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Cystic Fibrosis why we're here

British Thoracic Society

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Peer review report

John Radcliffe Hospital and Paediatric Network Clinics

5 February 2015

Contents

1. Executive summary

Overview of the service

The Oxford Paediatric Cystic Fibrosis service delivers high-quality care to 185 children and young people. Of these, 56 have full care at the specialist centre, John Radcliffe Hospital (JRH). The rest share care with five network clinics: Northampton General (NGH), Reading Royal Berkshire (RBH), Milton Keynes, Heatherwood & Wexham Park, and Buckinghamshire (Stoke Mandeville & High Wycombe). Service Level Agreements (SLAs) are set up so each network clinic receives a standard amount of money per patient, irrespective of banding, all home intravenous (IV) antibiotics costs being claimed back from the specialist centre. Annual reviews take place at JRH, with network patients also seeing the Oxford multidisciplinary team (MDT) at one of the quarterly outreach clinics.

Network MDT staff are very committed, but appear overstretched with non-cystic fibrosis (CF) commitments. Insufficient time is allocated to CF, so MDT availability (out and inpatient) does not always meet the essential standard of care. Patient/family feedback is generally very positive.

Good practice examples:

- A robust, established hub-and-spoke model, with strong central leadership and enthusiastic, committed network teams that have considerable experience, striving to provide excellent care.
- Excellent “Mychox” guidelines available online, and IT infrastructure to provide reports for annual reviews etc.
- Home IV service funded centrally, providing equity of care across network.

Key recommendations:

- Review of the existing MDT manpower, where there is a shortfall, particularly in dietetics. A dietitian should be part of the JRH MDT at network outreach clinics.
- Psychology services should be rationalised, with either increased resources at the network clinics where lacking or limited locally, or agreed outreach from the centre psychologist to the network clinics.
- The review team recommended the appointment of a CF social worker or family support worker, to free up nursing time and improve the overall service to patients and families, providing support and resource at the centre and outreach for the network clinics.
- The transition to adult services needs to be more consistent, particularly to improve the process for those attending the network clinics. The move of the adult CF team and service to the JRH site should provide more opportunity to develop this further.
- The pressure and shortage of outpatient rooms at JRH for annual review clinics needs to be addressed.
- The network should consider central provision of physio equipment, to give more equity across the network.

Areas for further consideration:

- Consideration should be given to increasing the support from a CF-specialist pharmacist, with outreach from the centre to network clinics.
- It should be a priority for all MDTs involved in CF care, including the MDT at the network clinics, to attend the regional network meetings.
- Provision of ensuite facilities for inpatient wards should be considered.
- Following the annual review, feedback to the MDT at the network clinics should be improved, with the report made more readily available.
- User feedback via survey was lacking at most clinics, and should be instigated across the network.
- There should be a clear audit trail of the funding received by each network clinic to monitor and ensure that the correct level of service is in place.

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

Models of care

Summary

- There is a robust hub-and-spoke model with five well established network clinics of reasonable size. Those network clinics with fewer Oxford patients manage additional CF patients whose care is shared with London hospitals, eg Royal Brompton and Great Ormond Street.
- The full JRH specialist MDT (except for the psychologist, who only sees 50% of children) sees all children at annual review. Results are fed back to the local network consultant, an action plan is sent to the child and family, and further discussion takes place at the next clinic. Although there is an email or telephone discussion from the specialist to the local MDT, comments from local MDTs suggested that it would be useful for the full annual review report to be more readily available and disseminated to the local MDT, as well as the network consultant.

