.

Following discussion with the lead paediatric clinical psychologist and one of the consultant paediatric CF physicians at BCH, it would be fair to say that CAPA has mixed reviews. Of course, it has only been established since December 2013 in the environment of job freezes and institutional changes, and is therefore in the very early stages of development. There is a thought that allowing the process to take shape and develop over the next one to two years and the planned recruitment of two further 0.5 WTE posts would create an improved service for CF patients and their families.

There does appear to be a culture clash between the Cystic Fibrosis Trust's Standards of Care approach towards the psychological (and physical) wellbeing of patients with CF and their families, and the CAPA model. It is difficult to envisage the benefits outweighing the costs for paediatric CF patients and their families and carers at this present time.

Other comments

The paediatric clinical psychology service is centralised at BCH. Although SLAs with the other hospital sites have not been signed off, I am informed that the current share of the tariff should afford for some purchase of clinical psychology (or equivalent) provision at these hospital sites to ensure equity and accessibility to all patients and their families.

Current staffing level

(Current provision 0.6 WTE, recommended 1.5–2.0 WTE across South and Central West Midland Paediatric Cystic Fibrosis Service.)

Birmingham Children's Hospital

Band 7 0.5 WTE – Currently in post.

Band 8a 0.5 WTE – Interviews next week; anticipated commencement in post in approximately three months' time).

Band 7 0.5 WTE – Recruited; commences October 2014.

Heart of England Hospital

0.1 WTE – post holder currently on maternity leave (no cover).

City and Sandwell – No clinical psychology.

New Cross Hospital – No clinical psychology.

Redditch and Worcester – No clinical psychology.

University Hospital Coventry – No clinical psychology.

Hereford – No clinical psychology.

Areas of good practice:

- The clinical psychologist identified as the psychologist linked to the CF team is enthusiastic and dedicated to the work, and is reported to engage families in therapeutic work well.
- The CF MDT at BCH welcomes the support given by clinical psychologist(s) and is keen to develop this role further.
- Children, young people and their families referred to mental health services at BCH with an identified referred problem are assessed and can be offered a quick service according to their individual requirements in discussion with the referred client and their family.

Areas for improvement:

- Recruit to recommended complement of staff.
- Look at and develop the Cystic Fibrosis Trust's Standards of Care for clinical psychologists to ensure a proactive and preventative service for the paediatric CF service. To include (but this is not exhaustive):
    - Annual assessments for all patients.
    - Participation in transition to adult service at Heartlands Hospital (initial plans to develop service with clinical psychologist at Heartlands Hospital have been made).
    - Attendance at CF MDT inpatient and outpatient meetings.
    - Meeting families of newborn screened patients to introduce clinical psychology service and promote easy access to service.
    - Facilitation of psycho-social meetings.
    - Offer consultation and teaching to the CF MDT.
    - Consider audit/research and teaching and training opportunities.
- Develop service for paediatric CF patients and their families from the shared care centres.

Recommendations:

- Recruit to clinical psychology posts at the first opportunity.
- Continue to develop the CAPA system of service with a critical view to ensure that the service recommended to CF patients and their families (and financed via the CF tariff model) is in line with the Cystic Fibrosis Trust's Standards of Care.
- Consider how the clinical psychology service will be offered to patients accessing their CF care at the six centres other than BCH.

4.7 Social work

Birmingham Children's Hospital:

- There is no current social worker in post due to Barnardos withdrawing funding a few years ago. The team recognises the importance of specialised role of a CF social worker from the past experience and the CNS has been trying to bridge the gap to meet the patient's social and welfare needs since funding was withdrawn. A good understanding of prioritising of social work tasks was identified, with recognition that this was not comprehensive enough to support a large number of CF patients. The team engages and has links with the local city council social work team for support and guidance in generic social work needs. For more specialised information, they liaise with the adults' specialist cystic fibrosis social work team within Heartlands Hospital.
- Funding has now been agreed for a full-time equivalent specialist cystic fibrosis social worker Band 7 post, which will be funded by the NHS. A social worker has been appointed.

Areas of good practice:

- A committed team that knows the families well and has in-depth knowledge of cystic fibrosis.
- Nursing team has been able to prioritise essential social work needs, support patients and sign post where necessary.
- Team has networked with the adult cystic fibrosis team to provide advice and/or support in specialist areas. The team seeks support and advice from the generic social work team within the hospital.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	21	19	11	4
Female	21	10	14	2

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	46	32	4	1
From the ward staff	19	16	5	1
From the hospital	23	38	10	0

Areas of excellence

1. Accessibility/communication in hours
2. Physiotherapy on weekdays
3. Approachable, friendly, supportive

Areas for improvement

1. Communication between shared care clinics and centre
2. Out of hours – lengthy waits in A&E
3. Annual review is sparse

6. Appendices

Appendix 1

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

Birmingham 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	Feedback from parents and network colleagues suggests they could have more long-term planning and future direction, and that letters were taking up to eight weeks.

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	Amber	For network patients this will not meet Green until joint network MDT clinics at network sites are established.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	But there are some serious shortfalls in MDT, particularly at Redditch & Worcs.
	% 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	

2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	Green	Green	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	There are BCH guidelines but network guidelines need to be developed and agreed.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	100%	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red	Amber	There are joint CFRD/ CF clinics – need to focus on increasing availability for all patients.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Red	Red	Lack of en suite rooms a major concern: two more en suite side rooms needed at BCH ward 7 to meet spec.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Compli-cations	% of aminoglycoside levels available within 24 hours	60%	Green	Green	Some samples, eg Tobramycin levels, go to Heartlands Hospital, which can cause delay.
3.4 Cystic fibrosis related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Amber	GTT only every two years.
3.5 Liver disease	% of patients >5 years of age with a recorded abdominal ultrasound in the last three years	100%	Red	Red	Need to consider more regular liver USS. Advice from BCH Hepatology Supraregional Service is that this standard is not evidence based.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	Generally only one DEXA achieved pre-transition for most patients, does not meet the Cystic Fibrosis Trust's Standards of Care. Advice from BCH bone specialist colleague is that this standard is not evidence based; BCH patients are participating in a study looking at this.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/ shared care consultant/ patient or carer, within 10 days of consultation	100%	Red	Red	Delay in receiving letters a severe issue for both families and network clinicians, with delays of up to eight weeks.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Red	Red	As per box above. Panel was pleased to hear another 0.5 WTE admin person had been recruited.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Red	Red	Very little availability – CFNS team will prioritise.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% 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%	Amber	Amber	Responsive rather than routine preventative.
	% availability of clinical psychologist for inpatients	100%	Green	Green	
	% availability of social worker at clinic	100%	Red	Red	SW recently appointed but will need training and supervision.
	% availability of social worker for inpatients	100%	Red	Red	SW recently appointed but will need training and supervision.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0.60%	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	5 incidents	Green	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Red	Red	The most important block to improving network care.

Appendix 2

Staffing levels (paediatric) figures at 30/09/14

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

	75 patients	150 patients	250 patients	Birmingham Chidren's Hospital
Consultant 1	0.5	1	1	4.65 WTE (12 PAs CF)
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	1
Specialist registrar	0.3	0.5	1	2 WTE (Resp/CF)
Specialist nurse	2	3	4	4.5 WTE
Physiotherapist	2	3	4	2.75 WTE
Physiotherapy assistant				0.75 WTE
Dietitian	0.5	1	1.5	2.1 WTE
Clinical psychologist	0.5	1	1.5	2 X 0.5 WTE
Social worker	0.5	1	1	1
Pharmacist	0.5	1	1	1
Clinician's assistant				
Secretary	0.5	1	2	1
Database coordinator	0.4	0.8	1	1
Admin assistant				
CF unit manager				1

Appendix 3

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)

CF Registry data – 2012	
Demographics of Birmingham Children's Hospital	
Number of active patients registered (active being patients within the last two years)	108
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	108
Median age in years of active patients	10
Number of deaths in reporting year	1
Median age at death in reporting year	15

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number and % in age categories	0–3 years	19 (18%)
	4–7 years	22 (19%)
	8–11 years	25 (23%)
	12–15 years	25 (23%)
	16+ years	18 (17%)

Genetics	
Number of patients and % of unknown genetics	7 (7%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	n=4; 3 (75%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
		Male	Female
Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
	4–7 years	0	1 (7%)
	8–11 years	0	5 (31%)
	12–15 years	0	5 (31%)
	16+ years	0	5 (31%)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	19
	4–7 years	22
	8–11 years	25
	12–15 years	25
	16+ years	18
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	5
	16+ years	3
***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	2 (2%)	

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (1%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	7 (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	2 (2%) with PH; 2 (2%) without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantation assessment in reporting year	2
Number of patients referred for transplantation assessment in previous three years	4
Number of patients receiving lung, liver, kidney transplants in previous three years	2

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	49
	4–7 years	115
	8–11 years	108
	12–15 years	321
	16+ years	392
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	24
	8–11 years	52
	12–15 years	186
	16+ years	55
Total number of IV days split by age group	0–3 years	49
	4–7 years	139
	8–11 years	160
	12–15 years	507
	16+ years	447

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	(n=67) 28 (42%)
If not on DNase, % on hypertonic saline	2 (3%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	8 (7%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	8 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	2 (3%) with chronic PA; 17 (16%) without chronic PA

Appendix 4

Patient survey

Birmingham Children's Hospital

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	21	19	11	4
Female	21	10	14	2

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	49	32	11	2
Communication	48	24	16	5
Out-of-hours access	22	19	13	3
Homecare/community	32	14	6	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	39	31	16	3
Waiting times	25	37	20	6
Cross-infection/segregation	37	36	16	1
Cleanliness	36	43	13	0
Annual review process	27	27	9	5
Transition	11	9	6	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	10	11	12	5
Cleanliness	13	16	9	6
Cross-infection/segregation	13	11	9	5
Food	7	11	10	7
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	19	15	3	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	15	13	5	2

How would you rate:

	Excellent	Good	Fair	Poor
Home IV antibiotic service	7	7	2	0
Availability of equipment	13	20	3	1
Car parking	3	7	14	36

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	46	32	4	1
Of the ward staff	19	16	5	1
Of the hospital	23	38	10	0

Comments about CF team/hospital

Should be given own rooms all the time and have en suites that are cleaned properly. Also should have own fridge and working TVs in rooms. More variety of diet fizzy drinks for those with diabetes.

All members of team are positive and supportive. Generally can always get hold of them. Parking is awful, often a long way which is difficult with a young baby.

First line contact with CF nurse excellent, always helpful and keeps family up to date with what is needed for patient treatments. Even delivers syringes/needles, etc when running low. Excellent support. Hospital appointment – patient is autistic – so hospital are always sensitive to his needs and try and take extra care to explain what is going on.

The CF team have been a great support and passed on so much knowledge since my baby's diagnosis. Will always be so grateful.

The only difficulty I have experienced is with contacting the respiratory/CF consultant out of hours for advice. On following the answerphone advice to contact them, my experience has been the switchboard choose not to and each time this has resulted in lengthy waits in A&E which potentially could have been avoided.

Excellent care from the start, supportive and reassuring.

Very good team. Always there when I need any help. Very supportive.

We have nothing but praise for the staff at the hospital. A credit to the hospital.

The team at the Children's are very helpful and make you feel relaxed when you ask them questions. They also have a lot of patience.

Admission – we didn't have own toilet/bathroom. Car parking – expensive, terrible and difficult. CF team – depends, some excellent, some not great. Unhappy about cross infection, they expect CF patient to arrive at same desk at the same time; babies under one year wait long times in outpatients. Team is always accessible and give advice straight away which is great. CF team approachable also great.

I have always felt supported by the CF team. If I need advice, I have the option to call the CF nurses or I can leave messages for the doctors who do call back. Now that my daughter is allocated a room when we visit, I feel this makes things easier.

The CF team work really hard for the kids with CF at BCH. They are all lovely and I trust them to know what is best for my son. Getting care sorted for inpatient care is hard and we have had many issues with lines, eg losing them as no Heparin put down etc, which is very frustrating, especially as I do his IVs at home once the line is sorted. The nurses do always get back to me and I understand they are busy and sometimes delayed.

Cannot fault the care we have received from our team at BCH, we haven't needed inpatient care for a while. We have only ever had problems when on the ward and it was when a doctor was needed – but this was when our little man was a baby.

It would be nice to always see the same doctor for outpatient appointments. It's better now that we have our own room and don't mix with other CF patients.

As of up to yet excellent, no problems whatsoever and am really grateful for all the support and help we receive.

The CF team are brilliant and amazing, I love them.

The CF team are excellent in all areas. The Birmingham Children's wards however are very poor in most areas. The ward staff are usually hours late carrying out IVs. The wards are dirty, the cubicles/ rooms are dirty resulting in us as parents contracting a bacterial rash/infection after staying there. Parking expensive and lacking.

CF team do a fantastic job. I know I can call with whatever question no matter how small and they are always willing to help.

The support that we have received has been fantastic from all staff, however, our community nurse has been outstanding, always on hand for advice and support whenever we need it.

Friendly and approachable team.

All members of the team are friendly, supportive, approachable and put my child at ease.

Overall very happy with care at Birmingham Children's Hospital and feel lucky to live close by.

The CF team are doing a great job and help us every step of the way.

Appendix 5

Patient/parent interviews

Parent A (BCH full care)

Areas of good practice:

- Daughter directed straight to outpatient consultation clinic room – no waiting in open area.
- Care is good. Efficient in meeting parents'/daughter's needs and CF team always at the end of the phone.
- Homecare: Nasogastric feed service (Homeward) are excellent, deliver as scheduled every time. In hospital for the week to train mother to pass NG tube. It's impossible to get nurses to come out when needed, so goes to A&E.
- Overnight parent facilities on ward: Pretty good, but basic. Mum had bed and space to store food, plus Wi-Fi access.

Areas for improvement:

- Car parking is terrible.
- Filthy hospital on the ward, "cleanliness non-existent" on respiratory ward – had to clean daughter's cot.
- Children popping in and out of each other's rooms.
- Nurses "always" short-staffed.
- Cleaning not done properly – ie same mop head used for each room.
- At GP's surgery: Always an issue with flu jab, so had to get CF team to phone surgery, as no flu jab given to under 5s. Difficulty negotiating surgery's default repeat prescription process – CF CNS had to intervene and contact GP surgery.

Parent B (BCH full care)

Areas of good practice:

- Improved segregation arrangements at outpatient clinic. Child directed straight to consultancy room and stays in room as CF MDT rotates ("it speeds up the process and reduces cross infection risk").
- Rooms are cleaned, equipment cleaned and all smells clean.
- We see all of the CF team at outpatient clinic; care is consistent. Also offered opportunity to see clinical psychologist and/or social worker.
- Annual review bloods/X-rays done in advance of annual review appointment, so annual review does not take longer than a normal outpatient appointment. Annual review outcome reported back to mum by letter (copied to GP and school).
- CF Nurse performs annual school visit. Physiotherapist is coming to do home visit soon to train bubble pep usage.

No areas for improvement suggested.

Parent M (BCH full care)

Areas of good practice:

- Daughter has had no CF-related admissions to hospital. Homecare was most needed by mother when daughter was post diagnosis and in earliest years; less so now, but mother knows that she can get support and advice from the CF nurses whenever needed, by phone or email. And she's spoken to the consultants directly by phone when urgent. Mother's comment: "support is definitely there".
- Annual reviews are sparse, not had one this year and had to request one last year. Some annual review tests are carried out at routine outpatient appointments, which mother is happy with as otherwise annual review day is too intense. At outpatient clinic and annual review, mother and daughter are led straight to consultancy room; no waiting in open clinic area, which pleases mother. They request and are given late appointments as both parents work and also don't want to disrupt daughter's schooling. Outcomes of clinic appointments are reported back at next clinic or where specific treatment changes are required, via letter copied to GP.
- Mother likes the way the team communicates with her daughter in a child-orientated way.

Areas for improvement:

- Phlebotomy could sometimes be less harsh and more child-friendly when taking bloods from her daughter, who finds needles traumatic.
- Annual reviews are sparse, not had one this year and had to request one last year.

Patient One

- A 16-year-old female and her mother attended the interview; she was diagnosed at the age of four-and-a-half months with failure to thrive.
- The patient said the staff are all good and most are very friendly. She said she has had to get used to the new staff on the ward, who were less experienced.
- The CNS and consultants are like family to her. She is not keen on physiotherapy at the hospital as she likes to do her own physiotherapy regime; she also attends the gym.
- She does not like inpatient food and the portions are small, so she has tended to eat out, however this proves expensive.
- The mother carries out her daughter's IVs every 12 weeks.
- Parking at the hospital is fine as they have a blue badge and can park in the road nearby.
- The adolescent room in ward is good and she helped to design it.
- Waiting in the clinic is acceptable and usually the wait is not too long. She will transition to Birmingham Heartlands and has her first meeting with the team in August.
- The patient has been involved in research in the past; she has just refused a snap study as this would delay her transition.
- They have never had any problems or delays in receiving the letter to travel or any problems with insurance.
- The mother says that when her daughter does transition, it will be like losing family and she is very wary of it. She also stated that the team is "brilliant/fantastic" and always there. She can call them anytime, they always consider both their opinions and she is involved in decisions; she is more than happy with the care. The mother said that there used to be a very helpful social worker, however, they are no longer available.

