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Peer review report

Leeds General Infirmary and paediatric shared care clinics

02 October 2014

1. Executive summary

Overview of the service

The Leeds service has been through a significant period of change during which the team members have maintained a world class service and have addressed issues raised in the previous review. The network service is a good example of their determination to further develop their service. To maintain this commitment to excellence the service will require support that more appropriately reflects the cystic fibrosis tariff. Two areas require immediate attention: a detailed appraisal of administrative support to drive forward not just the Leeds service but also the network, and appointment of a senior nurse specialist to work at the heart of the team and provide the leadership to improve patient pathways across the network.

There is a need for investment in allied health professionals (AHP), including pharmacy and psychosocial, to sustain the important developments in network care. Transition processes need to be re-invigorated both in Leeds and across the network.

Good practice examples

- The Leeds team members have a wealth of experience, which is evident in their representation on national and international bodies and their commitment to research that is focused on improving patients' lives. A theme of "not standing still" runs through everything they do.
- The facilities are excellent. The unit has capacity to review patients safely and effectively. The unit also provides facilities for the team to meet and undertake administrative tasks in a location that facilitates patient interaction. It is clear this impacts positively on their team working.
- The Leeds team provides a high level of care for their full-time patients and for the patients who receive the majority of their care in a network clinic. They have good and thorough guidelines. The electronic notes are an exemplar to other UK centres and have a considerable impact on the quality of care received by the families. There is an improving coordinated network approach to CF care.

Key recommendations

There is an urgent requirement to address these two areas:

- The Trust needs to undertake a clear appraisal of how the CF team is supported administratively. Staff should be undertaking roles that are consistent with their experience and skill set. Time should not be wasted on straightforward tasks that could be better spent improving the patient journey, both in the Leeds unit and across the network. This will require investment to enable more senior administrative staff to undertake these pathway coordinator roles and improve the patient journey.
- There needs to be a senior appointment to lead the nursing team. The CF nurses need to be more aligned to the heart of the CF team and integral to all aspects of patient care. Leeds is a step behind all other UK CF clinics in this regard, and this partially reflects the excellent CF clinic nurses that the unit has always had. A Band 7 nurse is urgently required (or Band 8, if an Advanced Nurse Practitioner). This will provide a better service for the families, from newborn screening through to transition and will provide a sustainable solution to the consultant workload.

Areas for further consideration

The following require prompt consideration:

- The impact of the newly established network clinics on AHP/consultant workload and patient flows. Undertaking the annual review investigations at the network clinic with a joint review of those results may take some of the pressure off the Leeds Unit, but will require adequate resources and investment in staff, particularly for physiotherapy and dietetics.
- Psychosocial support. Some consideration of how the psychology and social workers will integrate their role with the CF team is required. This has been a strength of the unit and more resource is required to maintain this service and respond to the increasing needs of the network.
- Pharmacy support. There is considerable pharmacy experience in Leeds and this needs to be better utilised to improve both network and Leeds pathways. Plans for succession are required that enable the maintenance of the strong Leeds tradition.
- There needs to be a revisiting of transition processes, both for fulltime Leeds patients and for network patients. Clear pathways and lines of responsibility are required for these patients. Expanding the electronic CF records to the network clinics will contribute to their transition and improve all aspects of network care.

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

Models of care

Summary

Leeds provides the hub to a network of care, with clinics in Bradford, York, Scarborough and Calderdale. There has recently been a significant change in the partnership working arrangements of these clinics and that was evident from the enthusiastic contribution of the network clinics to this review process. In addition it was exciting to see representatives of the Hull clinic at this review, with the potential for a more formal partnership arrangement between these two centres.

The Leeds team has started undertaking clinics in the network centre and this has had an immediate impact on communication between the partners in the network. The approach of the teams to this review and the comments bode well for a strong and developing network. This will impact most notably on the processing of newborn screening results and on all aspects of CF care.

There are two concerns:

- Leeds still has a large number of fulltime patients. This may change as the network emerges, but at the moment it is difficult to sustain the high level of care these patients receive. At present this is only being achieved by all team members working above and beyond what is expected or possible in the long term.
- Scarborough has recently lost an experienced physician, who led their CF service. The service is currently supported by the York team (same Trust). The panel was worried that this is a sustainable arrangement and this situation requires close monitoring. Historically a small number of patients from Barnsley have travelled to Leeds for their annual review, receiving the majority of their care in Barnsley. This is not an ideal situation and is time-limited as those patients will transfer to adult care in the next five years.

Multidisciplinary care

Summary

The Leeds clinic is well represented on all fronts, often with health professionals who have international reputations. There is a good ethos of team working and a multidisciplinary approach to decision making. It is clear that the core CF team includes the admin and inpatient staff. At present, the dietitians and physiotherapists do not review all patients that attend outpatients, choosing instead to target patients that have concerns or have not been seen recently. This enables a more detailed consultation, but does mean that they are derogating the national specification standards. The panel appreciates their approach, but this needs reviewing internally to ensure that all patients are receiving an appropriate excellent level of care. The Leeds team was concerned that rigid observation of the national specification standards (for example seeing up to 17 patients per clinic briefly) might result in the actual standard of care received being poor. Overall, more resource is required to support both in- and outpatient exposure to the MDT, as outlined above. These resources are essential if the network clinics are to continue to be a success.

Principles of care

Summary

There are clear principles of care outlined in the Leeds guidelines and in service level agreements with the network partners.

The principles of care are of the highest standard and have been an exemplar for other centres.

Historically, the Leeds team was one of the first to recognise issues around transition and established a transitional care clinic in the early 1990s. It was clear from interviews and patient feedback that transition processes have slipped a little of late, with patients and their families not feeling clear lines of responsibility. To some degree this reflects the evolution of both units and the team accepts that some reinvigoration of transition processes was required both in Leeds and across the network.

Delivery of care

Summary

It is evident that the high level of care that patients receive in Leeds and the network reflects team members working above and beyond what they are expected to do. Also most have considerable expertise.

To maintain this high level of delivery will require urgent and significant investment.

A reappraisal of administrative support will enable experienced staff to focus on supporting the patient journey and improve communication between the team and the network.

There is an urgent need for senior nursing leadership to develop the role of the CNS in the Leeds network. This person should be at least Band 7 and preferably Band 8.

In addition, there are requirements for additional time to support physiotherapy, psychology, pharmacy and dietetics (detailed later in this report).

Commissioning

Summary

The service has implemented the CF tariff approach and put in place service level agreements between the hub and spokes. The service has made good initial steps in developing their shared care network and there has been some rationalisation of clinic venues after review. In further developing the network it is recommended that:

- A network board be established and formal meetings held by network members to discuss and agree priorities for the service and share best practice and that these meetings involve representatives from management and all clinical disciplines.
- Network protocols and procedures be developed to promote good practice and equity across the whole service.
- Staffing numbers be reviewed for all providers.

Suggested areas for network prioritisation are:

- Formal governance and quality structures and reporting arrangements, and review of the SLAs to support this approach.
- Transition arrangements for all patients, including planning of capacity with the relevant adult services.
- Review of staffing numbers to meet service specification and roles within the network.
- Implementation across the network of the high school package.
- Home IV provision.

Another area noted for resolution is the allocation of an identifiable budget to the service for provision of nebulisers to patients.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	192

			Male	Female
FEV_1	Number and % of patients with FEV_1 <85% by age group and sex	0–3 years	0	0
		4–7 years	1 (3%)	2 (7%)
		8–11 years	7 (23%)	6 (22%)
		12–15 years	11 (36%)	9 (32%)
		16+ years	12 (38%)	11 (39%)

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

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	12 (7%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	11 (92%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	6 (3%)
	Number and % of patients on chronic macrolide without chronic PA infection	19 (23%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

Two senior consultants have recently retired placing considerable stress on the service. The Trust has appointed three new Consultant posts, which is excellent and has obviously recharged the team. Although new in post (and one yet to start), it was evident from the peer review that the new appointments would bring great energy to the team and were very open to driving forward the service.

It is a critical time therefore for the Leeds CF team and imperative that they are supported in the next stage following this review. A major contribution to supporting the sustainability of the Leeds service will be the appointment of a senior cystic fibrosis nurse specialist (CFNS), to act as a catalyst to driving forward the involvement of the CFNSs in all aspects of the patient journey.

The enthusiastic involvement of network consultants in the review day bodes well for the longer term performance of the Leeds network and although no definitive assessment of consultant role in those clinics was possible in the time frame, it was evident that a true partnership ethos was being generated.

Specialist nursing

Leeds General Infirmary

Overview

Leeds has 172 full care and 63 shared care patients. Network care has recently become more established. There will be five Band 6 CF nurses making a total of 2.94 WTE in hours, which is slightly below the recommended staffing ratio. The CF nurses are very experienced enthusiastic and approachable. They are well supported in attending national and international study days and are members of the CFNA group. They each have a case-load of 40 patients and they are able to cross-cover for each other.

Areas of good practice:

- The transition process is well established with good links to their adult colleagues.
- CF study day for shared care staff established.
- Established and well run newborn screening service.

Areas for improvement:

- Establishing equitable support for network patients is in its infancy. The CF nurses are enthusiastic and keen to improve this.
- Need to improve communication in nursing team due to working patterns to ensure continuity for patients. The nursing team are is exploring processes to enable this.
- The nursing team would like to develop nurse- led clinics and non-medical prescribing.
- Additional permanent administrative staff particularly on clinic reception are required.

Recommendations:

- To have credibility in the CF network there would be a Band 7/8 CF nurse within the Leeds centre who would have a lead role and act as a champion for CF nursing within the network and run a CF nurse network group.
- Having a lead CF nurse is essential to drive forward change within the team eg the establishment of nurse-led clinics and aiding personal and centre development by the introduction of non-medical prescribing.

Halifax/Huddersfield and Calderdale

Thirteen patients are covered by a very experienced 0.8 WTE Band 6 community-based nurse who specialises in cystic fibrosis. One day a week allocated for CF care. Cover is provided by the community team. The post is fully supported to attend local study days. The post holder is not a member of the CFNA. The post holder is not able to attend ward rounds due to time constraints but does attend monthly CF clinics in Huddersfield and Calderdale Hospitals.

Areas of good practice:

- Good communication with network centre nurses.
- Non-medical prescriber.

Areas for development:

- Would like to be able to assess all home IV patients at home midway and at end of course as currently not able.
- Would like pre-prepared IVs to be available to the CF patients in this area.

Recommendations:

- To have structured CF nurse network meetings.