Multidisciplinary care

Summary

- There is an enthusiastic and committed MDT at JRH and the five network clinics. There is a need, however, for more dietetic and psychology support, together with more consistent physiotherapy provision across the network. Increased physiotherapy resource is required to improve inpatient physiotherapy at weekends and availability for home visits, as appropriate, so that there is a more equitable service across the network. Where resources are particularly limited, eg in dietetics, the centre has endeavoured to target the most vulnerable patients.
- The review team were of the opinion that provision of a social worker dedicated to CF would free up nursing time and provide better liaison with social care agencies.
- The pharmacy provision at Oxford should be increased in order to meet standards, and support the pharmacists at the network clinics.
- There is a need for some administrative support for the nursing team.
- Not all the local MDT members had attended a CF educational meeting in the past year. The annual Oxford Regional Network meeting was valued by those who attended as an excellent opportunity to learn, discuss and network. Network MDT staff should be encouraged and enabled to prioritise this meeting, as part of their ongoing CF education and professional development.
- There are excellent local operational guidelines and policies ("Mychox"), available on the JRH intranet and via the internet for all the network clinics to access.
- Children and young people with CF are participating in various multicentre trials. JRH and some of the network clinics are actively auditing aspects of their CF service, and implementing changes accordingly.

Principles of care

Summary

- Infection control is generally good, except for lack of ensuite bathrooms at many of the hospitals.
- There is pressure on the outpatient rooms at CF clinics and annual reviews at JRH.
- Most clinics are not doing weights and heights in the patient's room. If done in a communal room, time must be left between patients and equipment cleaned.
- Management of respiratory and other complications is appropriate, but nutritional status (other than at NGH) is of concern. This is being addressed, with the current limited dietetic resource focused at those patients with lower BMI centiles.
- Many hospitals had a lack of aminoglycoside levels within 24 hours, but in-house assays are likely to be available during 2015 at JRH.

Delivery of care

Summary

- Consultant and specialist nursing availability was good, but dietitian resource was variable. Some of the network centres lacked routine weekend access to a physiotherapist.
- There was variable access to psychology.
- There was no social worker, with the nurses performing some of their role.
- Communication of outpatient letters from the centre was excellent and prompt, and generally the same from the networks.
- There is an established homecare IV service using a private provider. Some concern was expressed by the panel about the lack of a prescription check by a pharmacist at some network clinics.
- Transition to adult services appears to be patchy across the network, requiring a more robust process and agreed pathway.

Commissioning

Summary

The Oxford service has a supportive management team and this has helped to implement the annual 'year of care' tariff for the last three years and agree SLAs with all of the spokes. The spokes are paid a set fee per patient, irrespective of the patient's level of care, as all home IV costs and excluded drugs are charged through the hub. This established approach works well as the spokes are aware of the funding they will receive per patient.

- It would, however, be helpful if the network could provide a clear audit trail for this funding as it is difficult to make a connection between the money paid to the spoke Trusts and what is received by the services, and to monitor that the correct level of service is in place.

Staffing at the OUH is being addressed to resolve some of the shortfalls with increases in psychology (0.6 WTE), dietetics (0.3 WTE) and pharmacy time (0.1 WTE). The service has no specific social-worker input, but it is fulfilled by the CF nurse at all of the services, who are aware of the local infrastructure for access to support for patients.

- Each spoke needs to ensure that there is sufficient CF nurse time to fulfil this additional role.

The network holds regular meetings to discuss progress and issues. The network should ensure that there is attendance from representatives of all MDT groups, (both the hub and spokes) at these meetings.

Transition clinics are held three or four times a year, with invitations to look around the adult unit for those planning to transition to the Oxford adult service. There is no formal transition programme in place to help prepare patients and their families and to assess their readiness for transition, regardless of their destination.

- It is recommended that the service adopts or develops a formal process to address this need.

There have been no complaints or incidents recorded relating to the service.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	167 (total network): 133 (Oxford) and 34 (Northampton)

			Male	Female
FEV$_1$	Number and % of patients with FEV$_1$ <85% by age range and sex	0–3 years	0	0
		4–7 years	2 (3%)	0
		8–11 years	5 (7%)	8 (13%)
		12–15 years	13 (18%)	11 (18%)
		16+ years	5 (7%)	4 (7%)

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	n = 21; 9 (43%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	7 (5%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	7 (100%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	4 (57%) with chronic PA
	Number and % of patients on chronic macrolide without chronic PA infection	17 (14%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

There are two consultants (one WTE) at the specialist centre, with consultants at each of the five network hospitals each providing care for 16–39 shared care patients (0.09–0.3 WTE).