Patient Two

- Mother to an eight-year-old boy, who was diagnosed at the age of four months. They live 10 miles away, which takes 30 minutes by car. They have another son of three years old who is a carrier. They attended Manor Hospital for diagnosis and then came to BCH. The staff are "fantastic".
- The nurses at BCH are "brilliant" and have telephoned her as late as 7pm; they go beyond the call of duty and take on the role of psychologist and social worker in their absence. The consultants are fantastic and are very contactable, even at weekends.
- Mum carries out her sons IVs at home. He is never in hospital for more than two to three days, she tries to get him home as soon as possible, she also carries out his physiotherapy. He has a Vest. However, if he carries out his acapella effectively he does not require the Vest. On diagnosis there was no home physiotherapy service. There are now physiotherapy therapy home visits, however, the therapists are not always known to them or experienced therapists.
- The car parking is bad; generally she cannot park in the hospital car park or the nearest NCP car park and has to park further away and walk to the hospital. They do not have a blue badge.
- Due to a bed shortage, they have to wait for admission and never know when they are coming in, however it's usually within one week. On one occasion they were admitted to the admissions unit where she had no bed but a chair to sleep on. Staff were all busy and not experienced in cystic fibrosis.
- For inpatient stays they are not always allocated a room with en suite and have to share a bathroom, however not with another CF patient. The rooms are basic and difficult to keep clean due to lack of space when a patient is in for a long stay. She would not take her son to the play room as she would not know who else would be in there and what condition they had; she prefers to take him out to play. She does not bath or shower her son as she would not wish to use bathrooms on the ward.
- The nurses on wards two and seven are generally brilliant. The dietitian is very good, although difficult to contact due to staff shortage.
- Psychology is very good, but there is a long wait for an appointment. This has improved, she said, but as parents they would have benefitted from this service sooner for their son and themselves.
- She prefers to wait for a bed in BCH instead of going to her local hospital, Good Hope. She would only take her son to attend outpatients at Good Hope if the same MDT attended the clinic.
- The food is very good on the ward. Her son is a fussy eater and they take him out to the local pizza restaurant.
- Outpatients have improved; patients are taken directly to the clinic room and this runs smoothly.
- The play centre is fantastic. Her son was needle phobic and used to have to be held for bloods/ IVs. However, since the centre opened, this is no longer an issue thanks to the distractions and play specialists.
- A&E runs well, X-ray depends on the child friendliness of the staff member, however some are excellent. In terms of lung function testing, the staff member who happens to support Arsenal gets the best lung function results.

Areas for improvement:

- Waiting times for admission.
- Inpatient rooms.
- TVs in rooms have video players but not DVD.
- Nebuliser part cleaning facilities – can take to the kitchen to wash as the mum is reluctant to use the basin in the room; she brings in her own Milton to clean the sink.

Appendix 6

Environmental walkthrough: Outpatients department
Outpatients/CF clinic

	Hospital name	Birmingham 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	Very large waiting area for general outpatients clinics, with separate reception desks. CF patients do not wait; they book in at reception and are escorted straight to a room.
Do patients spend any time in waiting room?	No	CF patients check in and are taken directly to the clinic room; if they were to arrive early they would be sent away or seated in another waiting area.
Is there easy access to toilets?	Yes	Separate male, female and disabled toilets, and baby changing.
Where do the height and weight measurements take place? Is this appropriate?	Yes	In clinic room.
Where are the lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	All rooms are ventilated, have windows to outside and are well equipped.
For annual review patients, are any distractions provided?	Yes	Small number of washable toys, paper and pens. Staff encourage patients to bring their own toys.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Eight patients. Joint diabetic clinic, with own diabetologist and specialist nurses.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get an information pack?	Yes	Information pack provided by adult nurses on first appointment at BCH.

Additional comments

- There are seven rooms for clinic use, plus an office/MDT meeting room. The corridor to the clinic room is large and light, with some artwork and plenty of seating; however, the CF patient would not sit here.

CF and Respiratory Unit

- Also located on the ground floor is the new CF and Respiratory Unit, which opened in October 2013 and is for outpatients only in the day time. This doubles up at night for respiratory sleep studies. Outside the secure entry door are pictures of staff members. This is a three bedded unit for 0–17 year olds, with an office and toilet. The rooms are named Amazon, Everglades and Daintree, and the toilet is called the Swamp.
- The rooms are bright, large and well equipped. One room is used for counselling and newborn babies; after screening, there are two bright comfortable chairs and a cot, and parents are brought here for the first visit after diagnosis.The walls are bare and in need of some artwork, however this is a bright modern area.

Environmental walkthrough: Ward
Ward name: Ward 2 (primary school age)
Microbiology status: General medical

		Hospital name	Birmingham Children's Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Two rooms suitable for CF care.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Total of 12 rooms, including two with en suite facilities suitable for CF.
Number of side rooms?		Two	Not clean, especially shower and washbasin.
Do the en suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Yes	If more than two rooms were required for use, CF patient would have to share bathroom facilities with non-CF patients.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward.)		N/A	Medication is kept in the treatment room. Rooms have a lockable cupboard in the side table for other purposes.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Rooms have TVs and also Starlight TV/games are 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 bed in room. Ronald McDonald house for families and other parent accommodation within the hospital.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	Open to families, restricted to parents at ward rounds and meal times.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Not in rooms, but in parents' room.
What facilities are provided for teenagers?			

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapist can takes patients to gym and outside gardens.
What facilities are there to help with school and further studies?		Hospital school available during term time. Play and youth workers fill in during holidays.
Is there a relatives' room?	Yes	Features seating and tea and coffee facility.
What internet access is there?	Wi-Fi	
What facilities are there to enable students to continue work and study?		Healthcare plans in place, maintaining connection with schools and colleges.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Washer and air dried in room or staff kitchen.
What facilities are provided for those with MRSA?		En suite room, barrier nursed – follow hospital policy.
What facilities are provided for those with *B. cepacia*?		En suite room, planned admittance and isolated from other CF patients.
What facilities are provided for those with other complex microbiology?		Could be taken to negative pressure room in new unit if occurs.
Are patient information leaflets readily available on ward?	Yes	Available on ward and on demand.
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

- Ward 2 is located on the ground floor with security door entry.
- On the day of the visit, the ward appeared cluttered and untidy. There was some artwork on the walls and many noticeboards.
- Touring an en suite room, the shower plughole was dirty – this was discussed with staff. The basin was discoloured due to cleaning materials, which is used to avoid cross infection. It was pointed out that the basin was old and worn. The room was of a reasonable size, however there was no window; the lighting showed a sky scene in place of the window. We were informed that artwork for the wall was in the planning stage.
- Play room: On the day of the visit, the play room appeared very untidy, unclean and run down. The play table was covered in old sticker markings, there were toys scattered about and a general lack of good housekeeping. This was raised with staff members.
- We were informed there were plans in place for a new play room in the near future, and extra housekeeping was being put in place.

- During the peer review process, BCH Trust has recognised that the timescales involved in the building of a new hospital are too long for them not to do anything to enhance the environment and improve the provision of side-room facilities on inpatient wards. They are also aware of the physical restrictions to expansion posed by the current building the wards occupy. As such, and as discussed at the peer review feedback session, the Trust board has approved an outline business case, and will consider a full business case in January 2015 for the development of a new, £35m new build which will remain as a legacy building in the city centre, and will provide the necessary additional space and capacity that the Trust anticipates it will require until a move to a new hospital is possible. As well as providing additional capacity, the new build will provide the space necessary to enable refurbishment of existing CF clinical space, including a review of en suite provision, while ensuring that patients are kept safe throughout. It is anticipated that work will start on this new build in January 2016, with completion by the end of 2016.
- With respect to the cleanliness element, a robust action plan has been developed and implemented by the BCH Trust to address the areas highlighted as inadequate.

Environmental walkthrough: Ward
Ward name: Ward 7 – Older children and adolescents
Microbiology status: General medical

		Hospital name	Birmingham Children's Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	One side room with en suite facilities.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Total of nine rooms and two open bays for general use.
Number of side rooms?		Nine, one en suite	Adequate, with window.
Do the en suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Yes	Could be allocated a bathroom, would not share with other CF patients.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward.)		N/A	Kept centrally, however there is a lockable cupboard in bedside cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Also mobile starlight unit 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	Z bed in room. Ronald McDonald House for families and other parent accommodation within the hospital.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	Open to families. Restricted to others at ward round.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	No fridge; staff will assist parents from the staff kitchen.
What facilities are provided for teenagers?			Adolescent room: Sofa seating, starlight TV/Wii is stored here. Desk and chairs for two and a bean bag. TV, play station games, DVDs, X-Box and music centre. All equipment has to be locked away as there is a problem with theft on the ward. Untidy and unclean at time of visit. A major refurbishment is planned for the adolescent room, which we were shown the plans for. This is due to take place in August.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapist takes patient for exercise to gym or outside area.
What facilities are there to help with school and further studies?		Hospital school, available term time. Play and youth workers fill in at holiday time
Is there a relatives' room?	Yes	Seating, fridge, toaster, microwave, kitchen sink and hand basin, water machine.
What internet access is there?		Wi-Fi
What facilities are there to enable students to continue work and study?		Healthcare plans in place, maintaining connection with schools and colleges.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Basin in room to wash and dry.
What facilities are provided for those with MRSA?		En suite room, barrier nurse and follow policy.
What facilities are provided for those with *B. cepacia*?		En suite room with planned admittance, barrier nurse and follow policy.
What facilities are provided for those with other complex microbiology?		If required, could be housed in new unit – sent to negative pressure room.
Are patient information leaflets readily available on ward?	Yes	General leaflets on walls and on request.
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

- Located on the first floor with security door entry. On first impression, the ward seemed cluttered, shabby and in need of updating – we were advised that it is due to be painted in two years' time and artwork is planned.
- Walls feature noticeboards displaying feedback comments, what they are doing well and what they have done to make things better. Feedback is actioned by the management. There is a feedback/ comments box. There was a ward team noticeboard which is empty of any staff photos or information, awaiting completion.
- Creative station: This is a table with three chairs, in the corridor, where the play therapist takes patients to draw/colour. There are paper crayons/pens available. There is a fish tank, with a fish which has been donated.

	Hospital name	Birmingham Children's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?		See below.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Pharmacy: Space sufficient. On discharge, prescriptions are brought to the patient. Outpatients take prescription to the medicine chest, which is located at the main entrance. Drugs are prescribed here within 10–15 minutes (target 30 minutes). A bleep system is due to start so that patients and parents will be bleeped when the prescription is ready. Radiology and DEXA space are sufficient.
Do patients have to wait at the pharmacy for prescriptions?		No, they return when prescription is ready.
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	
Are there patient comments/feedback boxes?	Yes	

Additional comments

- BCH parking charges: Dropping off period of 10 minutes.
  - Up to one hour = £2.00.
  - Up to two hours = £4.00
  - Up to four hours = £5.00
  - Up to six hours = £6.00
  - Up to eight hours = £8.00
  - More than eight hours = £10.00

- Blue badge holders have to pay if using the hospital car parks.

- Parents of long stay patients can apply for a weekly/monthly pass, which costs £10 per week. There is limited availability and a waiting list.
- Due to the location of the hospital in the city centre and the small number of hospital spaces parents have to use the NCP car parks or pay and display on-street parking (maximum stay two hours = £5.50).
- NCP charges vary, from £1 per hour to £7 for two hours, depending on the location of the car park.
- Medicine chest: This is a private company. There are plans to bring in a bleep system for collection of prescriptions in the near future.

City and Sandwell Hospital (17 patients)

Delivery against professional standards/guidelines not already assessed

Consultants

Areas of good practice:

- Feels very supported by BCH team, regular meetings, reciprocal clinics, good network and support.
- New CF ward link nurse has really improved links with ward, which were previously weaker due to the ward and outpatients being on different hospital sites, five miles apart.
- Improved consultant cover as have second consultant now to cover annual leave as well as visiting BCH consultant for clinics. Clinics consultant delivered.

Areas for improvement:

- Numbers have decreased from 26 patients to 14 because they do not see the newborn screened patients for initial visit. As a result, only a few patients living in their patch want to move care to City and Sandwell once they are used to BCH team. As a network clinic with appropriate guidelines and MDT cover, it would seem appropriate for City and Sandwell to see newly diagnosed newborn screened babies from diagnosis, for babies from City and Sandwell catchment area.
- Joint network MDT clinics need to take place at City and Sandwell Trust, with both the City and Sandwell MDT and the BCH MDT present, to improve communication and joint working and professional development at MDT level.
- Limited access to side rooms with en suite facilities. Patients also need to have the option of a home IV service if appropriate for patient

Recommendations:

- Liaise with BCH network team to develop a pathway that involves City and Sandwell CF MDT in seeing newly diagnosed newborn screened babies from diagnosis, for babies from City and Sandwell catchment area.
- Establish joint network MDT CF clinics at City and Sandwell with BCH consultant, physio, dietitian and CFNS alongside local MDT.
- Provide sufficient side rooms with en suite bathrooms at City and Sandwell to meet the infection control requirements of the CF service specification. Recent national infection control guidance regarding *Mycobacterium abscessus* in CF patients makes this even more of an urgent priority.

Specialist nursing

City and Sandwell is a small centre and therefore the nursing services are covered by BCH. There is a link nurse who liaises with the nursing team at BCH. Inpatients are rare but support from BCH is available both in the hospital and in the community. Transition and newborn screening are done by BCH. The link nurse is a member of the CFNA and attends regular meetings. Cover for leave is provided by BCH.

Areas of good practice:

- Link nurse is experienced and attends educational opportunities to keep up to date.
- Good communication links with BCH.
- Participates in audit.

Areas for improvement:

- This is a small clinic and would benefit from more MDT support from BCH.

Recommendations:

- Because of low numbers, nurse feels that cover may be stopped.

Physiotherapy

There are three physiotherapists working with the 14 patients at this hospital. It is a small team, with staff who know the families very well.

Areas of good practice:

- 100% of patients are seen by a physiotherapist at outpatient clinics and there is cover for annual leave.
- There are strong links with BCH.
- At least one member of staff is able to attend network MDT meetings and local ACPCF meetings, and will feedback to others.

Areas for improvement:

- Patients are only seen by a physiotherapist once a day throughout the week.
- Staffing levels can be a challenge at present, however this will improve when a senior member of staff who will lead the service returns from maternity leave in January 2015.

Recommendations:

- On-call physiotherapy cover is changing to a totally paediatric service, which it is hoped will address shortfalls to weekend treatments.
- Patients need to be seen twice a day during the week and a service review needs to be done to establish how this could be achieved.
- Annual reviews will continue to be done at BCH and a copy of this delivered to the local physiotherapist before the patient's next local appointment.

Dietetics

City and Sandwell nutrition service has no established WTE service provision. Historically, a dietitian attends the monthly Outpatient clinic. Based on 16 patients, the dietetic WTE should be 0.1 WTE. Inpatients are guaranteed a ward review at least once during their admission.

There is no cover for periods of leave. Standards of care cannot be met for inpatients under the current service provision. The current post holder has been unable to attend any CF conferences or local CF meetings, and is not a member of the UK Dietitians Cystic Fibrosis Interest Group. To maintain her CPD, she has shadowed the CF dietitian at BCH in the last 12 months.

Areas of good practice:

- Experienced dietitian who has been in the post for last 10 years.
- Good relationship with CF MDT.
- Good relationship with CF dietitian at BCH.

Areas for improvement:

- All CF inpatients should be reviewed twice weekly.
- The post holder should be given the opportunity and time to attend relevant CF meetings to maintain her CF knowledge and ensure CPD.
- Service provision should be made to allow for leave cover and clinic follow-ups.

Recommendations:

- Establish adequate dietetic funding provision to meet nutritional standards of care for CF inpatients and outpatients, as well as leave cover (0.1 WTE).
- Develop shared care network clinics with specialist BCH dietitian alongside nutrition guidelines, protocols and resources for network clinics.
- Dietitian to join UK Dietitians Cystic Fibrosis Interest Group and attend CF meetings to ensure adequate CPD in CF nutrition.

Pharmacy

Number of patients: 14
Pharmacist time dedicated to CF: 0 WTE
Cystic Fibrosis Trust's Standards of Care recommendation: 0.1 WTE

- Pharmacist is not able to attend relevant UK CF specialist interest group meetings annually.
- Weekly attendance of ward rounds, but no specific MDT meeting attended due to low numbers (though generally good communication with the medical team).
- Ward cover available in absence, junior rotational pharmacist.
- They have not attended any European or international CF conference/study days.
- They have not been involved in any CF team audits/research.
- No particular involvement in key life stages for those with CF.

Areas of good practice:

- Good inpatient service provision, ward round attendance and good communication with BCH specialist pharmacist.

Areas for improvement:

- Increased pharmacy service provision to outpatient clinics (minimum standard involvement in annual review), and attendance at UK CF specialist interest group meetings. However, staffing levels only adequate for current level of service provision – any additional services would require funding.

Recommendations:

- Attend annual UK CF specialist interest group meeting.
- Increase involvement with the MDT and outpatient annual review clinics if funding allows.

Please refer to the BCH section for:

- Psychology
- Social work

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

City and Sandwell 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	Correspondence could be more timely.

2 Multidisciplinary care

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

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	Samples are processed at the local lab, which is aware of the Cystic Fibrosis Trust's Standards of Care and sends any queries to Colindale PHL Reference labs.
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	Only one patient – who is seen in the combined CF/ diabetes clinic at Birmingham Children's Hospital.