York

Fifteen patients attend York. There is one 0.8 WTE band 6 CF nurse who also covers allergy/ respiratory. Six Scarborough patients are now under York's care. There is good support from the consultants. There is no CF nurse cover when she is unavailable, the patients do not usually ring Leeds. There is support for the nurse to attend relevant local and national meetings.

Areas of good practice:

- Provides comprehensive newborn screening service.
- Embraces shared care clinics at York but patients were already encouraged to attend Leeds.
- CF Nurse attended CF course at Brompton Hospital.

Areas for improvement:

- Provide social work/psychology locally and develop a parents group.
- Continue to improve the transition process.
- Attend CF clinic at Leeds if York patients cohorted to aid communication.

Recommendations:

- The current business case should reflect the increased nursing time required to continue to support CF patients and further develop the service.
- Need for social work or psychology provision locally, as the lack further impacts on the CF nurse workload. Although patients have access at Leeds this is a considerable distance away.

Bradford

Overview

There are 24 patients who until recently have been totally cared for at Bradford. There is 1 WTE full time Band 6 nurse who takes a lead role in the care of CF and also PCD patients.

There is cover by the Band 7 Respiratory nurse. The CF nurse provides an excellent service and is an experienced and motivated nurse. There is support from the Trust to attend local and national study days.

Areas of good practice:

- Good availability enables home visits and offers a complete newborn screening service.
- Approaches network centre for advice and help with difficult cases.
- Very supportive of new shared care clinics, actively encourages patients to attend the network centre.

Areas for improvement:

- Transition arrangements are not as robust as the network centres. Transition document needs to be developed.
- Develop nurse-led clinics and non-medical prescribing.

Recommendations:

- Continue close working relationship with network centre which has been an asset to all.
- Develop strong links with adult CF team.

Barnsley

There are a total of 12 patients at the centre, three patients are shared with Leeds, the rest with Sheffield. The Band 7 paediatric community nurse is responsible for the patients and covers difficult asthma as well. The nurse is not a member of the CFNA group but attended a local study day. The nurse felt supported by consultants and tertiary centre where annual review takes place. There will be no new patients that will share care with Leeds.

Physiotherapy

Leeds Centre

Staffing: Band 8a 1 WTE, Band 7 0.5 WTE, Band 6 0.5 WTE, Band 5 0.5 WTE, Band 2 0.5 WTE

Total: 2.5 WTE qualified staff (**MINUS 0.5 – see below) 0.5 non-qualified staff

For 173 full care patients and all shared care patient commitments.

**1.4 WTE of this was given for CF in 2013 but unfortunately 0.5 WTE Band 6 time has been diverted to paediatric orthopaedic service to address shortfalls in staffing there.

Areas of excellence:

- Very dedicated team, led by a very experienced specialist.
- Lead who has strong links with the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF).
- There is active involvement in audit and service improvement projects, up-to-date staff with ongoing CPD for different grades who treat CF patients, attendance at national and international conferences, access to local and national guidelines and patient leaflets (also available to networks).

- Good service for inpatients, meeting ACPCF standards, variety of airway clearance, access to equipment, weekend service including twice daily if required, parents are not expected to cover for shortfalls, excellent service for newborn screened babies, budget available for airway clearance equipment.

Recent service improvements include:

- Improved links with network therapists with new outreach MDT clinics, annual network meetings and staff from networks free to go to Leeds for training.
- More extensive and formalised physiotherapy annual review with improved documentation for some patients.
- All patients on home IVs reviewed by physiotherapist at hospital.

Areas for improvement:

- Shortfalls in staffing have led to the following:
  - Not enough time to complete physiotherapy annual review for all patients within the year (prediction that only 50% completed by year end).
  - No opportunity to implement plans to improve communication between centre and network physiotherapist at time of annual review (pre-assessment form, phone contact if required).
  - Clinic staffing inadequate – only 40–60% of patients seen. Limited clinic cover for annual leave.
  - Limited opportunities for further development of skills/training/CPD for network physiotherapists.
  - Very limited homecare service.
  - Limited facilities for exercise – very small indoor area for exercise when outdoor space is inaccessible.
  - Service has not taken over funding of vibrating mesh technology nebulisers (drug company funding no longer available).

Network Centres

Bradford

Overall good service for inpatients outpatients, overseen by physiotherapist with an interest in and experience of CF, who is a member of the ACPCF.

Area for improvement:

- No physiotherapy homecare service (including school visits, home IVs).

York (including Scarborough patients)

Very experienced and enthusiastic service lead who has introduced many positive changes to the physiotherapy service since the Scarborough patients were taken over by York in March 2014 with additional clinics being covered in the short-term. However the business case for additional physiotherapy staffing has not been approved and maintenance of the current service is not sustainable in the long-term.

Areas for improvement (if additional staffing not approved):

- Limited physiotherapy cover for York CF clinics and no attendance outreach clinics.
- Limited capacity for homecare service including home/nursery/school visits
- No capacity for developing standard operating procedures or carrying out audit and service improvement projects.
- Limited time for staff to access paediatric-specific CPD for physiotherapy staff at Leeds (adult CF team provide service).

Calderdale

Community paediatric physiotherapy team covers the outpatient service, acute adult respiratory inpatient team covers the inpatient service. Overall good service for CF with established links between two teams.

Areas for improvement:

- Nebuliser service is not run by physiotherapy or nursing staff – currently a consultant fulfils this role.
- No formal CF/paediatric CPD for those providing IP service (covered by adult staff).
- No capacity for routine daily exercise for inpatients.

Main Recommendations:

- A minimum of an additional 1.0 WTE Band 7 is required for Leeds physiotherapy team (0.5 WTE diverted to paediatric orthopaedic service to be returned to CF team plus an additional 0.5WTE). This should be used as a priority for providing more input at clinics and the opportunity to provide all patients with an annual review.
- Additional 0.8 WTE physiotherapy required to enable adequate staffing for York clinic following the transfer of Scarborough patients.
- Continued improvements in communication/ongoing paediatric-specific teaching and training between Leeds and network staff to ensure good practice is shared (including inpatient adult staff at Calderdale).

Other recommendations:

- There should be a plan to develop a more extensive homecare service across the whole network either as outreach from the Leeds centre or in partnership with local physiotherapy services to provide support when on home IVs or for school/nursery/gym visits as required.
- Budget needs to be identified at Leeds for purchase of mesh technology nebulisers.
- Responsibility for the day-to-day running of the nebuliser service at Calderdale should be transferred from the consultant to a named person within the physiotherapy or nursing staff.
- At Leeds identification of a larger indoor space to be made available for exercise in winter/poor weather.

Dietetics

At the regional centre the service is led by a consultant dietitian, (0.88 WTE) Band 8b with over 20 years' experience in cystic fibrosis. She is supported by a Band 6 at 1.0 WTE who has three years' experience in cystic fibrosis. Overall staffing meets the current Cystic Fibrosis Trust staffing recommendations with 0.5 WTE per 75 patients based on the centre's 233 patients (173 fulltime care and 59 network clinic patients). There is a CF specialist dietitian available at every outpatient clinic and inpatients are reviewed daily. The dietitian is present for all CF MDT meetings and ward rounds. MDT meetings are weekly, ward rounds three times weekly, post clinic meetings once weekly and research meetings four times a year. Service cover provision is provided usually by each dietitian but urgent cover can also be provided by another non specialist Band 6 dietitian (or Band 7 with previous experience in CF), although rarely necessary. Dietetic annual review is carried out on each patient, however a formal report is not written for full-care patients. The dietetic team is an integral part of the CF team approach to care at the key life stages, such as diagnosis, transition, and end-of-life care, transplantation, and family planning.

Food service provision uses cook-freeze which receives mixed reports from patients and carers. There is a choice of three menus and there is also snack provision.

Areas of excellence:

- Both dietitians are members of the UK CF Dietitian Interest Group and have regular attendance at UKDCFIG meetings.
- The specialist team has the opportunity to attend the European CF Conference and national CF study days.
- The consultant dietitian attends and presents at numerous North American CF Conferences, last attended in 2012. She has also attended and presented at two Australian CF Conferences and a Middle East Respiratory Conference.
- Both dietitians are actively involved in their shared care education session and provide regular support to the shared care dietitians.
- One of the two dietitians usually attends the annual Trans Pennine meetings.
- The Band 6 dietitian has completed the Masters 20 credit module in Dietetic CF Care as part of her specialist training.
- The dietitians are actively encouraged and involved in audits and research within the CF team and are part of the MDT research meetings.
- They are both involved in the data collection for CF Trust patient registry.
- Audits have included bone mineral density, plasma vitamin levels (informal), and outcomes of gastrostomy feeding.
- The consultant dietitian has been/is on a number of consensus groups including: European Cystic Fibrosis Bone Mineralisation Guidelines; European Cystic Fibrosis Research in Allied Health and nursing professions; ESPEN European CF Nutrition Guidelines UKCF Trust UK CF Nutrition Guidelines; European CF Society Best Practice Guidelines, Nutrition Section.

Area of improvement:

- The network clinics have limited if any designated funding for dietetics in CF and CF care and improved education and networking by the centre staff is crucial. There is no formal homecare service.

Recommendations:

- Communal use of dietetic resources across network clinics; review of patient resources.

Pharmacy

Leeds Children's Hospital (based at Leeds General Infirmary)

Pharmacist support for CF patients is provided by an experienced advanced clinical pharmacist.

No. of patients: 173 full care, 60 shared care CF pharmacist time shortfall: 1 WTE pharmacist time dedicated to CF: 0.4 WTE + general pharmacy 7 hours (inc technician). Cystic Fibrosis Trust's 'Standards of Care (2011)' (1 WTE /150 pts) (+22% timeout allowance)= 1.4 WTE

Assessment of advanced clinical pharmacist against Cystic Fibrosis Trust's 'Standards of Care (2011)'.

- Member of the UK CF pharmacist group (CFPG), attended ESCF 2014 conference and CFPG study day. Not attended local network study days or been involved with CF audits/research.
- Attends weekly MDTs and ward rounds. Available for outpatient clinics via bleep/phone.
- Ward Cover provided in pharmacist absence but no cover for outpatients/MDT meetings.
- Involved in supporting formulary applications, IFRs and writing/reviewing guidelines.
- No specific involvement with life stages. Developing a targeted leaflet for babies/infants.

Areas of good practice:

- Good inpatient service provision, relationship with MDT and protocol development. Recent development of guidance on management of paediatric non-tuberculous mycobacterium.
- Leeds Medicines Management and Pharmacy Services (MMPS) has a paediatric homecare technician and there is provision for all patients to have homecare premade IVs.
- There is good access to the aseptics and preparative service run by Leeds MMPS (until 8pm weeknights and 5pm weekends). There is also emergency access to aseptics technicians.