Annual reviews are carried out at the centre, with quarterly outreach clinics at the network hospitals, attended by one of the centre consultants, accompanied by a representative of most of the Oxford multidisciplinary team (MDT). All the network clinics admit children with CF, with home IVs funded by the centre, delivered by a homecare provider. The service level agreement (SLA) therefore has a fixed split to each centre, based on the number of patients, rather than varying according to patient banding.

The service was impressive, with many positive aspects, and it was encouraging to see improvements in staffing levels even during the peer review process.

Areas of good practice:

- There is an experienced, enthusiastic, committed, cohesive medical team, with an excellent lead consultant and communication between the network clinics.
- IT systems:
  - High-quality data collection and database, generating letters and reports to facilitate prompt communication of clinic encounters and annual reviews.
  - The ‘mychox’ CF website provides up to date information and guidelines, accessible to health professionals and families.
- The annual regional network meeting for the MDTs provides an excellent opportunity for education, sharing of ideas and networking.

Areas for improvement:

- Standardisation of transition to adult CF services, particularly when transition is not to the Oxford adult service.
- Representation of all the core disciplines at the outreach clinics.

Recommendations:

- Improved dissemination of information from the Annual Review to the multidisciplinary teams at the network hospitals.
- Succession planning for staff, to ensure no gaps in service provision as staff retire/semi-retire.

Specialist nursing

This report has been written based upon information received from the centre/networks and the visit at JRH, Oxford Paediatrics on 5 February 2015.

Oxford has two WTE CF clinical nurse specialists (CNSs) at Band 7 and 6 for the 58 children in Oxford and 132 children in the five network hospitals (which are within one hour's drive away from Oxford). The Band 7 has an MSc and Band 6 has a BSc and both are members of the Cystic Fibrosis Nurse Association (CFNA). These nurses are the first point of contact in the area via a landline at JRH (mobile signals are poor around the hospital). Telephone calls are triaged and reviews are arranged. Out-of-hours is covered by the respiratory team and wards.

They attend local, national and international conferences, although funding is often hard to obtain. As part of the MDT at Oxford they have established yearly education/team-building meetings for the network hospitals.

Vacancies for ward staff have been difficult to fill, as applications have not been forthcoming.

Network hospitals have CF CNSs/CF Nurses (mainly hospital-based community teams) who work varying hours and have other responsibilities, except for the CF CNSs in Northampton and Wycombe/Stoke Mandeville. Network CF CNSs/CF nurses are band 7 except the CF CNS Wycombe/Stoke Mandeville, who is band 6. All have qualifications at degree or postgraduate level. Cover for sickness and holidays are variable, ranging from another member in the community team to the consultant with whom they work with. Cover for out-of-hours appears to be the wards. Succession planning is an issue in the networks and needs to be addressed.

Some network CF CNSs/CF nurses are members of the CFNA and attend local national and international conferences, although again funding is hard to obtain. These nurses value the yearly meetings established by Oxford and find them beneficial for networking and team building.

All children and their families are seen at Oxford for annual assessments, which are organized by the CF CNSs. Following an annual review a letter is sent to the consultant at the network from the Centre consultant. Action points from the review relevant to CF CNS/CF nurse in the network are discussed via e-mail or telephone. The Oxford nurses attend all of the network clinics four times a year to review patients and have face-to-face contact with the network CF CNSs. Newly diagnosed children in the networks are seen by the Centre team at the next available joint network clinic to meet the team.

The MDT at the centre/networks see children and their families at each clinic visit and a CF CNS/CF nurse is in attendance, but does not necessarily review the child and family, although they are aware of issues surrounding the child and family.

Recently, there have been capacity issues within the Day Care area/outpatients in Oxford in obtaining rooms to maintain segregation with additional/other clinics running concurrently. At the Centre/networks there are limited or no single ensuite rooms/cubicles, although in Oxford there are two negative pressure cubicles.

The Band 7 at Oxford also carries out sweat-testing together with two experienced technicians. The Band 6 is being trained at present. Training, internal and external quality controls reportedly meet standards.