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	While side rooms are always available, they are not always en suite.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	N/A – clinic size too small	N/A	
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 Compli-cations	% of 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	This is not in concordance with the Cystic Fibrosis Trust's Standards of Care and needs urgent review.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	BCH	Amber	The recording and responsibility for this discussion needs to be clarified to ensure it occurs.
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%	BCH	Amber	May achieve one pre-transition, not meeting Cystic Fibrosis Trust's Standards of Care.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consult-ations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Red	Red	Patients are given the appropriate information and referred to the social worker as necessary.
	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% 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	Red	Patients are only seen by a physiotherapist once a day during the week – needs addressing.
	% 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%	? Being assessed	Red	Only occurs once a week – needs addressing.
	% availability of clinical psychologist at clinic	100%	Red	Red	
	% availability of clinical psychologist for inpatients	100%	Green	Green	
	% availability of social worker at clinic	100%	Red	Red	Need a way for families to access social work support.
	% availability of social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	Green	Currently no families doing home IVs, but this facility and training is available for willing families.
4.4 End-of-line care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	None	None	
5.2	Number of clinical incidents reported within the past 12 months	<1%	1	1	
5.3	User survey undertaken a minimum of every three years	100%	Red	Red	User survey required.
5.4	Service level agreements in place for all	100%	Green	Red	Not yet signed.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	City and Sandwell Hospital
Consultant 1	0.5	1	1	1.5 PA
Consultant 2	0.3	0.5	1	0.75 PA
Consultant 3			0.5	One session a month
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	One session a month
Physiotherapist	2	3	4	One PA a month
Dietitian	0.5	1	1.5	One PA a month
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	No fixed PA
Secretary	0.5	1	2	One clinic a month

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 City and Sandwell Hospital	
Number of active patients registered (active being patients within the last two years)	17
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	17
Median age in years of active patients	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	2 (11%)
	4–7 years	3 (17%)
	8–11 years	4 (24%)
	12–15 years	4 (24%)
	16+ years	4 (24%)

Genetics	
Number of patients and % of unknown genetics	1 (6%)

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)			
		Male	Female
Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	2 (67%)
	12–15 years	1 (50%)	0
	16+ years	1 (50%)	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	2
	4–7 years	3
	8–11 years	4
	12–15 years	4
	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	0
	16+ years	0
***Burkholderia cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	1 (6%)	
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 (6%)
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 transplantation assessment in reporting year	0
Number of patients referred for transplantation 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	46
	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	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	46
	16+ years	14

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	n=10; 4 (40%)
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 (6%)
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

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate the following:

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

How would you rate the overall care?

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

Comments about CF team/hospital

Very good hard working team.

People with CF need to be given a better variety of food, not just sandwiches for lunch.

Patient/parent interviews

No patient interviews – no phone numbers submitted.

	Hospital name	City Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Seating for 30+. Large play area, well equipped with toys.
Do patients spend any time in waiting room?	No	Patients do not wait in waiting area. They check in and go directly to the clinic room.
Is there easy access to toilets?	Yes	M/F toilets and baby changing room.
Where do the height and weight measurements take place? Is this appropriate?	Yes	Separate room, well equipped. Patients taken here on arrival, then taken to clinic room.
Where are the lung function tests done for each visit?		All clinic rooms have equipment for testing.
Are clinic rooms appropriately sized?	Yes	Three rooms and staff meeting room. All rooms are a good size, fully equipped, bright with seating and toys. All have cleaning/ sanitising and sinks. Each room has a trolley outside with a patient check list. The team in turn rotates the patient room.
For annual review patients, are any distractions provided?	Yes	Toys in rooms and access to play therapist.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	One patient – is seen at combined clinic at BCH.
Transition patients – can they get tour of outpatients' facilities?	Yes	If required for new patients/parents.
Transition/new patients – do they get an information pack?	Yes	Information available.

Additional comments

- Situated on a new site that opened eight years ago. There are two entrances to the ground floor large reception area, one from the main road and one from the car park at the rear. Good, clear signage to paediatric outpatients' clinic, which is also situated on the ground floor.
- Clinics are held monthly and nine patients attend each clinic with staggered appointments. There are two exits from the clinic for cross-infection purposes.
- Patient notes are kept at clinic, locked away. Notes can be transferred across to Sandwell Hospital, which is five miles away; there are also electronic notes/letters available.
- There is a bus shuttle service to Sandwell Hospital every 30 minutes.

- Transition starts at 16 years old after school exams.
- Treatment room: For bloods, mobile on ceiling for distraction.
- Medical assessment unit: Two beds. Not generally used for CF but available if required.
- Interview room: For general use.
- MDT meeting room: For team meetings at clinic.

Environmental walkthrough: Ward
Ward name: Lyndon 1 (under 12 years)
Microbiology status: General

		Hospital name	Sandwell Hospital – 13 patients (one inpatient)
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Total of 13 side rooms. Three are suitable for CF care.
Number of side rooms?		3	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Two rooms have a shower, one has a bath.
Do CF patients have to share any bathroom facilities?		No	Due to low patient numbers, this has never been an issue as only one patient comes into hospital.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward.)		Yes	This is controlled by staff; drugs are stored in a locked trolley.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	TV available in rooms 7am to 7pm. Starlight TV with games (DVD, Wii) facility can be wheeled into rooms.
If no, are there any concessions for CF patients?		NA	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	All rooms have Z beds. The larger rooms are generally used for CF, due to a longer stay. A full size bed is put in the room for parents.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	Open to parents. Extended family can visit 10am–7pm, however, can be flexible.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Not in side rooms, but in patient room.
What facilities are provided for teenagers?			See Lyndon Ground Ward (adolescents).

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapy twice daily. Therapist can take child to gym. Equipment is not left in rooms.
What facilities are there to help with school and further studies?		Two teachers available, contracted from James Brindley school.
Is there a relatives' room?	Yes	Microwave, kettle, tea and coffee, fridge and sink.
What internet access is there?	None	None at present, this is planned for the near future.
What facilities are there to enable students to continue work and study?		Classroom in Lyndon Ground Ward. Teachers take students to morning school if they're well enough, for two hours per day. Open hours are 9am–1pm. The school room is well equipped with two computers with internet access. Desks and chairs for four. A laptop has been ordered for use in patient rooms.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in room.
What facilities are provided for those with MRSA?		Own room. Follow guidelines.
What facilities are provided for those with *B. cepacia*?		Own room. Follow guidelines.
What facilities are provided for those with other complex microbiology?		Own room. Follow guidelines.
Are patient information leaflets readily available on ward?	Yes	Specific leaflets are printed on demand.
Transition patients – can they get a tour of ward facilities?	Yes	New patients could get a tour if required.

Additional comments

- The ward is situated on the first floor. There is a noticeboard showing pictures of all staff members. The ward is decorated with bright ceiling-hanging decorations promoting 'change for life'.
- Patients will be able to use the outside play area on the ground floor when completed, if escorted by parents.

Environmental walkthrough: Ward
Ward name: Lyndon Ground (adolescents) 12+
Microbiology status: General

		Hospital name	Sandwell Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Eight rooms total.
Number of side rooms?		One	Suitable for CF.
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	Due to very low patient numbers, this has never been an issue as only one patient comes into hospital. Other rooms could be used if needed.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward.)		Yes	Controlled by staff, locked in trolley.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free 7am–7pm. Tokens can be purchased. There is also a TV in the adolescent room.
If no, are there any concessions for CF patients?		No	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Z bed in all rooms, larger beds put in rooms for longer stays.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open for parents. Extended family can visit 10am–7pm, but can be flexible.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Parents' kitchen.
What facilities are provided for teenagers?			Teenage area with TV, seating and football table.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapy once daily. Therapist can take child to gym. Equipment is not left in rooms.
What facilities are there to help with school and further studies?		Two teachers available, contracted from James Brindley school.
Is there a relatives' room?	Yes	Microwave, kettle, tea and coffee, fridge and sink.
What internet access is there?	None	None at present, this is planned for the near future.
What facilities are there to enable students to continue work and study?		Classroom Lyndon Ground Ward. Teachers take students to morning school if well enough, for two hours per day. Open hours 9–1pm. The school room is well equipped with two computers with internet access. Desks and chairs for four. A laptop is on order for use in room.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in room.
What facilities are provided for those with MRSA?		Own room. Would follow guidelines.
What facilities are provided for those with *B. cepacia*?		Own room. Would follow guidelines.
What facilities are provided for those with other complex microbiology?		Own room. Would follow guidelines.
Are patient information leaflets readily available on ward?	Yes	Specific leaflets are printed on request.
Transition patients – can they get a tour of ward facilities?	Yes	New patients could get a tour if required.

Additional comments

- Lyndon Ground (+12 years) and Lyndon 1 (0–12 years) were reconfigured in 2012 and more side rooms were created out of offices.
- There is child-orientated artwork on walls and a noticeboard for patient/parent information about the ward.
- The two patients who stay in as inpatients are one adolescent and an under 12 year old, they never come into contact due to the separate wards.
- Kitchen: Where snacks are prepared. The children have a sandwich lunch and an evening meal. Vouchers are issued for extra food, using a sticker. Patients can then go to the restaurant and get whatever they want.
- Treatment room: Features distractions, can be used if required.
- Medication dispenser: Soon to be in use. This has locked drawers and will dispense drugs individually. It is controlled by a member of staff swiping their ID card to activate.

- Outside play area: In the process of converting a large fenced, paved and covered area outside the ward. Plans have been agreed for a sensory area, adolescent area, general play area and family area with tables and seating.
- A new hospital is planned: Midlands Metropolitan Hospital. The site for this is at the demolition stage and planned for completion in 2018.

	Hospital name	City Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	If clinic was delayed, a token could be issued for free parking.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	To unit.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Parents are encouraged to use the community pharmacy – the hospital has an arrangement with GPs for reimbursement. Unlikely to meet due to low number of patients. Radiology – by appointment. DEXA – at BCH.
Do patients have to wait at the pharmacy for prescriptions?	No	
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	Very large patient support centre on ground floor, near hospital reception area. This has a reception, seating and large selection of general leaflets.
Are there patient comments/feedback boxes?	Yes	On wall at patient support centre.

Additional comments

- Patient satisfaction surveys are carried out periodically. This has been delayed and the next one is due within the next month.
- The hospital Trust carries out an annual survey.

	Hospital name	Sandwell Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Drivers can purchase parking tickets. £10 for four visits of any length of time in one day.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		N/A
Do patients have to wait at the pharmacy for prescriptions?		N/A
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	Leaflets on walls at ground floor entrance – clearly visible.
Are there patient comments/feedback boxes?	Yes	On wall.

Additional comments

- There is an electronic bus service information board showing next bus times and routes. Paper bus timetables are also available.

University Hospital Coventry (45 patients)

Delivery against professional standards/guidelines not already assessed

Consultants

Areas of good practice:

- Coventry physio staffing improved since last peer review: now are present in clinic and on ward at least once a day. Good inpatient and outpatient facilities.
- Lead consultant is two PA, very experienced in CF, and second consultant is 0.5 PA, so appropriate and offers cover for holidays etc. Newborn screened newly diagnosed patients seen from diagnosis or soon after by well-established and experienced Coventry team. User survey emphasised excellent clinical care and excellent hygiene and cross-infection precautions. Excellent facilities on environmental walk-through.
- Community CFNS service highlighted by service users as a particular strength of service.

Areas for improvement:

- The CF specialist nurse role is delivered by Community Trusts. One in Coventry, one in Warwickshire. Two very good individuals, a real backbone of service, not clear how they will be funded under new arrangements.
- Joint network MDT clinics need to take place at Coventry, with both Coventry MDT and BCH MDT present, to improve communication and joint working and professional development at MDT level.
- An urgent audit needs to be performed of chronic Pseudomonas infection rates at Coventry, as 2012 Port CF UK Registry data suggests rates of 27% at this site, whereas the national average is 12.5%. Initial discussion with the site suggests this may be due to misclassification at data entry stage, but this needs to be urgently evaluated. Initial audit of 2013 data conducted before this report was finalised suggest actual rates of chronic Pseudomonas of around 5%, which is below national average.

Recommendations:

- Clarify and secure ongoing CF nurse specialist role in order to retain these experienced and valued individuals, who offer a quality and highly valued service.
- Establish joint network MDT CF Clinics at Coventry with BCH consultant, physio, dietitian and CFNS, alongside local MDT. Consideration of succession planning for the senior experienced CF consultant needs to commence, particularly given the size and complexity of the caseload. CF dietitian time needs to be increased from 0.1 WTE to 0.29 WTE.
- Urgent audit of actual chronic Pseudomonas rates at Coventry. If the rates are indeed high, then appropriate interventions and ongoing, rigorous specific audit/root cause analysis should be considered. This action point has already been completed be the time of the final report and the actual rates in 2013 are below national average, which is excellent.

Specialist nursing

There are currently 45 patients at UHC and 1 WTE nurse, which meets current guidelines. Annual reviews are done at Birmingham. Newborn screening is done at BCH and introduced to the team a few months later. The nurse is based in the community, but has a link nurse on the inpatient ward. There is cover for leave. Transition and end-of-life care are managed at UHC with input from BCH. The nurse is a member of the CFNA and attends local and regional meetings.

Areas of good practice:

- Takes part in audit and research.
- Good communication with BCH.

Areas for improvement:

- Would benefit from using standardised guidelines and protocols.

Recommendations:

- Create more educational opportunities for link nurse.

Physiotherapy

The patients who attend this hospital are served by two 0.5 WTE Band 6 physiotherapists, and one 0.5 WTE Band 5 physiotherapist. Their roles do not have any dedicated CF time and also cover other aspects of paediatrics.

Based on the Cystic Fibrosis Trust's Standards of Care, 1 WTE would be the advised level of CF staffing, which is less than they have, but managers were unable to quantify exact funding levels.

They are covering for maternity leave which is due to end in September. The present members of the team are enthusiastic about their role and are keen to increase their knowledge by working with the team at BCH.

Newly diagnosed babies are not seen locally but go the BCH for their first few visits.

Areas of good practice:

- 100% of patients are seen by a physiotherapist at outpatient clinics and there is cover for annual leave.
- They are able to do community visits to patients on home IV antibiotics, when necessary.

Areas for improvement:

Inpatient physiotherapy treatment

- Patients are only seen by a physiotherapist once a day during the week and there is no routine physiotherapy treatment for CF patients at weekends. Exception to the above standard would only be for those patients who are struggling with their airway clearance. The risk matrix is therefore only 40% cover for inpatients

Inpatient monitoring

- Lung function monitoring is not completed during a course of IV inpatient treatment and there is no clear plan to monitor sputum samples during admissions. Also, there is limited access to exercise facilities.

Recommendations:

- Dedicated CF time for senior members of staff equating to 1 WTE.
- Increase the frequency of inpatient physiotherapy in order to reach the required standard of twice daily treatments throughout the week, by a review of the service and also education of the whole physiotherapy team as to the need for more frequent treatments.

Dietetics

Historically this post has 0.1 WTE funding to attend the weekly CF clinic and reviews CF IPs weekly, or more if necessary. Based on 43 patients, the staffing level should be 0.29 WTE. There is no leave cover. The dietitian attends CF MDT meetings and will discuss CF IPs with the consultant. Due to funding and cover issues, the dietitian has found it difficult to attend CF meetings and maintain CPD in this area. The dietitian is in the process of joining the UK Dietitians Cystic Fibrosis Interest Group. The dietitian does not attend transition clinics but will contact the adult dietitian to hand over patients. There have been a lot of complaints about the hospital food and many CF patients bring in their own food.

Areas of good practice:

- Dedicated dietitian with 20 years' experience in CF nutrition.

Areas for improvement:

- Inpatient standards are not being met as all patients should be reviewed twice weekly.
- There is no cover for leave.
- Improved ward food provision for CF patients.

Recommendations:

- Establish adequate WTE dietetic provision (0.29WTE) to meet the Cystic Fibrosis Trust's Standards of Care for inpatients and outpatients.
- Ensure dietitian joins UK Dietitians Cystic Fibrosis Interest Group and attends CF meetings to improve CPD.
- Develop shared care network clinics with specialist BCH dietitian as well as nutrition guidelines, protocols and resources for network clinics.

Pharmacy

Number of patients: 43
Pharmacist time dedicated to CF: Approximately 0.25 WTE
Cystic Fibrosis Trust's Standards of Care recommendation: 0.3 WTE

- Pharmacist is able to attend relevant UK CF specialist interest group meetings annually.
- Does not attend MDT meetings or ward rounds.
- Ward cover available in absence, provided by junior rotational pharmacist.
- Has only attended CF pharmacist group meeting.
- The pharmacist has not been involved in any CF team audits/research.
- No particular involvement in key life stages with those with CF.

Women and children pharmacist covers CF, however, there is no specific time assigned to CF (estimated 0.25 WTE spend on CF); backup is provided by junior pharmacists and in contact with BCH pharmacist in case of queries.

Provides inpatient ward cover Monday to Friday but is not involved in education/counselling of patients and does not attend MDT meetings. Currently there is no pharmacy service provision to outpatient clinics, and no particular audits or research in this area. No regular financial reporting, but will respond to particular queries.

Areas of good practice:

- Good inpatient service provision.
- Attends relevant annual meeting.
- Member of the CF pharmacist group.
- Good connection to BCH specialist pharmacist.

Areas for improvement:

- Attend MDT meetings.
- Increase pharmacy service provision to outpatient clinics (minimum requirement attendance of annual review clinics).
- Increase contact with patients.
- Staffing levels only adequate for current level of service provision, any additional services would require funding.

Recommendations:

- Increase involvement with the MDT and patients and attend annual review clinics.

Please refer to the BCH section for:

- Psychology
- Social work

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

University Hospital Coventry

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. See BCH.	Red	<90% of UHC patients seen at BCH for annual review.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Red. See BCH.	Red	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Red. See BCH.	Red	<90% of UHC patients seen at BCH for annual review.