Areas for improvement:

- A lack of allocated specialist pharmacist time has an impact on input on annual reviews, involvement with network and audits/research.
- Plans for absence cover for the pharmacist to ensure access for outpatients.
- The centre's review of the current homecare model identified a need for additional resources for repatriation of inhaled therapies (0.2 WTE Band 5 technician and 0.1 WTE pharmacist).

Recommendations:

- Review staffing resource to ensure adequate specialist pharmacist time.
- Review the need for support for shared care clinics and for the pharmacist to attend network meetings.
- Establish how all elements of the specialist pharmacist CF role are covered during periods of absence. Consider designated cover to help with continuity for patient care.

Shared care centres

In all shared care centres a basic clinical pharmacy service is provided with access available to medicines and all inpatients receiving review by a pharmacist Monday to Friday. Due to the small number of patients in some centres, CF patients make up a very small part of the pharmacist role, often a general paediatric pharmacist role, and there is no designated time. It is important that in shared care centres patients have access to pharmacy advice and support as at Leeds. All pharmacists recognise the importance of Continuing Professional Development (CPD) to provide up-to-date advice on CF, but most are not a member of the CF Pharmacist Group.

Summary of recommendations:

- All shared care pharmacists working with CF in shared care centres should be a member of the CF Pharmacist Group and be supported to attend local study days. Improving communication with the specialist pharmacist at Leeds may help with providing support to centres with few patients, where it is difficult for pharmacists to develop expertise due to small patient numbers.
- Larger centres need to review staffing to ensure they meet the Cystic Fibrosis Trust's WTE (Bradford 0.2 WTE and York 0.1 WTE) recommendations for the pharmacist.

Psychology

Clinical psychology provision currently stands at 0.45 WTE consultant clinical psychologist (CP). Recently, an additional 0.3 WTE Band 7 has been secured on a temporary basis. This is a shortfall of approx. 0.85 WTE against the Cystic Fibrosis Trust's Standards of Care based on the centre's 233 patients (173 fulltime care and 59 network clinic patients).

- The CP was jointly responsible for setting up the UKPP-CF group and attends annual psychosocial study days.
- The CP attends weekly CF MDT meetings during which three patients are discussed each week. The CP also attends twice-weekly CF clinic review meetings, held after each clinic, if available (he offers psychology appointments after clinic so is often unavailable for the review meetings).
- There is limited formal cover for sickness absence or annual leave due to the CP being the sole psychologist providing CF input, with the exception of the new temporary 0.3 WTE.
- The CP attended the 2013 ECFS Conference in Lisbon and the 2013 UKPP-CF study day. He is regularly involved as a field supervisor in trainees' thesis and service evaluation research, and is the Principal Investigator in TIDES.
- Due to the limited psychology resource, involvement in key life stages is determined by need. The CP is not routinely involved at diagnosis, but often provides support at 12 months post diagnosis, unless patients/parents are flagged up as requiring support sooner. The CP and the team would like him to provide more input around transition, possibly offering individual psychosocial work with each adolescent, to prepare them. Following the additional temporary increase in staffing, as a priority they have recently started to see every 16-year-old in clinic as they prepare for transfer to the adult unit. This will not be possible to sustain without funding to secure additional staffing.

Areas of good practice:

- Parent support groups for parents of pre-school children, held away from the hospital, are offered routinely, with the hope that these will be rolled out to parents of children of all ages if staffing levels are increased. The CP attends MDT meetings after clinics, contributing to discussion of specific patients, in addition to leading a discussion on psychosocial issues. The CP is available to offer psychology appointments to patients the afternoon they attend clinic in the morning, allowing for patients to be seen when already travelling to the hospital.

Areas of improvement:

- With more resource the CP and the team would like: to provide psychosocial review to all patients at Annual Review, including shared care patients when they visit Leeds; more formalised support/ input to each of the network clinics (to be detailed in the service level agreement); to be part of the routine transition process ideally for all patients but particularly for Leeds patients.

Recommendations:

- Improve equity of psychology across the network by increasing psychology staffing by 0.85 to 1.6 wte if CP is to provide support to patients of network clinics, or by 0.45 to 1.2 wte to provide support solely to Leeds patients. If the latter, additional psychology to be available locally and integrated into Network teams.

Social work

Provision:

There is one full time social worker (SW) working with the Leeds CF team for their 161 patients – she is qualified, experienced and managed through social work supervision. She is part of a specialist regional SW service which works with children's disability and illness, including safeguarding. The team can sometimes cover for each other in emergencies and are managed by a SW with a background in the service. There are sometimes SW students who can input into the service. Staffing is according to guidelines, though no lone worker can fulfil all requirements due to leave etc.

There is no formal social work provision for the network clinics though the social worker for Leeds does provide some support. Because patients who attend the Leeds service come from a wide geographical area (most of North and West Yorkshire), home visits are time consuming.

1. Annual reviews:

Leeds – the SW does not have the resources to carry out annual reviews for all patients, though will be aware/contribute to what reviews indicate about those she is working with. Network patients have no formal psychosocial assessment arrangements.

2. Outpatients:

Leeds – the SW sees as many children at outpatients' clinics as her time allows – as a single worker this means she cannot attend all clinics. She does not have the resources to attend network clinics.

3. Inpatients:

As above. The social worker relies on other team members to notify her of families who need contact with her if she is unable to attend/visit.

4. Strengths:

A qualified, experienced and knowledgeable worker in an established post for a number of years. SW support and effective systems of management.

CF specialism and increasingly seen as part of the team. Excellent resources for child protection issues within the disability field (though this does take time from general CF work).

5. Difficulties:

The SW holds child protection cases for patients falling within the city area – this takes time out of her 'full time CF' allocation – she is also part funded by social care which could mean that even more of her time is reclaimed by them should they reorganise.

There is time consuming duplication within recording etc due to working to two teams.

The SW and psychology professionals should be a strong group within the MDT but their importance, roles and resource needs seem only to have been recognised relatively recently, meaning that as a psychosocial team they are still in the process of development.

The SW being based within social care has meant in the past that she could be 'forgotten' by the team – for instance she was unaware of the UKPPCF; she has not been able to attend many regional, national or international CF meetings in the past. She was not on the team photo board, but is now on the VDU information screen.

The SW is increasingly asked to be involved with the 65 network clinic patients who appear to have no other SW input – this would be impossible to do effectively within existing SW time and resources, though a further central social work resource may be the only way to provide a full social work service to these 60 some patients. It will be down to team discussions and service level agreements to resolve how this could be funded and operate.

5. User feedback

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	10	9	6	3
Female	12	6	7	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	38	6	0	0
From the ward staff	24	8	2	0
From the hospital	25	12	3	0

Areas of excellence:

1 Outpatients – cleanliness

2 Accessibility of team

3 Cross-infection/segregation

Areas for improvement:

1 Inpatient – food

2 Car parking

6. Appendices

Appendix 1

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

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

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

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

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

Hospital name

Leeds General Infirmary

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 multidisciplinary team (MDT). (One consultation may include annual review.)	95%	Red. Working toward new service spec.	Red. Working toward new service spec.	Leeds team is aware the annual review process for full-care patients requires more structure.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a 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%	Green	Green	

2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	Because of low patient numbers we do not have a joint CFRD clinic. Patients are seen separately by the diabetes team in one clinic and the CF team in another clinic.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	

3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Red. Shortage of admin staff has impacted.	Red. Shortage of admin staff has impacted.	Leeds team aware of this important issue and it is a priority area for quality improvement.
	% 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. Staff numbers extremely low, now rectified.	Red. Staff numbers extremely low, now rectified.	CQUIN data partly due to wrong denominator (acute attendances as well as routine).

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%	Green. May not be necessary to be seen twice at weekends.	Green	There is the facility to review all CF inpatients twice daily at the weekends, however following assessment by the experienced CF physiotherapist on a Friday they may decide that a patient will be well enough to be seen once a day over the weekend and the parents will perform the physiotherapy in the afternoons. This can obviously be overruled if the physiotherapist reviewing the patient feels that the situation has changed.
	% 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 a clinical psychologist at clinic	100%	Green	Green	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Amber	Amber	
	% availability of a social worker for inpatients	100%	Amber	Amber	
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	

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

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	2	2	
5.2	Number of clinical incidents reported within the past 12 months	<1%	13	13	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green	Green	

Appendix 2

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Leeds General Infirmary
Consultant 1	0.5	1	1	0.5
Consultant 2	0.3	0.5	1	0.6
Consultant 3			0.5	0.8
Staff grade/fellow	0.5	1	1	0.3
Specialist registrar	0.4	0.8	1	1–1.5
Specialist nurse	2	3	4	2.94
Physiotherapist	2	3	4	2.9
Physiotherapist assistant				0.6
Dietitian	0.5	1	1.5	1.88
Clinical psychologist	0.5	1	1.5	0.5
Social worker	0.5	1	1	1
Pharmacist	0.5	1	1	0.4
Secretary	0.5	1	2	1.2
Database coordinator/clerk	0.4	0.8	1	0.5
CF unit manager				0.1
Sister CF clinic				0.69
Health care assistant				0.69
Bacteriologist				0.05
CF home care coordinator				0.64

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)

UK CF Registry data 2012	
Demographics of centre – Leeds General Infirmary	
Number of active patients registered (active being patients within the last two years)	192
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	183
Median age of active patients in years	8
Number of deaths in reporting year	0
Median age at death in reporting year	N/A

Age distribution (ref: 1.6 'Annual Data Report 2012')		
Number and % in age categories	0–3 years	43 (24%)
	4–7 years	38 (21%)
	8–11 years	35 (19%)
	12–15 years	35 (19%)
	16+ years	32 (17%)

Genetics	
Number of patients and % of unknown genetics	19 (10%)

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2012')	
Patients with a BMI percentile <10th centile on supplementary feeding	5

FEV_1 (ref: 1.14 'Annual Data Report 2012')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	1 (3%)	2 (7%)
	8–11 years	7 (23%)	6 (22%)
	12–15 years	11 (36%)	9 (32%)
	16+ years	12 (38%)	11 (39%)

Lung infection (ref: 1.15 'Annual Data Report 2012')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	43
	4–7 years	38
	8–11 years	35
	12–15 years	35
	16+ years	32
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	2
	16+ years	10

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	2 (1%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	5 (3%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	5 (3%)

Complication (ref: 1.16 'Annual Data Report 2012')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	26 (14%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	8 (4%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	2 (1%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH/ 1 without PH

Transplantation (ref: 1.18 'Annual Data Report 2012')	
Number of patients referred for transplantion assessment in reporting year	1
Number of patients referred for transplantion assessment in previous three years	3
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	8
	4–7 years	193
	8–11 years	234
	12–15 years	413
	16+ years	450
Number of days of home IV therapy in reporting year split by age group	0–3 years	306
	4–7 years	127
	8–11 years	57
	12–15 years	399
	16+ years	425
Total number of IV days split by age group	0–3 years	314
	4–7 years	320
	8–11 years	291
	12–15 years	812
	16+ years	875

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2012')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=98); 68 (69%)
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	12 (7%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	11 (92%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	6 (3%) with chronic PA 19 (23%) without

Patient survey

Leeds General Infirmary

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	10	9	6	3
Female	12	6	7	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	39	10	2	0
Communication	30	17	4	0
Out-of-hours access	23	18	3	0
Homecare/community support	16	18	5	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	31	17	3	0
Waiting times	28	16	4	1
Cross-infection/segregation	39	8	2	1
Cleanliness	40	10	0	0
Annual review process	26	15	3	0
Transition	4	1	0	1

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	15	15	2	2
Cleanliness	24	8	2	0
Cross-infection/segregation	23	6	3	1
Food	7	9	9	6
Exercise	11	9	2	3

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	16	2	0	0
Availability of equipment	18	12	1	0
Car parking	14	13	3	6

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	38	6	0	0
Of the ward staff	24	8	2	0
Of the hospital	25	12	3	0

Comments about CF team/hospital

"Our CF team at LGI has been so supportive/informative and caring. We appreciate that there are specialists in different areas eg dietitian, physio etc looking after my daughter."