All CF CNSs appear to carry out work that should be undertaken by a social worker/family support worker. Models of delivery of social care and criteria for referral to a social worker require investigating within Oxford and the network hospitals. There should be social worker investment at Oxford whereby the networks have links.

Interestingly, the Band 7 took her Masters in Applied Positive Psychology, as psychology support was very limited. As highlighted in the matrix, psychology support is limited.

The burden of administrative work and coordinating of the CF teams undertaken by CF CNSs/CF nurses could be lightened by the purchasing of a fax machine for the Oxford nurses, a laptop for the nurse at Wycombe/Stoke Mandeville (works on two different sites) and increase in clerical support.

Recent changes in the provision of home IV therapy in Oxford and the networks have improved quality, safety, infection control and uniformity. A new contract with a homecare provider has been set up and this appears to have been welcomed by children and their families. Aminoglycoside levels are usually undertaken at the hospitals. This service is evolving, and establishing a common standard across the networks for IV administration has been discussed.

Transition appeared to be disparate at the centre/networks and this needs to be addressed. Ward staff at Oxford wishes for more knowledge and information with regards to lung transplants and palliative care. As adult CF services are transferring to JRH it is a good opportunity to look at transition processes with this adult team and surrounding adult Centres.

There are guidelines and policies from Oxford and the networks, but these could be restructured, streamlined and uniformed, ie as per risk matrix male infertility. Within Oxford and the networks there are some good practices that could be shared, ie study day for schools.

There appear to be good relationships with all CNSs/CF nurses. Every network commented on the good support they receive from the CF CNSs in Oxford. This is therefore a great opportunity for the CF CNS/CF nurses in the Centre/networks to produce new and up to date nursing guidelines, clinical skills and practice. Time relinquished from undertaking social work, psychology and administration should enhance nursing care and education equity for all children and their families at the Centre and networks and time for service planning with the MDT.

It is highly apparent that the Centre/networks have passionate and committed staff and demonstrated that areas highlighted in the risk matrix had or were in the process of being addressed.

Areas of good practice:

- Support and yearly education/teambuilding meetings for the network hospitals
- Attendance at network clinics four times a year
- Recently established and evolving common homecare provider across Centre/networks

Areas for improvement:

- Transition
- Social worker/psychology support
- Admin support

Recommendations:

- Social worker support
- Admin support
- Produce common standard for IV therapy across centre/networks

Physiotherapy

Staffing

Oxford has within the last year employed two part-time Band 7 physiotherapists, who are dedicated and keen to improve standards across the whole service. Making the Band 6 post rotational at Oxford will add to the CF experience within the CF team there. The staff in the satellite hospitals, who are equally motivated to provide a high standard, seven days a week, will be bolstered by the centre staff supporting them in their mission to achieve this.

However, the physiotherapy service is underpowered at 3.13 WTE versus 3.5 WTE recommended staffing levels for the patient numbers at Oxford and the five satellite hospitals. This affects time for staff mainly in the satellite hospitals to do continuing professional development (CPD), peer supervision and service development and affects the cover for ad hoc clinics and outpatient access. The community care is variable, with provision in some areas from community teams and none in others, and despite willingness from inpatient staff to provide this, current staffing levels offer no opportunity for this to happen.

Areas of good practice:

- Keen and enthusiastic physiotherapists who genuinely want to improve care, facilities and access to their service across the whole of the Oxford region.
- Excellent communication around annual reviews, with communication travelling in both directions.
- Membership of the ACPCF and attendance of conferences from all centre staff and many satellite staff, providing up to date care and opportunities to network. The Thames Valley Regional meetings are well attended by all inpatient hospital-based staff staff and some community staff.

Areas for improvement:

- Weekend provision for inpatients is good at the centre, but very variable in the satellite hospitals, with weekend staff often failing to appreciate the importance of regular airway clearance, using the correct treatments, and also the burden of care for families who have children in hospital and other commitments at home. Education of weekend staff is offered, but reflection by them and follow-up of poor practice needs to be tackled.
- Exercise facilities are hugely variable, with some inpatients not having any access to exercise and others offering good well-equipped gyms, but with poor air exchanges and no ventilation leaving patients at risk of cross-infection.
- Peer supervision needs to be available within the paid working day, staff currently are doing this during their own time or not at all.
- Equipment budgets need to be held and spent by the satellite clinic staff, many of whom are relying on charity money to provide airway clearance devices.
- Training for the physiotherapist around nebuliser equipment will improve access to advice and replacement parts when nursing staff are not available, giving a more seamless service for patients.