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. See BCH.	Red	Need to establish joint network MDT CF clinics at Coventry and ensure all patients get annual review.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Safe, Yes.	Yes	Dietitian time needs increasing. Nurse specialist position needs protecting.
	% 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 CF 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%	Amber	Amber	Network guidelines need developing.

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

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Compli-cations	% of 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. Not routinely.	Red	Needed to meet Cystic Fibrosis Trust's Standards of Care.
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. Not routinely.	Red	Needed to meet Cystic Fibrosis Trust's Standards of Care.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consult-ations	% 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	Parent interview indicates physio on maternity leave so not seen – this will be remedied in September.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Inpatient cover meets only approx. 40% of requirement, patients only seen once a day during the week.
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	Dietitian time needs increasing from 0.1 to 0.29 WTE for 45 patients.
	% availability of clinical psychologist at clinic	100%	Red	Red	Better access to psychologist required.
	% availability of clinical psychologist for inpatients	100%	Red	Red	Better access to psychologist required.
	% availability of social worker at clinic	100%	Red	Red	Better access to social worker required.
	% availability of social worker for inpatients	100%	Red	Red	Better access to social worker required.
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-line care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	University Hospital Coventry
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	16 PA
Physiotherapist	2	3	4	3.5 PA
Dietitian	0.5	1	1.5	2 PA
Clinical psychologist	0.5	1	1.5	As needed
Social worker	0.5	1	1	As needed
Pharmacist	0.5	1	1	0.25 PA
Secretary	0.5	1	2	0.5 PA
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)

CF Registry data – 2012	
Demographics of University Hospital Coventry	
Number of active patients registered (active being patients within the last two years)	47
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	47
Median age in years of active patients	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	8 (17%)
	4–7 years	5 (11%)
	8–11 years	13 (28%)
	12–15 years	12 (26%)
	16+ years	9 (18%)

Genetics	
Number of patients and % of unknown genetics	3 (6%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	n=4; 3 (75%)

FEV_1 (ref: 1.14 Annual Data Report 2012)			
		Male	Female
Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
	4–7 years	0	0
	8–11 years	1 (17%)	4 (50%)
	12–15 years	1 (17%)	3 (38%)
	16+ years	4 (66%)	1 (12%)

Lung infection (ref: 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	8
	4–7 years	5
	8–11 years	13
	12–15 years	12
	16+ years	9
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	1
	8–11 years	4
	12–15 years	5
	16+ years	3
***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	2 (4%)	

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	2 (4%)
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 transplantation assessment in reporting year	0
Number of patients referred for transplantation 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	78
	4–7 years	25
	8–11 years	251
	12–15 years	109
	16+ years	81
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	155
	12–15 years	65
	16+ years	159
Total number of IV days split by age group	0–3 years	78
	4–7 years	25
	8–11 years	406
	12–15 years	174
	16+ years	240

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	n=26; 13 (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	13 (28%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	7 (54%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	4 (8%) with chronic PA; 8 (17%) without chronic PA

Patient survey

University Hospital Coventry

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	8	3	0	0
Communication	6	5	0	0
Out-of-hours access	5	4	1	1
Homecare/community	10	1	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	5	6	0	0
Waiting times	4	6	1	0
Cross-infection/segregation	9	2	0	0
Cleanliness	8	3	0	0
Annual review process	5	2	2	0
Transition	1	1	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	4	4	0	1
Cleanliness	6	2	1	0
Cross-infection/segregation	8	1	0	0
Food	2	3	2	2
Physiotherapy availability to assist/ assess airway clearance and exercise on weekdays	3	3	2	0
Physiotherapy availability to assist/ assess airway clearance and exercise at weekends	1	1	2	2

How would you rate the following:

	Excellent	Good	Fair	Poor
Home IV antibiotic service	3	2	0	0
Availability of equipment	4	3	2	1
Car parking	0	2	6	2

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	9	2	0	0
Of the ward staff	7	1	1	0
Of the hospital	7	3	1	0

Comments about CF team/hospital

The care/support we have received from UHCW has been excellent. We have had amazing support from our community nurse and consultant. We have been lucky enough not to need inpatient care. We have also had great experience with the staff at Birmingham Children's Hospital. Thank you.

On our last clinic to BCH – waiting times had improved considerably but prior to that it was always a long, drawn-out experience. We also have very poor written communication, either waiting months for a report or not even receiving one from previous visit. UHCW compared to BCH – the physiotherapy care is less experienced and consistent and parking is always an issue.

Coventry CF team are brilliant really happy with them.

The CF team here are very helpful no matter what the issue or questions. All CF nurses are easily contactable whenever a problem arises. Admissions are always done around family plans when needed.

We mainly deal with Coventry University Hospital and our CF nurse, who are excellent. We find Birmingham is also great with his care; we are pleased with the care we receive.

Walsgrave is good for my son – we know all the team and it is friendly and helpful. Birmingham is the opposite.

Patient/parent interviews

Parent G (BCH/Coventry shared care)

Areas of good practice:

- Very good care from Warwickshire CF community nurse in local area.
- Very good CF team at Coventry – son hates needles and staff are very understanding and supportive. Adolescent unit needs a qualified person to insert IV line though.
- Coventry outpatient clinic: Normally okay. There quite a while, but staff are supportive and try to speed things up as child has panic attacks (child has special needs).
- Happy with cross-infection guidelines and segregation measures at Coventry outpatient clinics.
- Normally sees whole CF team at outpatients (Coventry) – usually a physiotherapist there, always CF nurse and dietitian. Sees Dr Simmonds more often, sometimes sees Dr Lewis.
- Community nurse Yasmin or CF nurse Kay will support DLA queries/application.

Areas for improvement:

- Food on ward at Coventry: Menu very limited – food on hospital menu is not what son would eat, although quantity and quality is good.

  Note: Father attends Birmingham Children's Hospital with son – father unavailable for comment at time of interviews.

Parent H (BCH/Coventry shared care)

Areas of good practice:

- Coventry: Efficient team and outpatient clinic, continuity is good (ie centre care and good shared care team), happy with segregation measures at Coventry clinic, good communication from team (ie X-ray results, community nurse with cough swabs).
- Sees doctor, CF nurse and dietitian at each Coventry clinic, but physiotherapist not always available. (Coventry). Physiotherapist on maternity leave, so child does not see a physio at each clinic.
- BCH: Excellent, experienced physiotherapist. New outpatient system of patient going straight into consultancy room and staying put, which is far better.
- Feels reassured by CF team's experience and knowledge; good clinical decisions and certainly physiotherapy treatment advice.
- Mother/son visit BCH specialist centre every six months.

Areas for improvement:

- BCH outpatient clinic not efficient for many years – sent from pillar to post, clinic didn't flow and a lot of waiting around – "it seems a bit disorganised". However, new system of patient going straight into consultancy room and staying put is far better.
- Written post-clinic reports from BCH are delayed. After last two outpatient clinics, there was no follow-up report.
- Communications: Sharing of information between BCH and Coventry network clinic is inconsistent.
- BCH: Shared ward (bays) with curtain between patient beds.
- Other info: This child does not received IVs pre-mixed; mother has to mix the IVs after portacath is accessed and first IV antibiotic dose given on the ward.

Parent K (BCH/Coventry shared care)

Areas of good practice:

- Mother was pleased with the CF team/care at BCH. They're directed straight into a consultancy room at outpatient clinic, clinic runs smoothly and her questions are answered well by the CF team. She said she can call the CF nurse whenever needed. Her experience of her daughter's inpatient stay on the ward was okay; the ward staff were very helpful. On the ward her daughter had her own side room, but had to share a bathroom.
- Mother stated she only attends BCH twice a year, including once for annual review, which she says runs well.
- Her daughter receives most of her care at Coventry, from Dr Simmonds' team. She sees a physiotherapist at each clinic appointment. Both the physiotherapist and dietitian give good advice according to patient's mother, who added that the dietitian is great. She is very impressed by the care and facilities at Coventry; on the ward her daughter had her own en-suite side room when she was two months old.
- Mother felt that communications between BCH and Coventry and her was generally good.

Areas for improvement:

- She did not have any comments to make here.

Parent L (BCH/Coventry shared care):

- Coventry: Mother referred to an “amazing” community nurse “who has been my lifeline”. Mother can phone or text the community nurse for support. She referred to the CF team as “brilliant”. She mentioned very good advice given by the CF team; dietitian regularly available and a lot of advice from the community nurse, including physiotherapy guidance. She felt that outpatient appointments can take a while, but said she understood the reasons why. At clinic, mother explained that hygiene/infection and segregation are “top notch”. They see a physiotherapist at the majority of CF outpatient clinics and she felt the physiotherapy support on the ward was “brilliant”.
- Her daughter had a recent stay on the ward. She felt the ward nurses/staff understood CF well and she was pleased with the cleanliness of the ward. She explained a misunderstanding at first, which made her uneasy, where the ward doctors didn’t understand the medications required, so she felt she was telling the doctor what to do.
- Mother had no suggestions for improvements to the service.

	Hospital name	University Hospital Coventry
	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	Three rooms.
Do patients spend any time in waiting room?	Yes	However, never more than one patient waits in any of the three separate waiting areas at any one time.
Is there easy access to toilets?	Yes	Unisex, disabled and baby changing.
Where do the height and weight measurements take place? Is this appropriate?	Two height and weight rooms	Babies measured in individual clinic rooms, all cleaned and wiped after use.
Where are the lung function tests done for each visit?		In clinic room, one spirometer and a lung function laboratory.
Are clinic rooms appropriately sized?	Yes	Large, well-equipped, bright, clean and airy.
For annual review patients, are any distractions provided?	No annual reviews undertaken and therefore no distractions provided.	Mainly go to BCH. No exercise shuttle walks done at present at Coventry.
If diabetics are seen outside of CF clinic, is the area and facilities appropriate for CF care?	2/44 patients diabetic. Seen in CF clinic at BCH 2 and Coventry 2.	Continuous glucose monitoring performed at Coventry. Work closely with two diabetologists and four diabetic nurses, who see patients in clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	

Additional comments

- On arrival at main reception, a friendly volunteer directed me to the CF clinic.
- Outpatients is clean, bright, airy and well decorated. It is a welcoming area with friendly, helpful reception staff and nurses.
- Considering 'Ready, Steady, Go' transition and also discussed input from dental services.

Environmental walkthrough: Ward
Ward name: Ward 14 (adolescent unit), Ward 15 (0–2 years and HDU) and Ward 16 (2–12 years)
Microbiology status: All microbiology (no *B. cepacia, M. abscessus*, or MRSA in clinic)

		Hospital name	University Hospital Coventry
		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.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Maximum three inpatients at any one time.
Number of side rooms?		Ward 14: Four Ward 15: Six Ward 16: 10	Each ward has a negative pressure room.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	All have showers.
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 until 7pm, TV then available in playroom or can watch DVDs.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?			Paediatric wards 15 and 16 have pull-out beds. Ward 14 has parent beds available.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open visiting	Parents have open access, including during protected meal times.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Fridges in some rooms and microwave and fridge available in kitchens.
What facilities are provided for teenagers?			Adolescent unit and chill-out room. Pool table, Wii, Wi-Fi, laptops. Aware of cross infection.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Swiss ball and mini trampette for rooms. Small physio room with equipment.
What facilities are there to help with school and further studies?		School teachers and classroom or can work in rooms. Parents bring in schoolwork and teachers liaise with school and parents.
Is there a relatives' room?	Yes	Relatives' day rooms and two separate overnight rooms with showers attached to HDU.
What internet access is there?	Wi-Fi	Mobile phone reception poor in some areas of hospital.
What facilities are there to enable students to continue work and study?		Staff are flexible and work around school and college or exams.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Bowls given and parents encouraged to bring in own sterilising equipment.
What facilities are provided for those with MRSA?		No patients at present. Barrier nurse and negative pressure available.
What facilities are provided for those with *B. cepacia*?		No patients at present. Barrier nurse and negative pressure available.
What facilities are provided for those with other complex microbiology?		No patients at present. Barrier nurse and negative pressure available.
Are patient information leaflets readily available on ward?	Yes	On ward, in clinic and can be printed off on request.
Transition patients – can they get a tour of ward facilities?	Yes	Transfer at 17 and transition starts at 13 with encouragement towards independence. Fertility and contraception talks. Visit Heartlands Hospital twice with patient and Heartlands team visits paeds hospital once. Staff from Coventry accompany patients to first Heartlands visit after transition.

Additional comments

- The ward is bright, clean and modern with welcoming, friendly staff. It is well equipped and has a lovely play area and outside garden, which is utilised by play specialists from each ward. Play therapists also provide distraction therapy for procedures.
- Coventry CF patients are currently allocated to a generic nurse, as CFNS is on long-term leave. Recruitment to cover this absence has been agreed. Warwickshire CF patients have their own CF community nurse who is helping to cover the Coventry patients during this time.
- Excellent communication with CF team at BCH was reported. However, letters from BCH are slow due to a lack of administrative staff. Parents would appreciate a named consultant at BCH.
- All parents receive timely letters from clinics and discharge at Coventry.

	Hospital name	University Hospital Coventry
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free parking for parents staying overnight. Free parking for those on benefits. Anyone staying a week gets a free pass.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Assistant at main reception to answer questions and direct people.
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. Parents get a bleeper from the pharmacy when they drop in prescriptions; they can then go to the shops or cafes and are bleeped when prescriptions are ready. Slots are booked for X-ray and lung function so no waiting here either.
Do patients have to wait at the pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	
Are there patient comments/ feedback boxes?	Yes	Monthly feedback displayed on wards.

Birmingham Heartlands and Good Hope Hospital (HEFT – 43 patients)

Delivery against professional standards/guidelines not already assessed

Consultants

Areas of good practice:

- Onsite adult team is a real strength with good links, good transition set-up and homecare benefits.
- Recent increase in nursing, physio and dietetic time – so strong MDT. Enthusiastic consultant with three PAs for cystic fibrosis. User feedback very positive about lead consultant and MDT.
- CPD improving, CF nurse going to ECFC this time, aim for one member of team each year. Good links at clinician level with BCH, lead clinician involved in BCH CF clinics.

Areas for improvement:

- Joint network MDT clinics need to take place at the Heart of England Trust, with both Heart of England MDT and BCH MDT present, to improve communication and joint working and professional development at MDT level.
- Only 20% of admissions have en suite facilities in single rooms. Inpatient facilities for CF patients at Heart of England do not meet pages 9, 13, and 15 of the National CF Service Specification with regard to the provision of side rooms with en-suite bathroom facilities. This is an important infection control priority for CF inpatients and is a major concern in the service user survey for Heart of England site. Patient survey suggests cross-infection/segregation procedures could be improved for inpatients and outpatients at Heart of England. 2012 Port CF UK Registry data suggests chronic *Pseudomonas* infection rates of 31% at Heart of England, whereas the national average is 12.5%. Initial discussion with site suggests this may be due to misclassification at data entry stage, but this needs to be urgently evaluated.
- As a network clinic, it would seem appropriate for Heart of England to collaborate with the BCH team to work towards them seeing newly diagnosed newborn screened babies from diagnosis (for babies from Heart of England catchment area), once guidelines are agreed and Heart of England experience and cover is appropriate.

Recommendations:

- Establish joint network MDT CF clinics at Heart of England with BCH consultant, physio, dietitian and CFNS, alongside local MDT.
- Provide sufficient side rooms with en suite bathrooms at Heart of England to meet the infection control requirements of the CF Service Specification. Recent national infection control guidance regarding *Mycobacterium abscessus* in CF patients makes this even more of an urgent priority. Urgent audit of actual chronic *Pseudomonas* rates at Heart of England and, if the rates are indeed high, then consider appropriate interventions and ongoing rigorous specific audit/root cause analysis. (Subsequent to the peer review visit but before finalisation of this report, this audit was conducted, showing that rates of chronic infection at Heart of England Trust are above expected at 25% (three respiratory samples positive for PA in last 12 months, with no minimum

gap between samples). The rates have been stable for the last three years. An action plan has been formulated in conjunction with microbiology and disseminated. It includes a reminder to all inpatient and outpatient staff of infection-control policy, allocating inpatient bathroom facilities so no two CF patients share, following all infection control/isolation recommendations contained in the peer review report, and subtyping of all PsA positive samples to inform further root cause analysis. A more detailed report and action plan is available. Yearly re-audit is recommended and any further increase in prevalence of chronic *Pseudomonas* at Heart of England prior to the next peer review should be reported immediately to the local Commissioner and the National Clinical Reference Group for Cystic Fibrosis.)

- Liaise with the BCH network team to develop a pathway that involves Heart of England CF MDT in seeing newly diagnosed newborn screened babies from diagnosis (for babies from Heart of England catchment area).

Specialist nursing

- Heartlands Hospital has 1 WTE for 43 patients so complies with the Cystic Fibrosis Trust's Standards of Care. The nurse belongs to the CFNA and attends national and international meetings. Cover is available for leave by the respiratory nurse. The nurse participates in audit and research. The nurse is involved in the transition process to the Heartlands adult unit. End-of-life care and transplants are directed by the BCH team. Newborn screening is managed by BCH. The nurse is involved with research and audit.

Areas of good practice:

- Experienced nurse with good communication at BCH.
- The nurse is a prescriber and able to support home IV therapy.
- Transition clinics with adult unit on same site.

Areas for improvement:

- Would benefit from formalised annual review.
- Would benefit from a more formal educational remit for ward staff.

Recommendations:

- Standardised protocols and policies with BCH.