"I feel we manage my son's health very well, but the issues we have are the same we have always had and no one seems able to address."

"They are angels. Words cannot describe what an amazing team of people they are. We are totally blessed. Every member of the team can never do enough to help us. We love them all dearly."

"I can't really comment on Leeds as we only see them once a year but when we seem then they are excellent."

"Would like to thank all the CF team including ward staff for all the hard work they do."

"I have only ever received excellent care from CF day unit and ward at LGI (Leeds General Infirmary) - fantastic, friendly, knowledgeable, caring staff."

"As far as our family is concerned the CF team are the best there is."

"I just think they are fantastic, caring people who have looked after me and my son."

"The Leeds General Infirmary are thorough, efficient and generally friendly. However, communication can be problematic and always seeing different consultants can also be frustrating. Having not seen a CF nurse at home for a few years, I felt that I was unsupported in this area. Consequently when I needed more support, in the times of increased sickness I did not feel I could approach the nurses. I do have great respect for the CF team, however I do not feel I (and my son) have developed a good relationship with anyone in the unit. This may be due to the fact that they have large numbers of patients to treat and don't have the time. I am confident that the advice they give is good and that they have my son's best interest at heart."

"Overall very good."

"An excellent team and service. Thank you"

"It would be nicer/better to see or be under just one or two consultants. I feel sometimes some consultants are not up to date with my child. Follow up of appointments with written communication can be very delayed - sometimes months after appointments."

"Fantastic, reliable, caring, knowledgeable - great support as a parent my child is very well I can only thank the staff at York and Leeds."

"The team are all fabulous, every professional at the CF unit from reception/admin staff to consultant are all friendly, approachable and very professional. They are all passionate about their jobs and this is reflected in their work. I have nothing but admiration and praise for the whole team. I couldn't thank them enough for the work they do and the care they provide."

"We consistently receive excellent care from the LGI team. All staff (from receptionist to consultant) are friendly, supportive and knowledgeable. My daughter looks forward to her clinics - she enjoys the fuss made of her, likes trying to do well with her breathing tests and responds well to all the medical team – that is the biggest compliment I can pay them."

"Generally an excellent team but all consultants should take concerns about health realistically and not just be unhelpful optimists. Food on the ward really needs improving."

"We attend the CF unit in Leeds, having received treatment also at Kings College in London, who were great. The nurses, consultants, Drs and staff at Leeds provide a care of the highest level. We are very happy with the service we receive and would be devastated if we had to leave their unit."

"Due to retirement of both consultants at LGI and pending retirement of consultant in Scarborough in 2014, requested daughter's care is all transferred to Leeds as we know all team. Need some continuity, do not wish to transfer care to York. Dedication on both teams. Scarborough hospital appointment system changed to detriment – no fault of CF clinic or team."

"The CF team at Leeds are taking a big hit this year with the loss of two consultants with many years' experience, I do worry that the care will suffer due to this! I think some patients are getting lost/forgotten about due to staff not being replaced, especially the CF nurses that play a vital part in the lives of people with CF and their families."

"Shared care worked well as family life, however we feel let down by the transitional arrangements (to adult) available at LGI to shared patients. We have been told these are non-existent. Staff at both hospitals need to talk to the young person not the parent. At almost 17 my son finds this insulting."

"My son is only young still so have not been coming to the LGI for years and years but so far our experience has been excellent."

"Only time I have been unhappy with anything is when I was told to go for a walk when we arrived for an appointment, it was raining heavy and no choice but to wait in the main hospital for 20 minutes – cross-infection!"

"I have nothing but praise for my CF team and honestly believe my son would not be doing as well health-wise if it wasn't for their guidance and teaching. They are my rock!"

"It always feels that they genuinely care. Always listen and offer great advice, feels like your opinion as a parent matters and overall my daughter enjoys coming to see the team."

"All members of staff are always really helpful and I am always kept well informed of the treatments and knowledge and my child's health and wellbeing."

"The team are amazing, from receptionist to consultants. They are also willing to help and advise and over the past 10 years feel more like an extended family."

"Can't comment on LGI as have never stayed overnight, but every time I have been to LGI I have had first class treatment."

"The CF team at Leeds provide such an excellent service, which takes away the stress of trying to get the 'right' care for your child. They all do their very best and are dedicated professionals. Having experienced 'shared care' at a district general hospital for 10 years we truly appreciate the level of care my daughter now receives."

"They are excellent."

"Exemplary staff. Professional and supportive. Only frustration is ward 'waiting times' to have 'lines' admitted and commence IVs/Collect meds."

"Always been there for us. Very helpful, hard at times being 75 miles away as we don't drive."

"Physio and dietitian not always available."

"Fantastic team!"

"Always happy with our CF team. My daughter couldn't be in better hands. She likes her CF team and she knows they look after her well. The members of staff stay consistent which is very important. We feel very lucky to have such an excellent CF team taking care of our daughter."

"I find the cross-infection poor in outpatient clinic. I have been in the waiting area with two other CF children when she is on the growers outpatient day as well."

"Always pleasant and helpful."

Patient/parent interviews

Parent A

She is very happy with the CF service at Leeds General Infirmary.

Outpatients: She explained that she and her daughter are led straight into side room at outpatient clinic to reduce risk of cross-infection. She observed that staff always use hand gels for hand hygiene, although she feels they could encourage patient/parent use more. Mother is very happy with advice given by the CF team at clinic – "they're straight forward with me" and she feels the clinics run smoothly and pretty quickly.

Inpatient care: Her daughter is quite well and so does not have regular inpatient care. On last admission last year mother was happy with ward staff's care and expertise and with the timing of treatments. She reported that her daughter was really happy with the food on the ward and that her daughter received physiotherapy twice a day, although couldn't comment on weekend physio as daughter was not in hospital at the weekend.

Homecare: Mother is really impressed with the service provided by Calea who deliver the IVs and ancillaries. She finds it easy to contact the CF team when necessary and had a good experience when trying to contact the Sister on the ward one weekend – "she was great". Only once has mother tried using her local district general hospital at Airedale, but she described the experience as "a nightmare", waiting four hours to be seen. LGI, however, dealt with the situation "there and then", so a repeat experience is unlikely. The clinical nurse specialist has come out twice to her daughter's primary school and will do so again once she's moved to secondary school, according to the mother.

Annual review: Her daughter with CF has a fear of needles and her mother feels that the CF team is good at showing empathy by bringing her favourite nurse over to deal with 'bloods' and plan 'bloods' to reduce the number of times they access veins. Her daughter's annual review is staggered over a number of appointments which mother and daughter prefer. Her daughter has been referred to a CF psychologist too with whom they are happy.

Mum and daughter attend Leeds CF Centre every six to eight weeks.

Area for improvement:

Mother feels that the experience is different when she and her daughter have to deal with the GP at the CF centre, rather than the CF consultants. She has felt a bit 'fobbed off' on occasions when dealing with the GP and feels that solutions/treatment is less aggressive than it should be in such situations. She feels that the most experienced CF specialists should work closely with the GP to ensure the same response and treatments.

Parent B

Outpatient care: Daughter with CF has milder CF due to her mutation – no enzymes needed and little or no respiratory issues.

Mother is very pleased with the care her daughter receives from the Leeds CF team. The team speaks with daughter and mother at outpatient clinics and the experience is good from the off – ie stress free, with free, simple and smooth parking process. On arrival at clinic they go straight to their allocated side room. Mother feels it's a child-friendly, welcoming environment. Mother and CF team are serious about hand hygiene and mother feels the team does this regularly and encourages her and her daughter too. Mother described "brilliant advice from the CF team, staff are encouraging, make a fuss of daughter and so daughter looks forward to clinic".

Mother feels the CF team is very approachable, easily contactable by phone and responds the same day and sometimes within the same hour or two. Mother has good rapport with CF team whom she feels understands that she is well informed too.

Inpatient care: Daughter hasn't required any.

Annual Review: Mother is happy that annual review is staggered rather than all tests on the same day. She feels this helps keep CF low profile in her daughter's life rather than it be an over burden. Mother is pleased that written reports after routine clinics and annual review are promptly received.

Homecare: Mother mentioned there has been no requirement for homecare. Clinical Nurse Specialist made home visit and school visit in her daughter's early years but does not feel this is required currently. Mother is happy to keep her daughter's CF low profile at school and outside whilst she is doing so well symptomatically.

Areas for improvement: Mother and daughter see four doctors on rotation; mother described the variation between them: two doctors are optimistic and two are more 'straight down the line' in their manner/treatment. She prefers the 'light touch', optimistic approach for her daughter. Mother did stress though that this is not a big gripe, rather an observation.

Parent C

Parent C has an adolescent daughter who attends Leeds CF centre.

Outpatients: Mother is happy with good segregation procedures to counter cross-infection at clinic. There is no waiting around in open clinic area; parent and daughter directed to side room on arrival and all staff are aware of the various 'bugs'. Weight and sats measured in consultancy room, sometimes spirometry is measured in same room, or in the treatment room.

Mother is happy with decisions discussed and made at clinic and she feels the CF team is good at speaking to her daughter, which includes discussing trials, access to treatments and updates. Mother cannot praise the CF team highly enough and commended the dietitian. At outpatient clinic they see/have access to all of the CF team including clinical psychologist, but haven't needed to see the social worker as yet.

Inpatient care: Has had colonoscopy and IVs as an inpatient. Ward staff are very reassuring to mother and daughter when daughter has been afraid. A long line insertion performed by skilled member of staff, to mother and daughter's relief. Mother reported that medications are given on time, unless staff are extremely busy and "even HCAs are good at wearing aprons". Daughter receives physiotherapy at weekends too on the ward, although not from the regular CF physios. Mother also commended the play specialist.

Although her daughter likes the ward catering which mother felt is "ok for hospital", mother makes some food to take in for her daughter and there's a limited choice of food on the hospital menu given her daughter's dietary restriction above and beyond cystic fibrosis.

Annual review: Mother explained that annual review assessments are staggered rather than all on the same day. She and her daughter prefer the staggered arrangement as all staff are available and it's not an ordeal. Annual review and all outpatient routine clinic appointments are followed quickly by a letter to home and GP.

Homecare: Mother explained that Lancashire PCT fund her daughter's homecare (PEG feed deliveries). The Sister on the ward at Leeds however changes her daughter's PEG button every three months. She felt that Abbot's home delivery service is fine. Similarly, they felt Calea home IV service is excellent. When on home IVs, a long line is inserted in the special IV room on the ward, first dose of IVs is given at clinic, Calea then checks Tobramycin levels, and the CF nurse visits mid-course to check the site and do spirometry. Second week of IV drugs is then delivered by Calea and a mid-and end-course sputum sample is taken by CF team.

Transition: CF Nurse came to visit the family (and school) when the daughter was moving to high school, to talk about increased responsibilities in CF, fertility etc. Her daughter is seen on her own at adolescent clinic; two adult team meetings attended. Daughter will possibly move to adult service when in the Lower Sixth at school. CF team put on a CF parents meeting where a mum with two recently transitioned sons gave a talk of the experience as did Cystic Fibrosis Trust patient advocate Lynsey Beswick. Mother found this all helpful.

Area for improvement: Mother could not suggest any improvements that could be made to the current paediatric CF service at Leeds.

Parent D:

Outpatient clinic: Parent feels happy with the outpatient experience – "no problems whatsoever, really nice team, no patients mixing, clinic appointments work around us". Parent feels that hand hygiene from staff is good and they encourage the same of children and parents. Mother feels that the CF team's advice and explanations are good and she and her adolescent daughter see/have access to all of the CF team at clinic. They regularly see the social worker and receive good advice.

Inpatient care: Mother feels that the care on the ward is very good, her daughter has "grown up with all the nurses", the nursing staff's knowledge is good and that medications are given on time unless the team are really busy. She described food on the ward as "not too bad, though sometimes the meals are boring" but her daughter is provided with snacks between meals and there's an 'alternative menu'.

Annual review: Mother feels that the 'staggered review' works ok. Her daughter's annual review bloods are done on the ward if in hospital, rather than at a formal annual review clinic. Annual review outcome, like routine outpatient clinic appointment outcomes, is reported back to parent by letter.

Homecare: Mother described the homecare as "good", explaining that the CF nurse does a home visit to check Tobramycin levels and to deal with any issues. She described the Calea home IV package as "an excellent service".

Transition: Mother is happy with the current transition process.

This parent felt there is no area for improvement to the current CF service, a service with which she is already happy.

Parent E:

Outpatient clinic: Mother is very happy with clinic arrangements – children might only meet briefly at reception, then it's guaranteed separation as she and daughter are led to a clean, bright sideroom and the CF team rotates to minimise cross-infection risk. Weight and height are measured in a separate room where patients again do not mix. Spirometry takes place in the consultancy side room. Mother and daughter "see physio and dietitian every other visit, but could see them each clinic if necessary". They have never needed to see the clinical psychologist or social worker. Outcome of clinic visit is reported back to parents by letter. Mother receives written report on outcomes of routine outpatient clinic appointments.

Inpatient Care: Young daughter last had inpatient IV treatment three years ago. Mother feels that the ward staff's knowledge is very good and that medications were given on time. She was happy that patients had separate rooms and that she, as parent, had very good ward kitchen facilities. She was pleased with the visiting times. Her daughter received physio each day and at the weekend, although not from a CF specialist physio at the weekend. She remarked how good the play worker was and that toys were always wiped down between patient use. She also commended the patient food on the ward.

Homecare: Daughter has never needed home IVs. The CF nurse makes a home visit twice yearly and they have discussed home IV routine as a preparatory measure 'in case'. Mother feels that all of the CF team are easily contactable and good at returning calls, the same day or next day as appropriate.

Annual review: Mother explained, at her previous CF centre annual review was more formalised, with a dedicated annual review appointment and feedback appointment. At Leeds, she explained, "the annual review is more laid back; not a dedicated appointment," and she does not receive a written annual review report. She would prefer a more formal annual review clinic and reporting back process.

Area for improvement: A more formal, dedicated annual review appointment and feedback process.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Leeds General Infirmary
	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	As patient numbers are increasing, space in the clinic area is almost at capacity.
Do patients spend any time in waiting room?	Yes	Minimal
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Specific height and weight room.
Where are the lung function tests done for each visit?		In each room – during consultation.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Distraction box, 3D TV, Xbox.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Kept separate.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Ready Steady Go programme presented.

Additional comments:

- Keeping patients isolated is becoming increasingly difficult.
- Those with cystic fibrosis are prioritised over respiratory patients.

Environmental walkthrough: Ward

Ward name: L30

Microbiology status: MRSA, Pseudomonas

		Hospital name	**Leeds General Infirmary** – 170 (full time care) patients 0- 17.5 yrs.
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		10	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	50/50 mix	
Do CF patients have to share any bathroom facilities?		No	Main bathroom has a bath and shower.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Locker – parents issued with a key.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes – free service	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Fold out bed in room	Parents' kitchen.
Visiting hours – are there allowances for CF patients families out of normal hours?		Yes	One parent 24 hrs. Second parent 0600-2200 hrs. Others 1000-2000 hrs. (3 max)
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Kitchen
What facilities are provided for teenagers?			PS3s, PlayStations, XBox

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		Gym in physio room – no specific gym
What facilities are there to help with school and further studies?		Teacher in hospital – daily visits.
Is there a relatives' room?		Parents room.
What internet access is there?		Full internet access.
What facilities are there to enable students to continue to work and study?		Visits from Hospital teacher. Internet access enables use of own laptops.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Provided with a washing bowl – waste is put down toilet.
What facilities are provided for those with MRSA?		Barrier nursing.
What facilities are provided for those with B. cepacia?		Moved to a different ward (wards 9 and 40). Wards 9 and 40 provide same facilities as L30.
What facilities are provided for those with other complex microbiology?		Transferred to ward 9 or 40.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	Leeds General Infirmary
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?		Free car park (outpatient apps). Parking permit issued once patient has been in hospital for seven days. 19 designated spaces for outpatient visitors.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	No	Scripts are faxed ahead of collection time so are pre-prepared.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Service provision questionnaire.

Hospital name

Bradford Teaching 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	Not assessed.	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Not assessed.	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Not assessed.	

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**	**Not assessed.**	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Not assessed.	
	% of MDT who receive an annual appraisal	100%	Green	Not assessed.	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Not assessed.	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Not assessed.	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Not assessed.	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Not assessed.	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Not assessed.	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Not assessed.	
	% of patients with cystic fibrosis-related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Not assessed.	

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	Not assessed.	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Not assessed.	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Not assessed.	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Not assessed.	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Not assessed.	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Not assessed.	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Not assessed.	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Not assessed.	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Not assessed.	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Not assessed.	
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	Not assessed.	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Not assessed.	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Not assessed.	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Not assessed.	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Not assessed.	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Not assessed.	
	% availability of a CF specialist dietitian at clinic	100%	Green	Not assessed.	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Not assessed.	
	% availability of a clinical psychologist at clinic	100%	Red - access when needed.	Not assessed.	
	% availability of a clinical psychologist for inpatients	100%	Red - access when needed.	Not assessed.	
	% availability of a social worker at clinic	100%	Red	Not assessed.	
	% availability of a social worker for inpatients	100%	Red	Not assessed.	
	% availability of a pharmacist at clinic	100%	Red	Not assessed.	
	% availability of a pharmacist for inpatients	100%	Green	Not assessed.	

4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Not assessed.	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Not assessed.	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Bradford Teaching Hospital
Consultant 1	0.5	1	1	0.5 PA
Consultant 2	0.3	0.5	1	0.5 PA
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.5 WTE
Physiotherapist	2	3	4	1 session in outpatient with inpatient duties.
Dietitian	0.5	1	1.5	1 session outpatients per week with twice-weekly input for inpatients.
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

UK CF Registry data

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

UK CF Registry data 2012	
Demographics of centre – Bradford Teaching Hospital	
Number of active patients registered (active being patients within the last two years)	21
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2012')	20
Median age of active patients in years	8.5
Number of deaths in reporting year	0
Median age at death in reporting year	n/a

Age distribution (ref: 1.6 'Annual Data Report 2012')		
Number and % in age categories	0–3 years	4 (20%)
	4–7 years	5 (20%)
	8–11 years	5 (20%)
	12–15 years	5 (20%)
	16+ years	1 (5%)

Genetics	
Number of patients and % of unknown genetics	5 (20%)

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

FEV_1 (ref: 1.14 'Annual Data Report 2012')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	1 (20%)
	8–11 years	0	2 (40%)
	12–15 years	3 (100%)	1 (20%)
	16+ years	0	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	5
	8–11 years	5
	12–15 years	5
	16+ years	1
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	2
	16+ years	0

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

Complication (ref: 1.16 'Annual Data Report 2012')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (5%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	3 (15%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH 1 (5%) without PH

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

IV therapy (ref: 1.21 'Annual Data Report 2012')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	28
	12–15 years	173
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	28
	4–7 years	47
	8–11 years	42
	12–15 years	100
	16+ years	0
Total number of IV days split by age group	0–3 years	28
	4–7 years	47
	8–11 years	70
	12–15 years	273
	16+ years	0

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2012')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=13); 10 (77%)
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 (10%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (5%) with chronic PA 1 (5%) without chronic PA

Patient survey

Bradford Teaching Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"The team have been excellent and very accommodating. Given the best care for my son."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	St Luke'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	
Do patients spend any time in waiting room?	Yes	Although minimal.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	In a specific H&W room.
Where are the lung function tests done for each visit?		In consultation room.
Are clinic rooms appropriately sized?	Yes	Six large clinic rooms.
For annual review patients, are any distractions provided?	Yes	Play leader if requested.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Two patients have diabetes and they are seen at a duel clinic (CF and diabetes).
Transition patients – can they get tour of outpatients' facilities?		Process being developed with Leeds.
Transition/new patients – do they get information pack?	Being developed	Ready Steady Go and PCD already used.