Physiotherapy

- There is a newly established post at this hospital – a Band 7 physiotherapist 1 WTE, which is adequate for the number of patients cared for here. The induction process has been completed and the team is now able to address development of the service.
- There are strong links with BCH, which will facilitate education and service development.
- Opportunities exist to attend Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) study days as well as local ACPCF meetings and MDT network meetings.

Areas of good practice:

- Daily frequency of inpatient physiotherapy treatments meet the required ACPCF standards.
- The team attends ward rounds and MDT meetings, and there are very good inpatient exercise facilities.
- Transition arrangements and support are good, helped to a degree by the hospital's close proximity to the adult CF unit.

Areas for improvement:

- The Band 7 physiotherapist has identified several new areas for service development. Some of these involve more community support, particularly:
    - Support for newly diagnosed families.
    - Support, assessment and treatment for children on home IVs.
    - More intensive input for those classed as 'frequent flyers', with the aim of reducing hospital admissions.
    - Seeing families of newly diagnosed babies locally at the time of diagnosis as and when guidelines are developed in conjunction with BCH.

Recommendations:

- Within the new structure, it is recommended that the annual physiotherapy reviews and annual exercise tests are done locally, as opposed to at BCH.

Dietetics

- HEFT has had a 0.2 WTE dietetic service provision since September 2013. This is adequate for the current number of patients. All patients are reviewed in the weekly clinic by a dietitian, and inpatients are seen at least twice a week. The dietitian attends weekly MDT meetings and ward rounds. Cover for inpatients is provided by a Band 6 dietitian. There is no leave cover for outpatients. The dietitian demonstrates excellent CPD by regularly attending CF update meetings and is a member of the UK Dietitians Cystic Fibrosis Interest Group. Local consensus documents for nutritional monitoring of newborn screened infants and children with CF have been written and are reviewed every two years. The service has very close links to Heartlands adult CF centre and the dietitian attends transition clinics with patients.

Areas of good practice:

- Experienced dietitian with protocols and guidelines based on current evidence.
- Excellent relationship with the Heartlands adult CF centre, which has enabled a very good transition process and allowed the paediatric dietitian to maintain excellent CPD in CF nutrition matters.
- Dietitian has an excellent working relationship with the CF MDT.

Areas for improvement:

- Paediatric-specific CF leaflets and teaching resources would be helpful.
- CF diabetes care, especially children under the BCH diabetic team – establish a link between HEFT CF team and BCH diabetes team.

Recommendations:

- Develop shared care network clinics with the specialist BCH dietitian alongside nutrition guidelines, protocols and resources for network clinics.
- Establish adequate dietetic staffing to ensure outpatient for leave periods.
- If HEFT takes on newborn screened infants 0.2 WTE, dietetic staffing will not be adequate. Supporting infants and their parents is extremely time-intensive for the dietitian and staffing provision should be re-assessed.

Pharmacy

- Heart of England Foundation Trust
- Number of patients: 44
- Pharmacist time specifically dedicated to CF: 0 WTE
- Cystic Fibrosis Trust's Standards of Care recommendation: 0.3 WTE
- Pharmacist was not able to attend relevant UK CF specialist interest group meeting.
- No MDT or ward round attendance, however, close liaison with respiratory consultant and nurse specialist throughout inpatient stay.
- Ward cover available in absence, junior rotational pharmacist. Additional guidance on an adhoc basis from specialist adult CF pharmacist, when required.
- Pharmacist has not attended any CF conferences or study days.
- Service improvement:
    - Alignment of home IV pathway(s), including training pack.
    - New paediatric CF dispensing guide.
    - Inclusion of CF IV AB administration instructions in an IV admin guide.
- No particular involvement in key life stages with those with CF.

Areas of good practice:

- Good inpatient service provision.
- Good communication with BCH specialist pharmacist.

Areas for improvement:

- Become a member of the UK Cystic Fibrosis Pharmacist Group.
- Increase pharmacy service provision to outpatient clinics (minimum standard involvement in annual review) and MDT involvement, attending UK CF specialist interest group meetings and become a member of the CF pharmacist group. However, staffing levels are only adequate for the current level of service provision, any additional services would require funding.

Please refer to the BCH section for:

- Psychology
- Social work

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

Birmingham Heartlands and Good Hope 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%	N/A BCH	Amber	Annual review process needs improving.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	N/A BCH	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	N/A BCH	Amber	Annual review process needs improving.

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 BCH	Amber	Joint network MDT clinics needed at Heart of England.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a CF 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%	N/A BCH	Amber	Networking guidelines required.

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

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	A major concern to meet Cystic Fibrosis Trust's Standards of Care – only 20% of admissions into side rooms with en suite.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Compli-cations	% of 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%	N/A BCH	Amber	Ultrasound screening for CF liver disease does not meet Cystic Fibrosis Trust's Standards of Care.
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%	N/A BCH	Amber	DEXA scanning does not meet Cystic Fibrosis Trust's Standards of Care.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consult-ations	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of clinical psychologist at clinic	100%	Green	Green	
	% availability of clinical psychologist for inpatients	100%	Red	Red	Improved access to psychology required.
	% availability of social worker at clinic	100%	Red	Red	Improved access to social worker required.
	% availability of social worker for inpatients	100%	Red	Red	Improved access to social worker required.
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-line care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0.1	0.1	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green	Green	Service level agreement urgently needs signing.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Birmingham Heartlands and Good Hope Hospital
Consultant 1	0.5	1	1	3 PAs
Consultant 2	0.3	0.5	1	0
Consultant 3			0.5	0
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	1
Physiotherapist	2	3	4	1
Physiotherapist assistant				0
Dietitian	0.5	1	1.5	0.2
Clinical psychologist	0.5	1	1.5	0.2
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	0.1
Database coordinator	0.4	0.8	1	0

UK CF Registry data

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

CF Registry data – 2012	
Demographics of Birmingham Heartlands and Good Hope Hospital	
Number of active patients registered (active being patients within the last two years)	45
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	45
Median age in years of active patients	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	4 (9%)
	4–7 years	12 (27%)
	8–11 years	15 (33%)
	12–15 years	6 (13%)
	16+ years	8 (18%)

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)			
		Male	Female
Number of patients and % with FEV_1 <85% by age group and sex	0–3 years	0	0
	4–7 years	0	0
	8–11 years	2 (25%)	3 (60%)
	12–15 years	2 (25%)	1 (20%)
	16+ years	4 (50%)	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	4
	4–7 years	12
	8–11 years	15
	12–15 years	6
	16+ years	8
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	1
	8–11 years	5
	12–15 years	3
	16+ years	5
***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	3 (7%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	4 (9%)
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 transplantation assessment in reporting year	0
Number of patients referred for transplantation 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	13
	4–7 years	81
	8–11 years	192
	12–15 years	45
	16+ years	118
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	18
	12–15 years	39
	16+ years	55
Total number of IV days split by age group	0–3 years	13
	4–7 years	81
	8–11 years	14
	12–15 years	4
	16+ years	173

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	n=33; 14 (42%)
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	14 (31%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	14 (31%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	7 (16%) with chronic PA; 5 (11%) without chronic PA

Patient survey

Birmingham Heartlands and Good Hope Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following:

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

How would you rate the overall care?

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

Comments about CF team/hospital

CF team use Good Hope to do clinic, but we all sit in the same area. BCH can never get through on phone and CF team don't come out to visit. We sit in one room and they all (CF team) come to us.

Excellent relationship/communication at Heartlands hospital between us (family) and them. However, I feel communication is poor between the two centres and certainly written communication is non-existent from respiratory team (BCH) to us.

Our main care is via B'ham Heartlands rather than the children's. My daughter is currently transferring to adults.

Patient/parent interviews

Patient C (BCH/Heartlands shared care)

Areas of good practice:

- Fantastic CF team.
- Some lovely ward staff (though some less approachable) at Heartlands.
- Good respiratory nurse support at Heartlands.
- Outpatient clinic segregation has improved, so we're not sat in open waiting area now.
- Heartlands' Dr Denniston arranges post clinic letter to parent for two weeks after clinic. Also, parent receives letter of outcome from liver consultant following liver clinic appointment.

Areas for improvement:

- Communication from Birmingham Children's Hospital (BCH) to me not good. Daughter had annual review six to seven weeks ago, but BCH didn't know what had happened in last 10 mins.
- Never receive correspondence from BCH post clinic appointment.
- Results of blood tests transferred slowly to Heartlands from BCH, or not transferred across at all.

Other notes on parent C:

- She takes her daughter to Heartlands for Tobramycin levels. IVs are started on the ward at Heartlands and her daughter stays in on the ward for the first three days. Mother feels a lot rests on the respiratory nurse's shoulders. Daughter doesn't have pre-mixed IVs but mum would like this to be available to her. While on Heartlands paediatric ward, daughter receives physiotherapy once a day (but not at weekends). Mum covers the rest of the physiotherapy. Inpatient care was varied during daughter's last four days' admission – inconsistent knowledge/care on the ward. Mother feels all staff should understand the significance of cross infection in CF and so be vigilant in hand hygiene and infection-control/segregation requirements. Recent admission saw two other CF children playing together on the ward, either side of daughter's side room. Patients have own side room but have to share bathroom facilities, which concerns mother. Only two en-suite rooms on ward. Mother would also like to see evidence of hand washing and equipment cleaning by staff every time, and encouraging patients to meet the same standards.

- Daughter attends adolescent clinic every two months. Mum feels uncomfortable as it's a general respiratory outpatient clinic with others coughing around her and her daughter if they have to wait in open clinic area (on occasions).

Parent D (BCH/ Heartlands shared care)

Areas of good practice:

- Mother reported fantastic care from everyone in the Heartlands CF team, along with GP and pharmacist. Cathy (CF nurse) and Dr Denniston are her first point of contact.
- Mother valued the educational aspects, supportive nature and honesty of the Heartlands CF team, particularly Dr Denniston and CF nurse Cathy.
- She receives a letter after each Heartlands outpatient appointment. She sees the doctor, CF nurse, dietitian and physiotherapist at each clinic appointment, and the psychologist at the majority of appointments. The CF nurse deals with DLA/social welfare/benefits issues.
- Mother feels that the introduction of i-neb for her daughter has been the single most important change, which was driven by CF nurse at BCH.

Areas for improvement:

- Sharing care with BCH and Heartlands means there's less continuity. Mother and child do not feel such a close relationship with the BCH CF team.
- Patient does not receive a report/letter following annual review at BCH. She must wait until next appointment for feedback. Mother does not feel that annual review has the gravitas it should.

	Hospital name	Birmingham Heartlands and Good Hope 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 at Good Hope, No at Heartlands	Rooms are big and well equipped at Good Hope. Three smaller rooms at Heartlands. One is cramped and has no bed for examination. One can be accessed by an adjoining room if required.
Do patients spend any time in waiting room?	No at Good Hope and Yes possibly at Heartlands	This should be addressed at Heartlands. We discussed ways of achieving this
Is there easy access to toilets?	Yes	Unisex.
Where do the height and weight measurements take place? Is this appropriate?		In height and weight rooms for paediatrics. In individual rooms for adolescent clinic held in the adult centre at Heartlands. One room has no window or ventilation. Discussed possibility of height and weight being measured in individual rooms.
Where are the lung function tests done for each visit?		In individual clinic rooms.
Are clinic rooms appropriately sized?		Yes at Good Hope; at Heartlands, two are fine and one is too small.
For annual review patients, are any distractions provided?	No annual reviews done at Heartlands.	All done at present at BCH; however, possibility in future of these being undertaken at Heartlands if the network develops a standardised annual review.
If diabetics are seen outside of CF clinic, is the area and facilities appropriate for CF care?	4/44 diabetics	Two seen at BCH; two at Heartlands. Close communication with diabetes consultants and nurse. CFNS to learn continuous glucose monitoring to screen more patients.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Information pack given. Discussed possible use of 'Ready, Steady, Go' programme.

Additional comments

- Adolescent/transition clinic area is sufficient in all aspects and held in the adult centre in clean, well-equipped rooms.
- All paediatric clinic areas were clean and suitably equipped; decorated in a child-friendly manner.
- Patients would like copies of their clinic letters.
- Communication via letter from BCH is poor due to lack of administrative staff.
- A named consultant at BCH would be helpful for parents, children and the Heartlands team.

Environmental walkthrough: Ward
Ward name: 16
Microbiology status: Pseudomonas and Non-Pseudomonas

		Hospital name	Birmingham Heartlands and Good Hope Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			General paediatric ward.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Always in a cubicle; unlikely to get a room with shower.
Number of side rooms?		8	
Do the en suites have:	**Toilets?**	2 rooms only	
	Wash basins?	All rooms	
	Bath or shower?	2 rooms only	All have showers.
Do CF patients have to share any bathroom facilities?		Yes	May have to share. Discussed possibility of a named individual shower or bathroom for each CF patient.
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 until 7.30pm, then a TV card must be purchased. However, most use a laptop or iPad.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Awaiting delivery of new camp beds. At the moment they would possibly have to sleep in a chair or the parents' accommodation on unit.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	Protected meal times. Parents can be present.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	Only access to fridge in patient room.
What facilities are provided for teenagers?			No adolescent room or area. Small room available with Wii and PlayStation. Aware of cross-infection measures.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		Physio room with bike, Wii Fit and treadmill. Outside play area has table tennis and balls.
What facilities are there to help with school and further studies?		Hospital school. Two teachers and a classroom assistant liaise closely with patients' schools and work is brought in.
Is there a relatives' room?	Yes	Parents' room downstairs.
What internet access is there?	School has internet access.	Wi-Fi not available.
What facilities are there to enable students to continue work and study?		Team is flexible with IVs to allow children to go to work or college for exams, special occasions, etc.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	No	Working with infection control to solve this. At present parents take nebulisers home to clean once a week.
What facilities are provided for those with MRSA?		No MRSA patients. Would barrier nurse on Ward 15.
What facilities are provided for those with *B. cepacia*?		Barrier nurse on Ward 15 in bigger rooms, which have en-suite facilities and shower.
What facilities are provided for those with other complex microbiology?		Barrier nurse on Ward 15 in bigger rooms, which have en-suite facilities and shower.
Are patient information leaflets readily available on ward?	Yes	Printed from internet as required.
Transition patients – can they get a tour of ward facilities?	Yes	Transfer at 17 years.

Additional comments

- Maximum number of inpatients is three. Most likely one or two inpatients.
- Four play therapists provide distraction for PEG insertions and assist with physio blowing games and exercise. Play equipment all cleanable.
- Ward 15 has plans for an adolescent unit
- There is no youth worker.
- There is a lack of exercise equipment such as portable bikes for rooms.
- There is a soft play and sensory room, all cleanable.
- Ward 14 has day cases in separate cubicle.
- Assessment unit also has day cases in cubicles.

	Hospital name	Birmingham Heartlands and Good Hope Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	Can buy a weekly ticket if an inpatient. Looking into concessions for parking and will contact adult centre, which already offers concessions.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Reception at main entrance provides maps as well.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at the pharmacy for prescriptions?		Mostly prescribed by GPs. If prescribed, secretary may take to the Boots in hospital and parents collect later. Possibility of a short wait.
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	
Are there patient comments/feedback boxes?	Yes	'Friends and Family' system feedback via intranet. Also, 'You said, we did' memos displayed on ward.

Hereford Hospital (9 patients in Birmingham network, 17 altogether)

Delivery against professional standards/guidelines not already assessed

Consultants

Areas of good practice:

- Enthusiastic local CF consultant 2 PAs – links to both Cardiff and BCH CF centres.
- MDT established and good regional and local CPD.
- Good service user feedback.
- Good segregation.
- Home IV service available.
- The new hospital has good facilities, including en suite facilities.

Areas for improvement:

- Currently the clinical data entered into Port UK CF Registry for Hereford patients is not differentiated from other BCH patients, so it is not possible to assess specific Hereford outcome data.
- Joint network MDT clinics need to take place at Hereford Trust, with both Hereford MDT and BCH MDT present, to improve communication and joint working and professional development at MDT level. Currently only about half of Hereford BCH network patients attend their BCH annual review (due to distance?), although it is offered.
- As a network clinic, it would seem appropriate, once guidelines agreed and appropriate cover and experience/training is in place, for the Hereford MDT to see newly diagnosed newborn screened babies from diagnosis (for babies from Hereford catchment area).

Recommendations:

- Ensure Hereford patient data entered into the UK CF Registry is specifically labelled as Hereford data.
- Establish joint network MDT CF clinics at Hereford with BCH consultant, physio, dietitian and CFNS, alongside local MDT. Shared care service level agreement needs to be urgently agreed and signed. Hereford CF physio time needs to be increased to 0.3 WTE for the 17 patients, to allow the Cystic Fibrosis Trust's Standards of Care for inpatients to be met.
- Liaise with the BCH network team to develop a pathway and training that involves Hereford CF MDT in seeing newly diagnosed, newborn screened babies from diagnosis (for babies from the Hereford catchment area).

Specialist nursing

This is a small clinic of nine patients. There is an experienced paediatric respiratory and CF CNS who is enthusiastic and motivated to provide a good service. Cover is provided when on leave. The nurse is a member of the Cystic Fibrosis Nursing Association and attends regular meetings. Newborn screening and transition are commenced at BCH, but early team involvement is done. Annual reviews are done at BCH.

Areas of good practice:

- Good communication links with BCH.
- Experienced nurse.
- Shared guidelines in situ.

Areas for improvement:

- Written correspondence from BCH often takes a long time, resulting in information being delayed to team and parents.

Recommendations:

- Send annual review and outpatient correspondence with national guidelines.

Physiotherapy

There is no dedicated physiotherapy time for the eight patients that are looked after at this hospital and share care with BCH.