Additional comments:

- There is a problem with staffing when the dietician is on A/L.
- No EMIS system. 'System one' is used but this does not always 'speak' to other NHS systems.

Environmental walkthrough: ward

Ward name: 16 & 17 Children's Ward Acute Medical

Microbiology status: all microbiology

		Hospital name	Bradford Teaching Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?			None specific for CF care.
Do the en suites have:	**Toilets?**	Two rooms with.	There is only one room with full en suite facilities on ward 16 and two on ward 17.
	Wash basins?	Yes	
	Bath or shower?	Three in total en suite.	
Do CF patients have to share any bathroom facilities?		Yes	Rooms are deep cleaned often but not necessarily after every use.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Medication held by staff in a secure room.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes – free service	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Fold down beds in patient rooms
Visiting hours – are there allowances for CF patients families out of normal hours?		Yes	Parents – 24 hrs. 1100–1900 others (max three per bed).
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In the patient kitchen.
What facilities are provided for teenagers?			Wi-Fi available so own laptops can be used. DVD plays available.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Gym	The gym is not on the ward, the patients are taken to the gym by the physiotherapists.
What facilities are there to help with school and further studies?		School room with three teachers – schools can send in work that teachers help the patients with.
Is there a relatives' room?	Yes	
What internet access is there?		Unlimited access to internet.
What facilities are there to enable students to continue to work and study?		As above (teachers). A schools liaison officer also visits the ward.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Currently patients are able to wash nebuliser parts in their rooms and leave to air dry but not sterilise them.
What facilities are provided for those with MRSA?		Barrier nursing provided. Patients swabbed and tested on admission.
What facilities are provided for those with *B. cepacia*?		Provided with a standard en suite room. They would be placed on a separate ward if space allowed. If not, barrier nursed on this ward.
What facilities are provided for those with other complex microbiology?		Patients with complex microbiology are barrier nursed in own room. Again, they would be placed on a separate ward if space allowed.
Are patient information leaflets readily available on ward?	No	
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

- Bathrooms are not cleaned between uses.
- The ward was bright and clean but did feel a little dated.
- The staff interviewed said there was a good degree of nervousness in many patients and their families around transitioning to Leeds. The team are planning on working closely with the MDT at Leeds to ensure this process is as straightforward and comfortable as possible for those patients with particular concerns.

	Hospital name	St Luke's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	They never receive complaints about this.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Because of patient numbers, they are able to be staggered so there are never cross-infection issues.
Do patients have to wait at pharmacy for prescriptions?	No	Orders are phoned ahead of collection. An independent pharmacy (co-op) operates at this hospital.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	No	

Hospital name

Scarborough 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	Not assessed.	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Not assessed.	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Not assessed.	

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	Not assessed.	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Not assessed.	
	% of MDT who receive an annual appraisal	100%	Green	Not assessed.	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Not assessed.	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Not assessed.	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Not assessed.	

2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Not assessed.	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Not assessed.	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Not assessed.	
	% of patients with cystic fibrosis-related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Not assessed.	

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 Not all en suite, new ward block to be built.	Not assessed.	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Not assessed.	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green No isolates in 12 months.	Not assessed.	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Not assessed.	

3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Not assessed.	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Not assessed.	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Not assessed.	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A. No patients in this group.	Not assessed.	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Not assessed.	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Not assessed.	
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	Not assessed.	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Not assessed.	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Not assessed.	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Not assessed.	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Not assessed.	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Not assessed.	
	% availability of a CF specialist dietitian at clinic	100%	Green	Not assessed.	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Not assessed.	
	% availability of a clinical psychologist for inpatients and at clinic	100%	Red. Access when needed.	Not assessed.	

4.2 Inpatients/ outpatients	% availability of a social worker for inpatients and at clinic	100%	Red	Not assessed.	
	% availability of a pharmacist for inpatients and at clinic	100%	Red	Not assessed.	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Not assessed.	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green. Access to team.	Not assessed.	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Scarborough Hospital
Consultant 1	0.5	1	1	0.5 PA
Consultant 2	0.3	0.5	1	0.5 PA
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.5 WTE
Physiotherapist	2	3	4	One session in outpatient with inpatient duties.
Dietitian	0.5	1	1.5	One session in outpatients per week, with twice weekly input for inpatients.
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

UK CF Registry data

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

UK CF Registry data 2012	
Demographics of centre – Scarborough Hospital	
Number of active patients registered (active being patients within the last two years)	6
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	6
Median age of active patients in years	12
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 'Annual Data Report 2012')		
Number and % in age categories	0–3 years	0
	4–7 years	1 (16.5%)
	8–11 years	0
	12–15 years	4 (64%)
	16+ years	1 (16.5%)

Genetics	
Number of patients and % of unknown genetics	3 (50%)

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

FEV_1 (ref: 1.14 'Annual Data Report 2012')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	2 (100%)	0
	16+ years	0	0

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

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

Complication (ref: 1.16 'Annual Data Report 2012')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (16.5%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	0
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

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

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

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2012')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n= 5; 3 (60%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2012')	
Number and % of patients with chronic PA infection	0
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	0
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA 1 (16.5%) without chronic PA

Patient survey

Scarborough Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Due to retirement of both consultants at LGI and pending retirement of consultant in Scarborough in 2014, requested daughter's care is all transferred to Leeds as we know all team. Need some continuity do not wish to transfer care to York. Dedication on both teams, Scarborough hospital appointment system changed to detriment - no fault of CF clinic or team."

"Scarborough CF team has been fantastic to us and we can't rate them enough!"

	Hospital Name	Scarborough Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	No	Limited enclosed waiting room. Some toys for use.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	No	A separate room which is also the staff nurse's office, a small slightly cramped office although functional. Future plans would include having mobile equipment for use in clinic rooms.
Where are the lung function tests done for each visit?		Clinic room, portable machine is rotated round the rooms.
Are clinic rooms appropriately sized?	No	Can feel cramped at times, depending on how many parents/siblings and team members in the room.
For annual review patients, are any distractions provided?	N/A	Not carried out here at present. Patients will go to Leeds and York.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	No	
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	Use Leeds pack.

Additional comments:

- On arrival at the hospital there appeared to be a huge amount of parking; the panel was later informed that there had been a new car park opened that day, however another car park will close to make way for a new build. This will house the new children's outpatients' clinic and will consist of six consultant rooms; this is due to be completed in 2015.
- The signage at reception area was clear. The clinic is located on the basement floor, once down the stairs the corridor which leads to the clinic is very long and dimly lit, the décor is plain and drab, and there is no child-orientated artwork on the walls. The entrance to the clinic had a sign above the door which was quite small. Through the door there is a reception desk and seating for the clinic patients. The walls are plain, drab with no artwork; there are some toys for use on a table. There are pictures of the team on the wall.

- Since the senior consultant retired, the service having only six patients was too small to be sustainable. The team at York is happy to have an outreach clinic there to keep the present service running and this is also welcomed by the staff nurse and community nurse at Scarborough.
- Scarborough Hospital no longer has cystic fibrosis inpatients and they will now go to York Hospital. The York team held the first clinic recently; this has already received positive feedback from the parents as their children get to see the whole team, half the team rotated between the two clinic rooms. The clinic appointments were staggered and six patients were seen in five hours and the rooms were aired in between patients.
- Clinic is planned to be held bi-monthly, next clinic due in May.

Environmental walkthrough: Other

	Hospital name	Scarborough Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	At present patients pay on arrival. £1.20 1 hour. £2.50 2 hours. £3.50 3 hours. £6 5+ hours. There appeared to be ample parking. A new car park opened on day of visit. However parking will be removed to make way for the planned new build.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Clearly signed at main entrance. Small sign at clinic entrance.
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 – appointments are staggered very unlikely patients should come into contact. The staff nurse informs me she sometimes collects prescriptions. The waiting area is a row of seven seats in the corridor. A doorway leads to the pharmacy reception – a very small area. X-ray has seating for 20+ patients, large enough area to sit apart at each end of room if required. Appointments are staggered. No DEXA.
Do patients have to wait at pharmacy for prescriptions?	Yes	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	At the main entrance with leaflets.
Are there patient comment/ feedback boxes?	No	Will soon have friends and family.

Additional comments:

- The staff nurse intends to speak with the consultant concerning future arrangements for prescription collection during clinic. She says she is willing to collect the prescriptions for the patients. At present it is highly unlikely the patients will meet at pharmacy.

York paediatric CF service

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	Not assessed.	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Not assessed.	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Not assessed.	

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 Hope to improve by Jan 14.	Not assessed.	Leeds/York teams report now green (at the time of the peer review visit Oct 2014).
	Do staffing levels allow for safe and effective delivery of service?	Y/N	N	Not assessed.	
	% of MDT who receive an annual appraisal	100%	Amber	Not assessed.	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Amber	Not assessed.	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Amber	Not assessed.	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red	Not assessed.	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Not assessed.	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Not assessed.	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Not assessed.	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	N/A	Not assessed.	

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 Toilet only	Not assessed.	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Not assessed.	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Not assessed.	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Not assessed.	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Not assessed.	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Not assessed.	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Not assessed.	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A	Not assessed.	
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%	Amber	Not assessed.	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Red	Not assessed.	
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	Not assessed.	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Not assessed.	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Not assessed.	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Not assessed.	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Not assessed.	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Not assessed.	
	% availability of a CF specialist dietitian at clinic	100%	Green	Not assessed.	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Not assessed.	
	% availability of clinical psychologist at clinic	100%	Red.	Not assessed.	
	% availability of a clinical psychologist for inpatients	100%	Red	Not assessed.	
	% availability of social worker for at clinic	100%	Red	Not assessed.	
	% availability of social worker for inpatients	100%	Red	Not assessed.	
	% availability of pharmacist at clinic	100%	Green	Not assessed.	
	% availability of a pharmacist for inpatients	100%	Green	Not assessed.	

4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Not assessed.	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	Not assessed.	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0%	Not assessed.	
5.2	Number of clinical incidents reported within the past 12 months	<1%	1	Not assessed.	
5.3	User survey undertaken a minimum of every three years	100%	Red	Not assessed.	
5.4	Service level agreements in place for all	100%	Red	Not assessed.	Leeds team reports this as green: CF SLA in place for York and Scarborough Trust.