The physiotherapist estimates that they are able to cover the four hours per month that is involved in attending the clinic sessions. Opportunities exist to attend local MDT network meetings, however, time and resources can sometimes restrict attendance. An extra challenge here is the fact that they serve two centres, which equates to attending two network meetings in order to serve both equally.

Areas of good practice:

- 100% of patients are seen by a physiotherapist at outpatient clinics and there is cover for annual leave.
- There are strong links with the team at BCH.
- They are able to do community visits when necessary.

Areas for improvement:

- Funding for adjuncts has historically come from the physiotherapy budget and has sometimes been challenging to obtain. However, this should now come from the CF budget as it is included within the tariff.
- Patients are only seen by a physiotherapist once a day during the week and there is no routine physiotherapy treatment for CF patients at weekends.

Exception to the above standard would only be for those patients who are termed as 'acute'. Consequently there is only 50% cover for inpatients on the risk matrix.

Recommendations:

- Carry out annual reviews at BCH and send information from these to local hospital before the patient attends their next appointment.
- Perform annual exercise tests locally.
- See families of newly diagnosed babies locally rather than at BCH.

Dedicated CF time should be established to cover the above recommendations, and should be 0.3 WTE.

Dietetics

Current dietetic staffing is 0.05 WTE for nine BCH shared care patients. This meets the staffing recommendations of the Cystic Fibrosis Trust's Standards of Care. Prior to May 2013, there was no dietetic service. The dietitian is a member of the UK Dietitians Cystic Fibrosis Interest Group and has attended national and local CF meetings to maintain her continuous professional development in CF nutrition. No clinic cover is provided during periods of leave, but inpatient cover is provided by a Band 8 dietitian. The dietitian has participated in an audit of growth chart plotting recently, and fully participates in MDT meetings for patients. To date the nutrition service has not been involved in the transition process, as this is usually carried out by the specialist centre BCH.

Areas of good practice:

- Small, local service, allowing strong relationship to be developed between dietitian and family.

Areas for improvement:

- This is a relatively new service and would benefit from nutrition guidelines, protocols and resources.

Recommendations:

- Develop shared care network clinics with specialist BCH dietitian alongside nutrition guidelines, protocols and resources for network clinics.
- Provide adequate dietetic staffing to ensure dietetic cover for the CF clinic during periods of leave.

Pharmacy

Number of patients: 8
Pharmacist time dedicated to CF: No set time dedicated, but about 0.07 WTE spent on CF patients.
Cystic Fibrosis Trust's Standards recommendation: 0.05 WTE

- Pharmacist currently not attending UK CF specialist interest group meetings and wasn't aware of the group, but would be interested in attending.
- No MDT or ward round attendance, but liaises closely with the respiratory paediatrician and CNS.
- Ward cover available and provided by Band 7 pharmacist.
- Pharmacist has not attended any CF conferences or study days.
- Involved in guideline development for paediatric CF.
- No particular involvement in key life stages with those with CF.

Areas of good practice:

- Good relationship with the CNS and clinician knows patients well.

Areas for improvement:

- Attendance at MDT meetings, and increased pharmacy service provision to outpatient clinics would be useful. However, staffing levels only adequate for current level of service provision, and any additional services would require funding.

Recommendations:

- Join the UK Cystic Fibrosis Pharmacist Group and try to attend the annual meeting.
- Increase involvement with the MDT and outpatient clinics (minimum standard involvement in annual review) if funding allows.

Please refer to the BCH section for:

- Psychology
- Social work

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

Hereford 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%	BCH	Red	Only about half the patients attend (though appointments are offered). The benefits of the annual review need to be emphasised to families.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	BCH	Amber	Not possible to see Hereford data separately from BCH data – needs to be clearly badged as Hereford data.
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	BCH	Amber	Poor attendance – see above.

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	Amber	Not all attend BCH; need to arrange local joint MDT network clinics at Hereford.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	Safe, but MDT time does not meet Cystic Fibrosis Trust's Standards of Care, especially Hereford physio time.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	BCH	Amber	Networking guidelines required.
	Are there local operational guidelines/ policies for CF care?	100%	Green	Amber	Network guidelines required.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	Clarification required about where Hereford respiratory samples are cultured and whether culture techniques meet the Cystic Fibrosis Trust's Standards of Care – please can Hereford team clarify.
	% 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	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	N/A – no PA patients in last year.	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Compli-cations	% of 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%	Amber	Red	Needs addressing.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	N/A BCH	Red	Needs addressing.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A – no patients this age.	N/A	Make sure systems are in place to ensure this doesn't get missed in future.
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%	N/A BCH	Amber	Generally just one scan pre-transition – does not meet service specification.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consult-ations	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including at weekends	100%	Red	Red	Trust is non-compliant with this aspect of service specification. Physio WTE needs increasing to 0.3 WTE.
	% availability of a CF specialist dietitian at clinic	100%	Amber	Amber	Needs addressing, particularly cover for leave.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	Needs addressing.
	% availability of clinical psychologist at clinic	100%	Red	Red	Access to psychology support required.
	% availability of clinical psychologist for inpatients	100%	Red	Red	Access to psychology support required.
	% availability of social worker at clinic	100%	Red	Red	Access to social worker support required.
	% availability of social worker for inpatients	100%	Red	Red	Access to social worker support required.
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-line care	% of patients receiving advice from the palliative care team at end of life	75%	N/A – no patients at this stage.	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Red – in progress.	Red	Needs signing off by the end of September 2014.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	University Hospital Coventry
Consultant 1	0.5	1	1	2 PAs
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.5 WTE
Physiotherapist	2	3	4	0.1 WTE
Dietition	0.5	1	1.5	0.1 WTE
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)

Hereford data entered into Birmingham Children's Hospital

Patient survey

Hereford Hospital

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following:

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

How would you rate the overall care?

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

Comments about CF team/hospital

Birmingham CF nurses couldn't be more nice, also are very good at explaining so me and my husband understand and put worries at ease.

Both CF teams are fantastic but one criticism I feel is worth mentioning is the fact that not only do I not receive a copy of the letter/report following a Birmingham clinic visit, but more importantly I have to give any information relating to the visit to Hereford or my GP because they are still waiting for any correspondence from my Birmingham clinic visit eight weeks (on average) previously.

Good care. Can sometimes be communication problems, etc but nothing major and no complaints. CF team very helpful.

Patient/parent interviews

Parent F (BCH/Hereford shared care)

Areas of good practice – BCH:

- Caring doctor, perfect advice and explanations given.
- Annual review process and appointment at BCH is fine – all tests performed.

Areas for improvement – BCH:

- Outpatient appointments require a 1–1.5-hour wait.
- Feel physiotherapist manner is too 'forceful'.
- Nobody (in CF team) talks to me… they talk to my son.
- Segregation is not as good as at Hereford.

Areas of good practice – Hereford shared care clinic:

- Some nurses are brilliant – kindness, helping him on ward (mother's had a few problems with some nurses).
- Outpatients: Sees physiotherapist at every appointment (though physiotherapist difficult to get hold of by phone). Also sees doctor and receives dietetic advice at each appointment (from general dietitian on ward).
- Mother has seen improvements on the ward at Hereford Hospital over the last three years – CF nurse has driven this and helped ensure care plans in place for her son.
- Home visits: Has had two Hereford physiotherapist home visits: on one occasion Hereford's CF nurse visited home to flush portacath, and on another Hereford's CF nurse arranged psychologist support.
- Inpatient care: There's an exercise bike on the ward; physiotherapy daily (albeit only once) apart from at weekends, when there is no physiotherapy.

Areas for improvement – Hereford shared care clinic:

- Food on ward is not nice – eg chips not nice, lasagne stuck together.

	Hospital name	Hereford Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Seating for 12. Selection of toys. Staff are vigilant of CF patients arriving and their whereabouts. The receptionist knows all CF patients and parents are aware of contact rules.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	Two toilets and disabled toilet.
Where do the height and weight measurements take place? Is this appropriate?	Yes	Separate curtained area.
Where are the lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	N/A	Patients go to BCH or Cardiff.
If diabetics are seen outside of CF clinic, is the area and facilities appropriate for CF care?	No	One patient. Arrange for diabetologist and dietitian to see patient at clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	New patients – on first clinic appointment.
Transition/new patients – do they get information pack?	Yes	Use the Cystic Fibrosis Trust's new patient pack. There is a new ward leaflet introduced for the paediatric unit and services in future.

Additional comments

- The hospital is a modern building; the main reception has a coffee shop, general shop and a reception desk with PALS boards.
- The children's unit is located on the second floor and is recognisable by the child-oriented scenes on the floor as well as the clear signage.
- There are four clinic rooms for use. Clinic is held once monthly and nine patients are seen. Patients are booked in three groups of three, and care is taken to ensure they do not meet. The clinic rooms are all bright with a mural on the wall, of a good size and have toys which are cleaned at the end of clinic
- Seminar room – MDT base on clinic day.

- There is a door leading from the ward to outpatients; this is a secured entrance for staff only.
- There are general information leaflets on the walls.
- Patients can contact staff 24/7. The CNS has a mobile and this is covered when on leave; there is also open access to the ward at all times.

Environmental walkthrough: Ward
Ward name: Children's
Microbiology status: General and surgical 0–17

		Hospital name	Hereford Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Total of 10. One HDU. One +pressure. One – pressure. Two en suite.
Number of side rooms?		3	Suitable.
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	Locked away in clean utility room and issued by staff.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Starlight access. CBBC free on ward. General channels after 7pm.
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/chairs. Two bedrooms in parent unit.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Parents/family – open. Others – 2–7pm.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	None in rooms. In parents' or ward kitchen.
What facilities are provided for teenagers?			Teenage room.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Trampette, space hopper, static bike for rooms. Access to gym with physiotherapist.
What facilities are there to help with school and further studies?		School on the ward open 9–11.45am. There are two teachers who will liaise with schools. Seating for six students.
Is there a relatives' room?	Yes	The parent unit has two bedrooms, a kitchen and shower room.
What internet access is there?		None.
What facilities are there to enable students to continue work and study?		Home Education Service – students can take exams if required. School room has two computers connected to Virtual Learning Environment.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Can be cleaned by parent or staff in kitchen/ utility room. Not in rooms as taps are temperature regulated.
What facilities are provided for those with MRSA?		Pressure room and follow guidelines.
What facilities are provided for those with *B. cepacia*?		One patient. Pressure room and follow guidelines.
What facilities are provided for those with other complex microbiology?		Pressure room and follow guidelines.
Are patient information leaflets readily available on ward?	Yes	Printed on demand, or directed to Cystic Fibrosis Trust's website.
Transition patients – can they get a tour of ward facilities?	Yes	If required.

Additional comments

- The ward has security entry with a camera monitored by the nurses.
- Daily board shows who is working when, and reminders for staff.
- Rooms are bright, well equipped and modern, with overhead TV and a window looking out to the helipad. En suite with shower/wet room, sink, pull-down bed/chair. Lockable cupboard by bed.
- The larger rooms are used for longer stays, which have the murals on wall. Gym equipment can be brought into the room.
- Snacks: In addition to the daily menu, patients are given a snack menu to choose from; the menu offers a range of balanced and nutritional snacks and drinks, and has been designed by the dietitian.
- Two-bed bay with en suite. This room could be used for CF by blocking the use of one of the beds.
- Two x four bed bays available for general use.
- Clean utility room: Key pad entry. Contains a pod for pharmacy and lab specimens.
- Dirty utility: Sluice, specimens.

- HDU: With window to nurse's station.
- Baby food kitchen.
- Staff kitchen: Microwave, toaster, fridge and sink.
- Teenage (recreation) room: Mural and children's artwork on walls. Football table, Starlight TV with games console. Board games, music, sink.
- Assisted bathroom: For use if preferred.
- Playroom: For younger patients, mural on wall, contains various toys with table and seating, a large Wendy house, Starlight TV, music.
- Outside play area: Soft flooring, well equipped with many toys; cars, climbing frame, seesaws, with a clear glass balcony wall.
- Parents' unit: Two shower rooms and toilets. Two bedrooms with recliner chair so two parents could stay.
- Kitchen: Contains drinks making facility and fridge.
- Sensory room: Well equipped with hand-painted, glow-in-the-dark mural on walls and black-out blinds.
- Parents' sitting room: TV and sofa seating.
- Laundry: With washer and drier.
- There is a mural which covers one side of the wall throughout the whole ward and some side rooms. The mural took 18 months to complete. It was started by a sibling of an ex patient who did it in his own time, before being completed by the ward staff who fundraised to pay for his time and the materials.
- Other various donations have funded: a trampette, spirometer, static bike, DS, games, Wendy house and a fish tank donated by a local pet shop.

	Hospital name	Hereford Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Ticket issued for free parking (staff ticket) for patients who are admitted. Reduced parking fee for long appointments (2+ hours). If on benefits, patients can claim price of ticket back by showing benefit letter.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Large board. All departments listed.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Pharmacy has seating for 20. Due to parent awareness, it is very unlikely they will meet. Radiology is by appointment. DEXA scans take place at BCH or Cardiff.
Do patients have to wait at the pharmacy for prescriptions?		Due to long wait, parents drop off prescriptions and pick them up later.
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	Large PALS notice at main reception with leaflet rack. Leaflets on ward.
Are there patient comments/feedback boxes?	Yes	Box on ward. Suggestion boxes by all lifts.

Additional comments

- Friends and family survey completed on discharge.

New Cross Hospital, Wolverhampton (43 Patients)

Delivery against professional standards/guidelines not already assessed

Consultants

Areas of good practice:

- Outstanding service user survey – entire experienced CF team highly appreciated by parents, with excellent quality and accessibility of service. Good inpatient facilities, including side rooms with en suite. Lead consultant is extremely experienced and sits on National Clinical Reference Group for Cystic Fibrosis.
- MDT has good access to CF-specific CPD, and at least one member of the team goes to the European conference every year. Good clinical outcomes on Port UK CF Registry.
- Newborn screened babies with CF seen from diagnosis across catchment area. Good clinician liaison with BCH clinicians.

Areas for improvement:

- No great resource response to the 2008 peer review report. Physio recommended 0.2 WTE should go up to 1 WTE, and dietetic 0.1 WTE should be 0.4. Consultant 1 PA should really be 4 PA (given the number of patients), split between two consultants to allow cover. The current team is working above and beyond sustainable levels to deliver the service.
- Succession planning is a major concern for this service as the senior consultant likely to retire in the next two years. A new consultant with 2 PAS for CF should be appointed at least a year in advance of this retirement, to allow continuity of handover, with second 2 PAs for CF to be in job plan of replacement post.
- Joint network MDT clinics need to take place at New Cross, with both New Cross MDT and BCH MDT present, to improve communication and joint working and professional development at MDT level.

Recommendations:

- Increase physio recommended 0.2 WTE to 1 WTE, and dietetic 0.1 WTE to 0.4. Consultant 1 PA should really be 4 PAs (given the number of patients), split between two consultants to allow cover.
- Appoint a new consultant with 2 PAs for CF at least a year in advance of upcoming retirement, to allow continuity of handover, with second 2 PAs for CF to be in job plan of replacement post. New Cross must prioritise these posts for the service to be sustainable.
- Establish joint network MDT CF clinics at New Cross with BCH consultant, physio, dietitian and CFNS, alongside local MDT.

Specialist nursing

- The nurse is 1 WTE and New Cross currently has 43 patients, which is within the guidelines of the Cystic Fibrosis Trust's Standards of Care. The nurse is experienced and a member of the CFNA. The nurse attends both regional and international study days. Cover is provided for leave. Cover is flexible and community support is provided. New Cross accepts referrals from the newborn screening laboratory. Transition is currently being reviewed as a new adult centre is in development. Transition clinics are held at New Cross.

Areas of good practice:

- The nurse is a prescriber, very experienced and motivated.
- A flexible service is offered with support to community when on home IV therapy and follow-up discharge care.
- Good communication with BCH.

Areas for improvement:

- Would benefit from standardised pathways and guidelines.

Recommendations:

- More shared care clinics with BCH.

Physiotherapy

- There is an experienced Band 7 physiotherapist responsible for the CF service at this hospital
- They have five hours dedicated CF time (0.13 WTE), which is supplemented with some uncalculated help from a Band 6 and Band 5.
- There is the opportunity to attend local MDT network meetings, national and local ACPCF study days, and they have attended an international CF conference.
- Physiotherapists attend ward rounds and team meetings and are involved in CPD and audit.
- The lead physiotherapists have recently undertaken a patient satisfaction review of the service
- There are strong links with BCH.

Areas of good practice:

- A comprehensive annual physiotherapy review is undertaken locally, including exercise testing.
- Families of newly diagnosed babies are seen locally rather than at BCH.
- 100% of patients are seen by a physiotherapist at outpatient clinics and there is cover for annual leave.

Areas for improvement:

- Patients are seen by a physiotherapist once a day during the week, unless they are unwell or have an increased sputum load.
- They are also only seen once a day at weekends. Achieving this is constantly a challenge to the paediatric service due to resistance from the adult on-call service.

Recommendations:

- To support this service adequately, it is essential that there is an increase in dedicated physiotherapy CF time to 1 WTE, as recommended in the previous peer review.
- By establishing tariffs and service level agreements, funding of physiotherapy adjuncts should come from the CF budget and not the physiotherapy budget.

Dietetics

The current dietetic funded service is 0.1 WTE to cover outpatient clinics, including baby clinics and annual reviews. The recommended staffing level according to the Cystic Fibrosis Trust's Standards of Care is 0.3–0.4 WTE for 43 patients. No cover is available for leave periods. Inpatients are reviewed when necessary but the current shortfall in funding means that patients are not reviewed twice weekly as per the Cystic Fibrosis Trust's Standards of Care. The dietitian does not attend CF ward rounds but does participate in MDT discussions after clinics. The dietitian is a member of the UK Dietitians Cystic Fibrosis Interest Group and demonstrates good CPD, attending CF meetings locally and nationally. The dietitian is involved in audit and research within the service, including an audit of insulin treatment in children with cystic fibrosis. The dietitian is also involved in the transition process and provides a hand-written handover for the adult services. The dietitian sees newborn screened infants and will see patients either in clinic or on a home visit if required.

Areas of good practice:

- Experienced, dedicated and committed dietitian.
- Flexible approach with families, including home visits.
- Excellent working relationship with the MDT.

Areas for improvement:

- The Cystic Fibrosis Trusts's Standards of Care for diatetics are not being met for inpatients.
- Due to inadequate funding, there is no cover for outpatient clinic.

Recommendation:

- Establish adequate dietetic funding to ensure the Cystic Fibrosis Trust's Standards of Care are met (0.3–0.4 WTE).
- Develop shared care network clinics with the specialist BCH dietitian, as well as nutrition guidelines, protocols and resources for network clinics.

Please refer to the BCH section for:

- Pharmacy
- Psychology
- Social work

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

New Cross 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%	BCH	Amber/Red	Joint MDT network clinics need to be established at New Cross to fully meet this specification.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	Service is safe but relies on goodwill of MDT as grossly understaffed in many areas.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	N/A BCH	Amber	Network guidelines required.
	Are there local operational guidelines/ policies for CF care?	100%	Green	Amber	Network guidelines required.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red	Red	Solution needed.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Red	Amber	Clinic set-up seems appropriate for size of 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 Compli-cations	% of 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	Routine annual liver USS required to meet the Cystic Fibrosis Trust's Standards of Care.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	Red	Does not meet the Cystic Fibrosis Trust's Standards of Care: needs addressing.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consult-ations	% 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	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Must be addressed to meet service specification, with increase in physiotherapy staffing.
	% 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%	Red	Red	Access to psychologist required.
	% availability of clinical psychologist for inpatients	100%	Green	Green	
	% availability of social worker at clinic	100%	Red	Red	Access to social worker required.
	% availability of social worker for inpatients	100%	Red	Red	Access to social worker required.
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-line care	% of patients receiving advice from the palliative care team at end of life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Red	Red	Service level agreements to be signed by end of September 2014.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	New Cross Hospital
Consultant 1	0.5	1	1	2 PAs
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	0.1 WTE
Specialist nurse	2	3	4	1.0 WTE
Respiratory Physiotherapist	2	3	4	0.1 WTE
General Physiotherapist				0.1 WTE
Dietitian	0.5	1	1.5	0.1 WTE
Clinical psychologist	0.5	1	1.5	No protected time.
Social worker	0.5	1	1	No protected time.
Pharmacist	0.5	1	1	No protected time.
Secretary	0.5	1	2	Four hours per week.
Database coordinator	0.4	0.8	1	No protected time.

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)

CF Registry data – 2012	
Demographics of New Cross Hospital	
Number of active patients registered (active being patients within the last two years)	45
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	45
Median age in years of active patients	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	8 (17%)
	4–7 years	14 (31%)
	8–11 years	8 (18%)
	12–15 years	8 (18%)
	16+ years	7 (16%)

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	N=3; 3 (100%)

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

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

Complication (ref: 1.16 Annual Data Report 2012)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	7 (16%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	8 (18%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	1 (2%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	2 (4%) with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantation assessment in reporting year	0
Number of patients referred for transplantation assessment in previous three years	1
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	10
	4–7 years	50
	8–11 years	39
	12–15 years	17
	16+ years	27
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	58
	8–11 years	43
	12–15 years	78
	16+ years	133
Total number of IV days split by age group	0–3 years	10
	4–7 years	108
	8–11 years	82
	12–15 years	95
	16+ years	160

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	n=28; 9 (32%)
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 (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	2 (4%) with chronic PA; 3 (7%) without chronic PA

Patient survey

New Cross Hospital

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	26	0	1	0
Communication	24	3	0	0
Out-of-hours access	20	7	0	0
Homecare/community	26	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	21	6	0	0
Waiting times	20	5	0	0
Cross-infection/segregation	21	5	0	0
Cleanliness	21	6	0	0
Annual review process	18	3	0	0
Transition	4	1	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	13	3	1	0
Cleanliness	12	5	2	0
Cross-infection/segregation	11	2	1	1
Food	6	6	5	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	15	1	2	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	11	2	3	1

How would you rate the following:

	Excellent	Good	Fair	Poor
Home IV antibiotic service	9	5	0	0
Availability of equipment	14	7	0	0
Car parking	6	7	6	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	24	2	0	0
Of the ward staff	18	2	0	0
Of the hospital	20	6	0	0

Comments about CF team/hospital

Our local team are very supportive both in terms of medical provision but also with pastoral care and school liaison.

Our son receives exceptional care from the CF team at New Cross Hospital, who are happy to see him at very short notice, at home and clinic, if I have any concerns. Their cross-infection prevention measures are extremely well controlled, which reduces anxiety when taking him to clinic appointments.

New Cross is our main care hospital and we cannot fault any aspect of the service we receive.

The CF teams are brilliant. If we ever need any advice, they are always willing to help us, just a phone call away. We sometimes ask stupid questions but all CF team members always respond and give us advice and are always more than happy to help. Consultant, especially, always phones us back herself and New Cross, they are so kind.

They break their backs (not literally but you understand very hard work) working so hard to ensure my son is looked after at both places – impressed am I.

The CF team at New Cross, Wolverhampton are fantastic, they are accessible and the support we receive from the specialist nurse is great.

The CF team at New Cross Hospital, from the very beginning of our daughters' treatment have been great, supportive every step of the way. We have become friends with all of the doctors, nurses, physios and dietitians. We could not have asked for a better team of people to take care of both our daughters' needs.

The CF teams are great. The only things I get a little stressed about is the parking; obviously after 2pm I notice a huge difference in trying to park, but I guess that's at most hospitals.

New Cross Hospital CF team have been and continue to be outstanding in the care and treatment they give to children and their families.

Very helpful, always feel they are doing their best. Friendly and approachable. I have no complaints with the service they provide.

I honestly feel from personal experience from when my daughter was been admitted to New Cross that her care received was second to none. The CF team I feel treat CF patients like royalty.

We use New Cross a lot more than Birmingham – my son has no problems at either hospital, he stays in New Cross a lot and he's happy to do this as he knows the nurses and all of them are very friendly and helpful to him and me. He's stayed in Birmingham a few times but again all staff have been friendly and helpful.

New Cross is amazing – one phone call we are sorted. Home visits if we need them. The nurse makes the bad times bearable, doctor and physio team give good advice and always there if I need them. Birmingham we only visit once a year but are good, doctor always got time for questions. The only bad point is the hospital food – tasteless, fat free (which is not good), not much choice, glad when we went home for proper fatty foods. Also at clinic times they need more rooms to keep the children apart; very good service other than that. Nothing is ever too much for them. Great team at New Cross.

Care at Birmingham Children's Hospital has improved since they introduced a system where the patient stays in one room with the different team members coming to them. This has improved waiting times and reduced possibilities for cross-infection. I felt that, as we only visit Birmingham twice a year, they do not know us well enough to build an excellent relationship or offer the best advice particularly with regards to physio and nutrition and any compliance issues. However, the consultants are always excellent and listen to our concerns. We have always received excellent care at New Cross and as they know the children well they can tailor treatment to meet their individual needs and personalities.

I cannot give enough praise for our CF team (New Cross). In both clinics and hospital stays our care has always been of an excellent standard and always with the best interests of our daughter. The team are very approachable and will do their utmost best to help and advise with any situation.

My CF nurse is amazing – always on hand to help me out and is friendly and approachable always.

The CF team have really helped me understand and cope with my daughter's illness – very good!

Patient/parent interviews

Areas of good practice:

- Parents' therapy evening.
- Dental nurse visits to clinic.
- Play therapist helps with swallowing difficulties.
- Combined transition visits.
- Improved repatriated annual review service in last three years includes exercise testing and all other tests, including DEXA.
- Personalised care from friendly, professional team.
- Teachers in area all invited to educational day and schools are visited regularly.
- Good liaison with catering has led to improvement in meals and snacks.

Parent I (BCH/New Cross shared care)

Areas of good practice:

- BCH CF team is very caring and approachable – a wonderful team.
- BCH: Parent had to stay overnight when her child had surgery for meconium ileus. She found the facilities brilliant and the parents' room and meals were good.
- New Cross: CF nurse is great. She makes a lot of home visits and the dietitian and physiotherapist provide wonderful support and good advice. When I required physiotherapy advice/support about the pep mask, the physiotherapist made a home visit the next day.

Areas for improvement:

- BCH: Cross-infection safety/segregation measures could be improved and staff could be more accommodating when parent asks to be put into a side room with their child.

Patient J (BCH/ New Cross shared care)

Areas of good practice:

- New Cross: Inpatient experience was lovely – separate side room with own toilet facilities (although shared bathroom).
- Good segregation measures in place – ie working ward schooling around other CF children.
- Outpatients: Fabulous experience, quick flow at CF clinic; within two minutes height, weight and SATs are being checked. Mother takes daughter to clinic every two to three months and there is rarely a member of the CF team unavailable. CF nurse referred mother/daughter to counsellor from GEM Centre.
- 24-hour, open access to paediatric assessment unit.
- Explanations from CF team always really good.
- Annual review held at New Cross clinic last year for the first time – experience was a lot less stressful than at BCH. All tests were done on the same day.
- BCH: Segregation measures at outpatients have improved significantly – ie no longer sitting in open outpatient clinic area, so now patients go straight into consultancy room and stay in that room.

Areas for improvement:

- Annual review process more stressful at BCH.
- Car parking at BCH still an issue.
- Shared bathroom on ward at New Cross.

	Hospital name	New Cross Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Three rooms minimum per clinic and five rooms available. No more than 10 patients per clinic
Do patients spend any time in waiting room?	Rarely	Rarely occurs, however, never more than one patient in waiting room at a time.
Is there easy access to toilets?	Yes	Unisex toilet facilities.
Where do the height and weight measurements take place? Is this appropriate?		Large height and weight room in clinic. Discussed doing height and weight measurements in individual clinic rooms as a possibility for the future.
Where are the lung function tests done for each visit?		Individual clinic rooms. Two spirometers available for Pseudomonas and Non-Pseudomonas patients. No *B. Cepacia* or *M. Abscessus* in clinic at present.
Are clinic rooms appropriately sized?	Yes	All are a good size and one is very large for bigger families. All well-equipped.
For annual review patients, are any distractions provided?		Bring in own phones. Toys available. Little waiting time as kept busy.
If diabetics are seen outside of CF clinic, is the area and facilities appropriate for CF care?		Paediatric consultant and nurse specialists work closely in clinic with CF team. Seven out of 43 patients are diabetic. Sub-cutaneous glucose monitoring carried out regularly.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	New, glossy, attractive brochure.

Additional comments

- Monthly annual review clinic. Three patients per clinic and extra clinic added as required. Some patients have annual review at BCH.
- Clinic set up well for young children. Consideration of a teenage clinic is underway.
- Clinic is very pleasant with nice, child-friendly decoration.
- Of special note is the dental nurse, who found that 20/43 patients were receiving no dental care and has now referred all of them for dental care. This is an example of good practice.
- All notes are paper-based and centralised. Clinic ward and offices are well placed together. Office spaces were well equipped and of a good size.

Parents' wish list

- Timely letters from BCH, as at present they do not receive the feedback letter from annual review for many weeks or months due to lack of administrative staff at BCH.
- Would love a named consultant at BCH, rather than seeing a different one each visit.
- Cross-infection control at BCH has improved, however, it is still not as good as at New Cross. Both hospitals need to be following the same guidelines as it can be confusing and distressing for parents and children when they attend BCH.

Environmental walkthrough: Ward
Ward name: A21
Microbiology status: All

		Hospital name	New Cross Hospital 43 patients
		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 suitable for CF care.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	Two side rooms with wash basins and toilet on ward, double cubicle can be blocked if necessary, with wash basin and toilet. No more than two inpatients ever to date. Three holding cubicles with wash basin and toilet in paediatric assessment unit can be utilised. Two oncology rooms with negative pressure and wash basin and toilet can be used if required.
Number of side rooms?		5	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	No	
Do CF patients have to share any bathroom facilities?		No	Would have own bathroom on ward.
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?		Free until 8pm	Also have portable TVs, which can be used after 8pm (therefore free).
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Chair beds and overnight relatives' room.
Visiting hours – are there allowances for CF patients' families out of normal hours?			Have open visiting all day for parents. Other visitors have to adhere to the times specified.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	In small parents' room.
What facilities are provided for teenagers?		Yes	Recently refurbished to a very good standard, Wii, X-box activities available. Access to youth worker and yet to be opened chill room for teenagers, once funding for staffing becomes available. Cross-infection measures will be in place.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes, play area and two gyms	Annual review area has good step test and shuttle walk area.
What facilities are there to help with school and further studies?		School room recently refurbished to a high standard. Enthusiastic teachers who liaise closely with children's school teachers and have run teachers' education day for all staff in the area to raise awareness.
Is there a relatives' room?	Yes	Small room in need of some minor refurbishment.
What internet access is there?	No	Direct internet access only in school room, where it has a good firewall. Patients and parents also bring in their own phones.
What facilities are there to enable students to continue work and study?		Well-equipped school room and teachers.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Tubs to wash nebulisers and sink in rooms, then air dry.
What facilities are provided for those with MRSA?		Barrier nurse, gown and gloves etc for direct, hands-on treatment.
What facilities are provided for those with *B. cepacia*?		Barrier nurse, gown and gloves etc for direct, hands-on treatment. No patients in clinic at present.
What facilities are provided for those with other complex microbiology?		Barrier nurse, gown and gloves etc for direct, hands-on treatment. No patients in clinic at present.
Are patient information leaflets readily available on ward?	Yes, given as required	Printed from intranet and given out by staff.
Transition patients – can they get a tour of ward facilities?	Yes	Previously transitioned to Heartlands and more recently more being transitioned to New Cross. Both have a transition process in place. Patients informed about New Cross website and can visit outpatients at present. New adult centre being planned.

Additional comments

- Safe hands system being trialled. Staff and patients are all tagged using a chip in a bracelet for patients and a lanyard attachment for staff. The chip monitors alcohol gel hand washing. Process involves consent and compliance. There are currently flaws in the system, which are being worked on and monitored by those trialling it at New Cross. This is a first in infection control/prevention in the UK. The system is from the US. At present it is free on trial.
- The ward is well run, has a cheerful, friendly atmosphere, clean and very child-friendly decoration and a play facility with a nice outside area. It is not teenage-friendly at present, however, this is on the list of priorities to action.
- School teachers are keen and enthusiastic, providing an excellent service and feedback to schools.

	Hospital name	New Cross Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Weekly pass for £14.50 for inpatients, none for outpatients. 15 minutes to one hour costs £2. However, oncology and renal patients are free. This requires further follow-up and is an ongoing problem for many patients.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at the pharmacy for prescriptions?	Yes	However, coffee bar and seating in large open space allows them to sit apart or come back to collect later. There is concern that the newly opened Boots counter is small and that if parents and patients are queuing together, there is a possible cross-infection risk.
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	
Are there patient comments/feedback boxes?	There is a feedback tree on the ward, where inpatients and families write on leaves and attach them.	This is followed up with a 'You said, we did' section on the wall, stating what the feedback has been and how staff have acted on it. This is a very good idea.

Alexandra Hospital, Redditch and Worcestershire Royal Hospital (33 patients)

Delivery against professional standards/guidelines not already assessed

Consultants

Redditch and Worcester

Areas of good practice:

- En-suite side room facilities for inpatients at Worcester.
- Good patient survey feedback, dedicated consultant with 2 PAs; patients seen by consultant at all clinic visits. Consultant highly regarded by parents, very caring. Good liaison at consultant level with BCH consultants, including attending BCH clinics.
- Single room per patient for outpatients, spirometry and microbiological surveillance established.

Areas for improvement:

- Service currently a long way off meeting service specification due to lack of dedicated CF physiotherapy and dietitian time. For 33 patients, 3 PAs consultant, 0.8 physio, 0.2 dietitian and 0.8 CF nurse specialist are required. A business case was submitted at the end of March 2014. Unless the MDT is appropriately resourced the service is not sustainable.
- Joint network MDT clinics need to take place at Worcester Trust with both Worcester MDT and BCH MDT present, to improve communication and joint working and professional development at MDT level.
- Once full Worcester CF MDT is established and trained, with appropriate guidelines and cover established, then as a network clinic it would seem appropriate for Worcester to see newly diagnosed newborn screened babies from diagnosis (for babies from Worcester and Redditch catchment area).

Recommendations:

- Invest in MDT to ensure local Worcester CF MDT meets service specification: 3 PAs consultant, 0.8 physio, 0.2 dietitian and 0.8 CF nurse specialist. To achieve this, the service level agreement must be signed. Unless this Trust invests in CF MDT within the next 12 months, we recommend that this network site should not continue to offer a CF service, and that funding should be withdrawn.
- Establish joint network MDT CF clinics at Worcester with BCH consultant, physio, dietitian and CFNS, alongside local MDT.
- Once full Worcester CF MDT is established and trained, liaise with BCH network team to develop a pathway that involves Worcester CF MDT seeing newly diagnosed newborn screened babies from diagnosis, for babies from the Worcester and Redditch catchment area (may take two to three years).