UK CF Registry data

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

UK CF Registry data 2012	
Demographics of centre – York Hospital	
Number of active patients registered (active being patients within the last two years)	14
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	14
Median age of active patients in years	7.5
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 'Annual Data Report 2012')		
Number and % in age categories	0–3 years	4 (29%)
	4–7 years	3 (21%)
	8–11 years	2 (14%)
	12–15 years	4 (29%)
	16+ years	1 (7%)

Genetics	
Number of patients and % of unknown genetics	0

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

FEV_1 (ref: 1.14 'Annual Data Report 2012')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	1(33%)
	12–15 years	3 (30%)	2 (67%)
	16+ years	2 (20%)	0

Lung infection (ref: 1.15 'Annual Data Report 2012')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	4
	4–7 years	3
	8–11 years	2
	12–15 years	4
	16+ years	1
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 (7%)
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	2 (14%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	1 (7%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

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

IV therapy (ref: 1.21 'Annual Data Report 2012')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	12
	12–15 years	18
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	16
	12–15 years	23
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	38
	12–15 years	41
	16+ years	0

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2012')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n= 7; 5 (71%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2012')	
Number and % of patients with chronic PA infection	1 (7%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA 4 (28%) without chronic PA

Patient survey

York Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

Comments about CF team/hospital

"Fantastic, reliable, caring, knowledgeable - great support as a parent my child is very well I can only thank the staff at York and Leeds."

"Exemplary staff. Professional and supportive. Only frustration is ward waiting times to have lines admitted and commence IVs/collect meds."

Outpatients/CF clinic

	Hospital name	York Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Patients are taken to rooms on arrival.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Portable equipment taken to clinic rooms.
Where are the lung function tests done for each visit?		Portable equipment taken to clinic rooms.
Are clinic rooms appropriately sized?	Yes	Four rooms; three good size, one smaller which can be a little cramped if parents bring siblings.
For annual review patients, are any distractions provided?	N/A	Patients go to Leeds.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Separate (adolescent) diabetes clinic. Had only one diabetic patient, therefore segregation not an issue.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?		Uses the Cystic Fibrosis Trust's new patient information.

Additional comments:

- Four clinic rooms. Six to eight patients seen at each monthly clinic on staggered appointments. Waiting room – well equipped, large area with a good selection of toys, seating for 20+. Leaflets displayed on walls. Newly diagnosed are visited at home and they then meet the team at the assessment unit. All team contact details are given to the parents and regular phone contact made.
- There are plans to convert an emergency exit into a 'way out' so that patients do not cross paths.

Environmental walkthrough: Ward

Ward name: 17

Microbiology status: All microbiology

		Hospital Name	York Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	There has never been more than one CF patient admitted at one time, should the need arise it would not be suitable at present.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Three rooms with toilet only.
Number of side rooms?		3	Total of 10 rooms, only three side rooms suitable for a CF patient. *See comments.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	No	
Do CF patients have to share any bathroom facilities?		Yes	Baths and showers.
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward)		No	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	All have wall mounted TVs.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Camp beds in rooms. Separate shower and toilet. Parents room – TV, seating, fridge and drinks making facility.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Parents and siblings can visit anytime. General times 3–8pm. They would not generally turn people away.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Patients kitchen – fridge and microwave.
What facilities are provided for teenagers?			Teenage room. TV. IT/internet. Games consoles and games.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is gym access to the physio room. Equipped with mini bikes, trampoline, exercise balls and slide. Trampette and bikes can be used in the rooms. Patients can also go out during stay.
What facilities are there to help with school and further studies?		School room. There are two teachers available Monday to Friday. Exam supervision if required.
Is there a relatives' room?	Yes	Parent's room. Fridge and TV.
What internet access is there?		Wired access in the teenage room.
What facilities are there to enable students to continue work and study?		Can bring own equipment, use of teachers.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Bowl in room to wash and air dry, or can boil in the kitchen. Parents can take home or bring in own sterilisers.
What facilities are provided for those with MRSA?		Have none. Would follow isolation policy.
What facilities are provided for those with *B. cepacia*?		One patient. Follow isolation policy.
What facilities are provided for those with other complex microbiology?		Have none. Would follow isolation policy.
Are patient information leaflets readily available on ward?	Yes	General leaflets. Print off as required.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

- They have a business case in the process of being passed to increase staffing to give protected time dedicated to cystic fibrosis. To make the adult service sustainable they want to invest in the paediatric service. There will be another business case put forward in the near future for improvements to ward rooms and create en suites to two side rooms and for more room in outpatients. The two rooms are situated at each end of the ward and both could be converted to accommodate en suite shower/wet rooms and would be segregated from each other.
- Patients – 25
- Security intercom for entry to the ward.
- Physio room – exercise tests for the annual review are carried out here.
- Teenage room with seating, equipped with sink, microwave, hot drinks tap and fridge. Use of two computers with wired internet available. TV, DVDs, music system, Play Station, XBox, Wii.
- Parents can use the ward kitchen facilities with microwave.

- Treatment room – large room equipped for lines etc.
- Sensory room – well equipped with padded seating mats, mirrors and many sensory distractions.
- Assessment unit – open 9am–8pm weekdays. When closed at weekends patients have direct contact with the ward. Two cubicles for CF use. Large and well equipped play room. Use of kitchen and patients and parents can have food off the trolley from the main ward. Patients would not stay here more than two hours.

Environmental walkthrough: Other

	Hospital name	York Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	It has recently been agreed that all CF patients can get free parking.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To ward. Clinic is a separate children's unit with its own entrance.
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	X-ray – large area. Pharmacy – IVs are home delivered, prescriptions via GP. No DEXA – this is carried out on A/R at Leeds.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	In main reception, general information leaflets and comments/feedback box.
Are there patient comment/ feedback boxes?	Yes	Periodically they have electronic feedback; this is a Trust-wise initiative. Will have 'Friends and Family' in the near future.

Huddersfield Royal Infirmary and Calderdale Royal 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	Not assessed.	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Not assessed.	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Not assessed.	

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.	Not assessed.	Leeds and Carderdale teams report this is now green by time of peer review visit in October 2014.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Not assessed.	
	% of MDT who receive an annual appraisal	100%	Green	Not assessed.	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Not assessed.	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Not assessed.	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Not assessed.	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Not assessed.	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Not assessed.	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Not assessed.	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	N/A	Not assessed.	

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	Not assessed.	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Not assessed.	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Not assessed.	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Not assessed.	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red 24hrs up to a few days.	Not assessed.	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Amber 5/6 pts eligible had GTT.	Not assessed.	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Not assessed.	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red	Not assessed.	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Not assessed.	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Not assessed.	
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	Not assessed.	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Not assessed.	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Not assessed.	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Not assessed.	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Not assessed.	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red Usually twice. Patient wanted 2nd treatment at home	Not assessed.	
	% availability of a CF specialist dietitian at clinic	100%	Green	Not assessed.	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Red	Not assessed.	
	% availability of a clinical psychologist at clinic	100%	Red	Not assessed.	
	% availability of a clinical psychologist for inpatients	100%	Red	Not assessed.	
	% availability of a social worker at clinic	100%	Red	Not assessed.	
	% availability of a social worker for inpatients	100%	Red	Not assessed.	
	% availability of a pharmacist at clinic	100%	Red	Not assessed.	
	% availability of apharmacist for inpatients	100%	Green	Not assessed.	

4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Not assessed.	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	Not assessed.	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Huddersfield Royal Infirmary and Calderdale Royal Hospital
Consultant 1	0.5	1	1	Two PAs per month.
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	Two PAs per month.
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	One day a week.
Physiotherapist	2	3	4	Two PAs per month.
Dietitian	0.5	1	1.5	Two PAs per month.
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	Ad hoc basis.
Secretary	0.5	1	2	As needed.
Database coordinator	0.4	0.8	1	
CF unit manager				No designated time allocated.

UK CF Registry data

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

UK CF Registry data 2012	
Demographics of centre – Huddersfield Royal Infirmary	
Number of active patients registered (active being patients within the last two years)	13
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	12
Median age of active patients in years	11
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 'Annual Data Report 2012')		
Number and % in age categories	0–3 years	2 (16.5%)
	4–7 years	2 (16.5%)
	8–11 years	2 (16.5%)
	12–15 years	2 (16.5%)
	16+ years	4 (34%)

Genetics	
Number of patients and % of unknown genetics	2 (16.5%)

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2012')	
Patients with a BMI percentile <10th centile on supplementary feeding	2 (16.5%)

FEV_1 (ref: 1.14 'Annual Data Report 2012')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	1 (50%)
	12–15 years	3 (30%)	1 (50%)
	16+ years	2 (20%)	0

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

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	2 (16.5%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	0
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complication (ref: 1.16 'Annual Data Report 2012')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (8%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	5 (8%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0

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

IV therapy (ref: 1.21 'Annual Data Report 2012')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	10
	8–11 years	0
	12–15 years	5
	16+ years	60
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	18
	8–11 years	0
	12–15 years	44
	16+ years	10
Total number of IV days split by age group	0–3 years	0
	4–7 years	28
	8–11 years	0
	12–15 years	49
	16+ years	70

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

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2012')	
Number and % of patients with chronic PA infection	1 (8%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA 0 without chronic PA

Patient survey

Calderdale Royal Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate the following?

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

Comments about CF team/hospital

"We cannot praise our CF team/hospital enough they have always been there for us day or night and have always done an excellent job."

"Shared care worked well with family life however we feel let down by the transitional arrangements (to adult) available at LGI to shared patients. We have been told these are non-existent. Staff at both hospitals need to talk to the young person not the parent. At almost 17 my son finds this insulting."

Outpatients/CF clinic

	Hospital name	Calderdale 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 - the space is adequate	The waiting area is very small.
Do patients spend any time in waiting room?	Yes	Minimal – escorted to own room ASAP on arrival and stay there for the duration of their appointment following a visit to the H&W measuring room.
Is there easy access to toilets?	Yes	In main waiting area.
Where do height and weight measurements take place? Is this appropriate?	In a H&W measuring room	Appropriate – half an hour is left between each use.
Where are the lung function tests done for each visit?		These are also done in the H&W room, which is not common practice at other services.
Are clinic rooms appropriately sized?	Yes	Very adequate and comfortable.
For annual review patients, are any distractions provided?		Annual reviews are done at Leeds.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		None of the patients at this service currently have diabetes.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Provided with information/Cystic Fibrosis Trust resources.

Additional comments

- A very pleasant outpatient's area. The one thing to highlight is the size of the waiting area but the staff interviewed feel that it is currently appropriate. The department is very light and airy.