Specialist nursing

Redditch and Worcester

The current nursing service has 0.8 WTE for 33 patients, which meets the current guidelines of the Cystic Fibrosis Trust's Standards of Care. The nurse is a member of the CFNA and attends meetings locally and nationally. The CF clinical nurse specialist attends all ward meetings and supports families and children in the community. The nurse is able to support home IV therapy. Currently, transition, newborn screening and end-of-life care are supported by the BCH. Shared care services with BCH are due to start in September. Cover for leave is provided by a respiratory nurse.

Areas of good practice:

- Experienced and motivated nurse who is able to offer flexibility to families in the community and hospital.
- Excellent communication with BCH.

Areas for improvement:

- To take part in audit and research.
- Earlier involvement with newborn screened babies to offer advice, education and support.

Recommendations:

- Once the new unit at Worcester is open, the nurse will be able to participate more in the transition process. Additionally, once shared care centres are more established, newborn screened babies can be introduced to the service earlier.

Physiotherapy

Redditch and Worcester

The physiotherapy team at this hospital has the enthusiasm to become involved with the CF team, however, at present there is no funding forthcoming. There are links with BCH, which would lead to training once funding is established. Patients are rarely admitted to this hospital for treatment and, when this happens, they are only seen once a day.

Recommendations:

- Establish a dedicated physiotherapist role at 0.5 WTE.
- Educate the on-call physiotherapy service about the requirement for twice daily physiotherapy treatments for all inpatients throughout the week.

Dietetics

Redditch and Worcester

Currently there is no dietetic service. A business case has been submitted to the hospital board for a 0.2 WTE dietitian. This post holder will be required to attend two CF clinics per month, carry out a nutritional assessment for annual reviews and be involved with new CF patients identified through the newborn screening programme. Currently this service fails to meet the Cystic Fibrosis Trust's Standards of Care for the nutritional care of CF patients.

Recommendations:

- Obtain 0.2 WTE funding and establish a dietetic post to meet the Cystic Fibrosis Trust's Standards of Care.

Pharmacy

Redditch and Worcester

Number of patients: 27
Pharmacist time specifically dedicated to CF: 0 WTE
Cystic Fibrosis Trust's Standards of Care recommendation: 0.2 WTE

- Pharmacist currently not able to attend UK CF Specialist Interest Group meetings, but usually tries to attend the local network meetings.
- No MDT attendance, but attending ward rounds.
- Ward cover available in absence, provided by junior rotational pharmacist.
- Pharmacist has not attended any CF conferences or study days.
- Involved in protocol development – paediatric CF protocol.
- No particular involvement in key life stages with those with CF.

Areas of good practice:

- Good relationship with the CNS, good connection to BCH specialist pharmacist, good inpatient service provision with participation in ward rounds.

Areas for improvement:

- Attendance at MDT meetings, increased pharmacy service provision to outpatient clinics (minimum standard involvement in annual review), more contact with patients. However, staffing levels only adequate for current level of service provision, and any additional services would require funding.

Recommendations:

- Join the UK Cystic Fibrosis Pharmacist Group and try to attend the annual meeting. Increase involvement with the MDT and annual review outpatient clinics, if funding allows.

Please refer to the BCH section for:

- Psychology
- Social work

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

Report and actual compliance below follows a Red, Amber, Green (RAG) rating defined as the following:

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

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

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

Hospital name

Worcestershire 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	Amber	Peer review panel were unable to clarify whether this is the case for 95% of patients.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	No. Has safe service.	Red	Trust management must invest in CF MDT or service funding should be withdrawn.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/ surgical or other disciplines?	100%	N/A BCH	Amber	Network guidelines required.
	Are there local operational guidelines/ policies for CF care?	100%	Green	Amber	Network guidelines required.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Unclear	Panel recommend that Dr Onyon checks which protocols etc micro lab uses on CF samples and whether they meet the Cystic Fibrosis Trust's Standards of Care (to ensure rare pathogens aren't missed).
	% 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	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Red	Amber	Small clinic, therefore may not be feasible but is worthy of consideration.
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 Compli-cations	% of aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	N/A BCH	Unclear	Local team to check this meets service specification.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	N/A BCH	Red	Does not currently meet service specification.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red. Only one patient, not appropriate.	Amber	Need to ensure process is clear.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
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%	N/A BCH	Red	Does not currently meet service specification.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consult-ations	% 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%	Red	Red	Trust management must invest in CF MDT or service funding should be withdrawn.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	Trust management must invest in CF MDT or service funding should be withdrawn.
	% availability of a CF specialist dietitian at clinic	100%	Red	Red	Trust management must invest in CF MDT or service funding should be withdrawn.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Red	Trust management must invest in CF MDT or service funding should be withdrawn.
	% availability of clinical psychologist at clinic	100%	Red	Red	Access to psychologist required.
	% availability of clinical psychologist for inpatients	100%	Red	Red	Access to psychologist required.
	% availability of social worker at clinic	100%	Red	Red	Access to social worker required.
	% availability of social worker for inpatients	100%	Red	Red	Access to social worker required.
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	N/A	Amber	Patients require access to home IV therapy as an option.
4.4 End-of-line care	% of patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months	<1%	0	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%	0	Red	Requires implementation.
5.4	Service level agreements in place for all	100%	Refer to BCH.	Red	Must be agreed by end of September 2014.

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Redditch and Worcestershire Hospital
Consultant 1	0.5	1	1	0.2 WTE/2 PAs
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.3 WTE
Physiotherapist	2	3	4	
Physiotherapist assistant				
Dietitian	0.5	1	1.5	
Clinical psychologist	0.5	1	1.5	Available.
Social worker	0.5	1	1	Available.
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	0.2 WTE
Admin assistant				One to two hours a week.
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)

CF Registry data – 2012	
Demographics of Worcestershire Hospital	
Number of active patients registered (active being patients within the last two years)	29
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	29
Median age in years of active patients	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 (14%)
	4–7 years	9 (31%)
	8–11 years	2 (7%)
	12–15 years	12 (41%)
	16+ years	2 (7%)

Genetics	
Number of patients and % of unknown genetics	2 (7%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2012)	
Patients with a BMI percentile <10th centile on supplementary feeding	n=1; 1 (100%)

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

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	9
	8–11 years	2
	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	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 transplantation assessment in reporting year	0
Number of patients referred for transplantation assessment in previous three years	1
Number of patients receiving lung, liver, kidney transplants in previous three years	1

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	22
	4–7 years	23
	8–11 years	22
	12–15 years	49
	16+ years	14
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	5
	8–11 years	0
	12–15 years	26
	16+ years	0
Total number of IV days split by age group	0–3 years	22
	4–7 years	28
	8–11 years	22
	12–15 years	75
	16+ years	14

Chronic DNase therapy (ref: 1.22 Annual Data Report 2012)	
DNase Pulmozyme	
% of patients aged 5–15 years on DNase	n=21; 8 (38%)
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	N/A
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	N/A

Patient survey

Redditch and Worcesteshire Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following:

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

How would you rate the overall care?

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

Comments about CF team/hospital

Ever since my daughter was diagnosed everyone involved has been wonderful and very helpful. I couldn't have asked for a better care team for my daughter and family.

CF team in Birmingham are good. Would like to be able to have inpatient stays in Worcester though due to distance (much closer), car parking and accessibility. It would fit much better with all family needs, eg other children's school, not having to miss work etc.

I am pleased to see that Birmingham now segregates patients by having designated rooms. The CF nurses there are always very helpful and friendly. I worry about the inconsistent way that doctors deal with atypical CF (both my children carry R117H and delta F08). Some doctors advise different levels of antibiotic doses, my eldest son was put on salt solution for the first year and daily antibiotics but my daughter hasn't been this worries me. I worry that there is a lack of expertise in dealing with atypical CF. It has become hard to contact CF nurses at Birmingham – their time seems very stretched now. At Worcester, doctor is fantastic always very thorough and willing to spend as much time with you as needed. Very impressed by the time and care given by doctor at Worcester.

Patient/parent interviews

Parent E (BCH/Worcester shared care)

- Mother's son receives really good care from BCH specialist centre and Worcester's network clinic, attending BCH every two months and Worcester once every few months. CF team responds promptly to her queries.
- They see the whole CF team at outpatient clinic at BCH, with access to psychologist and social worker.
- At Worcester she sees either Dr Castling or Dr Onyon and the respiratory nurse – sats, FEV_1 and weight checked routinely during consultation.
- Son has home visits from Worcester's respiratory nurse, if needed. She's recently had a visit from BCH CF team's physiotherapist to give technique guidance.
- Mother is happy with segregation/cross-infection measures at BCH and Worcester.
- She receives an annual report letter or phone call, which provides the outcome of the annual review at BCH.
- Dr Onyon/Dr Castling (Worcester) drove use of new treatment for mother's son: DNase, Colomycin and Seretide.

	Hospital name	Redditch 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	Two to three patients per monthly clinic. Four rooms available; two have no windows. The clinic is very warm and stuffy, however, a quote has been secured for air conditioning.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	Adults, disabled and child.
Where do the height and weight measurements take place? Is this appropriate?	Height and weight room	Cleaned before and after each patient. New height and weight equipment being planned for two rooms.
Where are the lung function tests done for each visit?		In clinic rooms.
Are clinic rooms appropriately sized?	Yes	One larger than others.
For annual review patients, are any distractions provided?	N/A	Annual reviews currently undertaken at BCH.
If diabetics are seen outside of CF clinic, is the area and facilities appropriate for CF care?	No diabetic patients	However, diabetologist and diabetes nurse specialist could attend clinic if required for joint consultations.
Transition patients – can they get tour of outpatients' facilities?	Yes	Nurse takes patients to visit and meet staff.
Transition/new patients – do they get information pack?	Yes	Led by BCH at present.

Additional comments

- Worcester and Redditch have 35 patients in total, including eight at Redditch. Staffing currently consists of the consultant and two respiratory nurses (1.2 WTE) with an interest in cystic fibrosis. There has never been a dedicated physiotherapist or dietitian. A business case has apparently been submitted for both a CF nurse specialist 0.8 WTE, physiotherapist 0.5 WTE and dietitian 0.2 WTE to cover patients at Worcester and Redditch. These posts will be based in Worcester and travelling monthly to Redditch, which has seen outpatients only since 23 June 2014. All inpatient care is now at Worcester.
- The percentage of tariff has not yet been finalised for Redditch and Worcester. It would be useful to know this for future business planning and improvements to the service, which has the support of BCH to grow over time. This will depend on the correct staffing being in place to meet the Cystic Fibrosis Trust's Standards of Care. Annual reviews could potentially be delivered in Redditch and Worcester if an appropriately trained MDT were in place.
- A named consultant at BCH would be useful for patients and staff. Verbal communication is very good with BCH, who are very helpful and supportive. Lack of administrative staff at BCH leads to long waits for follow-up letters.

	Hospital name	Worcestershire Royal Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Seating for 24. If patients arrive early, they are taken to a spare clinic room to wait while the clinic room is cleaned/dried.
Do patients spend any time in waiting room?	No	Patients are taken directly to the clinic room.
Is there easy access to toilets?	Yes	Two unisex toilets and baby changing room.
Where do the height and weight measurements take place? Is this appropriate?	Yes	In clinic room.
Where are the lung function tests done for each visit?		In rooms, using mobile spirometry equipment.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	N/A	Currently carried out at BCH.
If diabetics are seen outside of CF clinic, is the area and facilities appropriate for CF care?	No	No diabetic patients. Have a specialist on team and would have a joint clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	If required. Would give tour to new patient before date of first clinic.
Transition/new patients – do they get information pack?	No	In planning.

Additional comments

- Clinics are held monthly from 9am –12pm, with staggered appointments. There are six to eight appointment per clinic. There is a comments box at reception. Child-orientated art on the walls and an assortment of toys and books, plus TV on the wall.
- For future clinic appointments, the CNS would go to reception and book the next appointment, leaving the patient in the room.
- There is a separate exit for cross-infection purposes.
- The team hopes to grow the service (by adding an extra physiotherapist and dietitian). They hope to carry out annual reviews once the full team is in place.
- Treatment room: For bloods.
- Four bedrooms: For medical day care; CF patients go direct to ward.

Environmental walkthrough: Ward
Ward name: Riverbank
Microbiology status: General

		Hospital name	Worcestershire Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care (if overflow facilities required)?		Yes	
Number of side rooms?		7	Plus two en-suite rooms with double beds, which could accommodate siblings if required.
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	Staff store medication in drug room, in locked cupboards.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Until 8pm, then TV automatically switches off. Older children can go to adolescent room.
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 rooms. Room with en-suite facility – due for refurbishment.
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	Staff kitchen or in parents' room.
What facilities are provided for teenagers?		Yes	Adolescent room is newly refurbished. Brightly coloured with artwork on walls and new furniture, sofas and soft seating. Coffee table. TV, Starlight TV, Wii, DVDs and radio. Information leaflets available.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapist escorts to gym. No equipment allowed in rooms.
What facilities are there to help with school and further studies?		Two play specialists (2.5 WTE) liaise with parents, local education authority and with patient's school.
Is there a relatives' room?	Yes	Equipped with fridge, microwave, hot drinks facility, TV, sofas and snack machine. Due for major refit.
What internet access is there?		BT Open Zone. Free if registered at home, or £15 per month.
What facilities are there to enable students to continue work and study?		Teacher liaison.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Patients can clean equipment in rooms or staff can clean in medicine room.
What facilities are provided for those with MRSA?		Have no patients – would follow infection-control policy.
What facilities are provided for those with *B. cepacia*?		Have no patients – would follow infection-control policy.
What facilities are provided for those with other complex microbiology?		Have no patients – would follow infection-control policy.
Are patient information leaflets readily available on ward?	Yes	Printed on demand.
Transition patients – can they get a tour of ward facilities?	Yes	If required.

Additional comments

- The main hospital reception area is located on the first floor. It is a large, bright and modern area with a coffee shop, large Macmillan stall, general shop, phone, post box and cash machine. The 'League of Friends' volunteers meet, greet and direct visitors. The signage to the ward and outpatients department is clear; this is located on the ground floor.
- The ward is located next to the outpatients' clinic. There are two secure entrance/exits to the ward. The ward is bright, modern and spacious, with artwork and noticeboards on the walls. Staff pictures are displayed on a noticeboard. The rooms are well equipped, all with TV, sink and locking bedside cabinet, of a good size with very clean en-suite facilities.
- If there were more than one CF patient admitted, they would not come into contact with one another due to the shape of the ward.
- On the ground floor there is a separate security door entrance. This is not for general use, but for patient admission to the ward.
- Snacks: A number is issued to the family, staff call the restaurant and the patient can go and pick up their snacks. There is also a daily supply of snacks available on ward.

- The ward also has a nursery for one-year-olds and under, which has eight separate rooms; this is not generally used for CF patients.
- There are two negative pressure rooms with en suite.
- Sensory room is well equipped.
- Milk kitchen available for feeds.
- Drug room has two entrances, either side of the ward.
- Four-bed assessment room is for general patients, not those with cystic fibrosis.
- Treatment room is well equipped
- Three x four bed bays for surgical patients.
- Sluice.

	Hospital name	Redditch Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No – outpatients only since 23 June.	£3 for up to two hours. £4.50 for three to four hours. Lots of parking spaces always available.
Other hospital areas		
Clear signage to CF unit and or ward?	No	Signage to clinic needs to be much clearer. No sign on main corridor to direct patients to clinic.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Pharmacy – yes. Audit in place to assess if prescriptions can be dispensed in clinic. Radiology at Worcester – mainly sufficient, however, plenty of space at Redditch if required. All DEXA scans performed at BCH at present.
Do patients have to wait at the pharmacy for prescriptions?		Yes, occasionally, as mainly utilise GP prescriptions.
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	Yes	Poster in the corridor and leaflets in waiting room. The clinic nurse and receptionist are going to display in clinic rooms as patients do not wait in waiting room.
Are there patient comments/feedback boxes?	Yes	'Family and Friends' service.

	Hospital name	Worcestershire Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Costs £1. By obtaining a slip from the ward to be issued with a pass.
Other hospital areas		
Clear signage to CF unit and or ward?	Yes	Very clear.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Pharmacy has seating for 14. Patients' families are encouraged to use GP for drug issue. Radiology – would book appointment; seating for 35+. DEXA scanning – done at BCH.
Do patients have to wait at the pharmacy for prescriptions?		Yes – rely on patient awareness for cross-infection purposes.
Patient information		
Is the patient advice and liaison service (PALS) well advertised – leaflets, posters, etc?	No	No visible office/area. There is a 'Comments, compliments and complaints' leaflet available, which contains a feedback form.
Are there patient comments/feedback boxes?	Yes	At entry to ward and clinic reception.

Additional comments

- No reported parking issues. £3 for two hours and £4.50 for two to four hours. The ward features a noticeboard containing satisfaction surveys. Green coloured surveys display the good comments. If there were to be a red survey displayed, there would also be information on how the problem was addressed.

Appendix 7

Panel members

Dr Tim Lee*	Consultant	Leeds General Infirmary
Nanna Christiansen	Pharmacist	Barts Hospital
Michele Puckey	CF Specialist Psychologist	Royal Brompton Hospital
Denise Sheehan	CF Clinical Nurse	Great Ormond Street
Marie Creedon	Principal CF Dietitian	Great Ormond Street
Rosemary Ball	CF Specialist Physiotherapist	Leeds General Infirmary
Claire Oliver	Social Worker	Southampton General Hospital
Sarah Freeman	Commissioning	West Midlands
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for peer review panel

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