Environmental walkthrough: Ward

Ward name: 3 Children's Ward

Microbiology status: General

		Hospital Name	Calderdale Royal Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?			Not a dedicated CF ward but suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		16	
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)			Staff handle all drugs.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes – free	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull out beds in patient rooms.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	24 hr visiting.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?			Wii, Xbox.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		Patients taken to physiotherapy area for gym equipment use.
What facilities are there to help with school and further studies?		Teacher visits.
Is there a relatives' room?	Yes	
What internet access is there?		Full internet access.
What facilities are there to enable students to continue work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	There are separate treatment rooms within the ward (where a line would be put in for example). Sinks are provided in these rooms for the washing of these parts.
What facilities are provided for those with MRSA?		Barrier nursing in own rooms.
What facilities are provided for those with *B. cepacia*?		Separated – they would be barrier nursed on the ward.
What facilities are provided for those with other complex microbiology?		No patients with complex microbiology.
Are patient information leaflets readily available on ward?	No	None specific to cystic fibrosis.
Transition patients – can they get tour of ward facilities?	Yes	Visits arranged with Leeds.

Additional comments

- The ward has been newly refurbished. It is very light and airy. It is circular in shape so nobody feels overlooked. There is a nice outside play area. The inside play area is well equipped with a good range of materials for children to play and learn with.

	Hospital name	Calderdale Royal Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	The car park is extremely busy. Patients often struggle to park. The problem has been exacerbated whilst renovation work has been going on in and around the hospital.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	No	The script is sent ahead of collection and is ready to be collected at the end of the patients visit to the hospital.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Both leaflets and posters.
Are there patient comment/ feedback boxes?	Yes	Friends and family feedback cards are used.

Additional comments:

- The consultant would like to build up the nurses' expertise in CF care and so would like them to spend some time in Leeds.
- Car parking is expensive – especially for those staying on the ward. The cost is £5 a day and the spaces are extremely limited.

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	Not assessed.	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Not assessed.	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Not assessed.	

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%	Amber	Not assessed.	Leeds team comments that all three patients are offered twice yearly full MDT review but not all patients choose to attend both visits.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Not assessed.	
	% of MDT who receive an annual appraisal	100%	Green	Not assessed.	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Not assessed.	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Not assessed.	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Not assessed.	
	Are there local operational guidelines/ policies for CF care?	100%	Green	Not assessed.	

2.1 Multi-disciplinary care	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Not assessed.	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Not assessed.	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Not assessed.	

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	Not assessed.	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Not assessed.	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Not assessed.	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Not assessed.	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Not assessed.	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Not assessed.	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Amber Unsure	Not assessed.	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Not assessed.	
3.7 Reduced bone mineral density (BMD)	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Amber Unsure	Not assessed.	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Not assessed.	
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	Not assessed.	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Not assessed.	

4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Not assessed.	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Not assessed.	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Not assessed.	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber General physio.	Not assessed.	
	% availability of a CF specialist dietitian at clinic	100%	Green	Not assessed.	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	Green	Not assessed.	
	% availability of a clinical psychologist at clinic	100%	Red	Not assessed.	
	% availability of a clinical psychologist for inpatients	100%	Red	Not assessed.	
	% availability of a social worker at clinic	100%	Red	Not assessed.	
	% availability of a social worker for inpatients	100%	Red	Not assessed.	
	% availability of a pharmacist at clinic	100%	Green	Not assessed.	
	% availability of a pharmacist for inpatients	100%	Green	Not assessed.	

4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Not assessed.	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Not assessed.	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Barnsley Hospital
Consultant 1	0.5	1	1	Not defined.
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	Not defined.
Physiotherapist	2	3	4	Not defined.
Dietitian	0.5	1	1.5	Not defined.
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	Not defined
Secretary	0.5	1	2	Not defined
Database coordinator	0.4	0.8	1	

UK CF Registry data

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

UK CF Registry data 2012	
Demographics of centre Barnsley Hospital	
Number of active patients registered (active being patients within the last two years)	4
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2012)	4
Median age of active patients in years	11.5
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 'Annual Data Report 2012')		
Number and % in age categories	0–3 years	0
	4–7 years	0
	8–11 years	2 (50%)
	12–15 years	1 (25%)
	16+ years	1 (25%)

Genetics	
Number of patients and % of unknown genetics	0

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

FEV_1 (ref: 1.14 'Annual Data Report 2012')			
Number of patients and % with FEV_1 <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	0	0
	16+ years	1 (100%)	0

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

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

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

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

IV therapy (ref: 1.21 'Annual Data Report 2012')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	56
	12–15 years	0
	16+ years	28
Total number of IV days split by age group	0–3 years	0
	4–7 years	0
	8–11 years	56
	12–15 years	0
	16+ years	28

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2012')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	n= 3: 3 (75%)
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 (25%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (25%) with chronic PA 0 without chronic PA

No surveys received from Barnsley Hospital patients

	Hospital name	Barnsley 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	Staff are CF aware. Dedicated CF clinics every six to seven weeks. There are three clinic rooms. Six to 10 patients are seen at clinic and are given staggered appointments. Staff rotate round to the rooms. Spirometry tests are carried out in rooms; the rooms are aired for one hour between patients.
Do patients spend any time in waiting room?	No	Patients are sent directly to the room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Two rooms. A separate room for babies and older children. (No imminent plans for H & W to be done in individual rooms – this has been discussed and there are a number of practical barriers; however, they will bear in mind the issue of possible infection control issues from using a shared room for growth measurement and will actively consider how they can address this.)
Where are the lung function tests done for each visit?	In clinic rooms	
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	N/A	Annual review at Sheffield or Leeds.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	Have no diabetic patients. If they did they would go to the diabetes clinic.
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	Yes	Staff would be notified via fax from Sheffield or Leeds on diagnosis within 24 hours. Parents would be given information needed. For a new diagnosis the consultant would print out the Cystic Fibrosis Trust's info pack to give the family at the first visit; they also receive a copy of the detailed clinic letter on initial visit (and each visit subsequently).

Additional comments

- The clinic is situated on the first floor, access by lift. There is a large notice notifying patients outside the clinic that it is being redecorated. The corridor is child-friendly, decorated with animals on walls. Themed murals are planned for the rooms in the near future; Mickey Mouse, fairies and animals. The waiting area; enchanted garden. Large 18 seat waiting area containing children's table and chairs, a play assistant helping a child draw and colour. Large selection of toys and books, table top train set. Wall mounted TV. Water machine. Pictures of team members on wall. Leaflet stand. Adolescent waiting room – containing seating, TV, DVD's, Wii, games.

Environmental walkthrough: ward

Ward name: 37

Microbiology status: All microbiology (0-16yrs)

		Hospital Name	Barnsley Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Suitable	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		2	Total of 12 rooms. Two with en suite facilities.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	1 bath/1 shower	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bed for adults? (Include in notes policy of ward)		Yes	Rooms have lockable drug cupboards.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	All rooms have wall mounted TVs.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Fold up beds available.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Open	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In the parents room.
What facilities are provided for teenagers?		Yes	Teenage zone (The Retreat) for the over 12s. Room with seating. Well equipped with TV, games, table football, music centre and DVDs.

	Yes/no/ number/N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Physiotherapy gym. Trampette can be used in rooms.
What facilities are there to help with school and further studies?		Parents arrange with schools.
Is there a relatives' room?	Yes	Parents room with seating, containing fridge, microwave and kettle.
What internet access is there?		Wi-Fi was originally installed however there were security issues with parents, this is not in use. Patients can bring own facility if required.
What facilities are there to enable students to continue work and study?		Can bring own laptop, parents to liaise with schools. Patients in for IVs could be encouraged to go home and continue their treatments at home.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Basin in rooms.
What facilities are provided for those with MRSA?		Have none, have good infection control. Would follow the Cystic Fibrosis Trust's policy.
What facilities are provided for those with *B. cepacia*?		Would follow the Cystic Fibrosis Trust's policy.
What facilities are provided for those with other complex microbiology?		Would follow the Cystic Fibrosis Trust's policy.
Are patient information leaflets readily available on ward?	Yes	General leaflets available. CF leaflets would be printed on request as there are so few CF patients.
Transition patients – can they get tour of ward facilities?	N/A	

Additional comments

- 12 patients; nine attend shared care with Sheffield and three with Leeds.
- The hospital is a large modern building. Ward 38 is located on the 8th Floor. There is a good four-lift service. Security entry doors to the ward. The corridors walls have many notice and information boards. Very child friendly and bright artwork along the corridors.
- Team members are in regular contact with each other and have a good working relationship, they will always inform each other of any issues concerning the patients' conditions, however they do not have a designated time for team meetings, they are aware of this and this is something they plan to do in the future. Addendum Nov 2014: these regular Barnsley CF MDT meetings now occur regularly after alternate CF clinics, and are minuted.
- The play room is very large and very well equipped with toys.
- Treatment room – large well equipped room with distractions.
- Child assessment unit.
- Open Monday to Friday 9am–8pm. Out of these hours patients call the ward direct. There is a very large waiting room with many toys and distractions.
- Assessment cubicle, very well equipped, own en suite.

	Hospital name	Barnsley Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Overnight parents can get a pass for free parking or a set fee of £5 per week.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	The signage is new and very clear to read to both ward and 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 – a very spacious waiting area with 40+ seats. X-ray – also a large waiting area. DEXA – Sheffield Children's Hospital for the SCH shared care patients; Leeds General Infirmary for the Leeds shared CF patients.
Do patients have to wait at pharmacy for prescriptions?		Could wait, however due to low number of patients, they are unlikely to come in contact. Inpatients prescriptions internally supplied so no need to visit pharmacy.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Clinic entrance notice advertising PALS. Kiosk on ground floor main entrance, with information board.
Are there patient comment/ feedback boxes?	Yes	Clinic O/P reception. Comments box in teenage room.

Additional comments

- Regular monthly surveys – outcomes and suggestions are displayed on the walls of O/P, staff office and clinic.

Panel members

Kevin Southern*	Reader and Honorary Consultant	University of Liverpool
Lucy Paskin	CF Specialist Pharmacist	Birmingham Children's Hospital
Clare Dixon	CF Specialist Psychologist	Alder Hey Children's Hospital
Michelle Tabberner	CF Clinical Nurse Specialist	Birmingham Children's Hospital
Helen McCabe	CF Principal Dietitian	Great North Children's Hospital
Katie Ferguson	CF Specialist Physiotherapist	Kings College Hospital
Anne Dealtry	CF Social Worker	Nottingham Hospital
Sian Summers	CF Service Specialist	Commissioning Wessex
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

cysticfibrosis.org.uk