Recommendations:

- Staffing levels should be improved to meet that recommended for the number of patients seen at Oxford and its satellite hospitals. This would then allow for equitable home visits by a physiotherapist, and outpatient provision when required.

- Protected “professional time” for all the physiotherapist to meet at least annually to look at and identify common problems, achievements etc, would be time well spent and would boost the “unified service” approach.
- Following the standards of care for twice-a-day physiotherapy and following up with the staff and hospital managers within physiotherapy when this fails to happen.
- Addressing the access to safe areas to exercise during inpatient admission, and including obtaining information on the current air exchanges per hour in any gym or clinic spaces and taking steps to ensure minimal risk of cross-infection in these areas.

Dietetics

The CF nutrition service currently has 0.7 WTE at the specialist centre and 0.35 WTE in the five network hospitals for 185 patients. The Cystic Fibrosis Trust’s ‘Standards of Care’ recommend 1.25 WTE for 200 patients. Additional funding of 0.3 WTE has been agreed in Oxford, which, when the funds are released, will help bridge the gaps in the current service.

The specialist centre and some of the network dietitians are members of the UK CF Dietetic Interest Group. Attendance at international conferences is poor although the annual regional meeting is well attended. Audit and research is only carried out in the specialist centre.

The inpatient service fails to meet the recommended twice weekly reviews recommended in the Cystic Fibrosis Trust’s Standards of Care (2011) ward round (WR) and MDT meetings are attended at the specialist centre and in post clinic meetings across the network. Food provision did not evaluate well in the patient surveys despite additional food provision being available across the network.

Dietitians are available in most outpatient clinics, although cover is not provided when on leave or for ad-hoc appointments. All patients are seen by the specialist centre dietitian for annual review, but at present the outreach clinics are not attended. Transition is led by the specialist centre.

Areas of good practice:

- The dietitians across the network are very experienced and respected members of the MDT.
- The annual network meeting is an excellent forum for networking and sharing best practice.
- The electronic database at the specialist centre allows tracking of nutritional parameters. Extra resources have been created to help optimise pancreatic enzymes doses and consequently those with a BMI <10th percentile has reduced by 7% in the last three years.

Areas for improvement:

- Improve communication for annual review to network and input from the network to transition.
- Membership to the Dietetic Interest Group is recommended, failing that information could be cascaded down the network by the specialist dietitian.
- Increase attendance at international conferences and audit and research participation across the network.

Recommendation:

- Ensure input from the specialist centre dietitian to outreach clinics.
- Increased inpatient dietetic time including improving existing links with catering may help the evaluation of food improve in the future.

Pharmacy

Areas of good practice:

- There are a team of very dedicated, enthusiastic and motivated pharmacists within this network, who are willing and interested in expanding their services to see patients in clinics for annual reviews, attend ward rounds and multi-disciplinary meetings. These requirements are recommended in the Cystic Fibrosis Trust's Standards of Care. However, some of the pharmacists in the network are unable to carry out these services due to lack of resources; largely, a lack of pharmacists.
- Facilities for home IV medication and homecare medication is good within the network.
- At the Oxford Children's Hospital, the pharmaceutical service to inpatients is good, although it is only recently that the pharmacist has been able to attend multi-disciplinary meetings. However, 0.1WTE pharmacist is not enough to provide adequate services for medicines reconciliation and discussion of adherence during annual reviews, though the pharmacist has attempted to provide this by conducting some teleconferences with patients.
- At Milton Keynes, a paediatric lead pharmacist position is shortly to be advertised. This will strengthen pharmaceutical services at this site.

Areas for improvement:

- Within the network there needs to be increased provision of dedicated pharmacists to provide all the services recommended by the Cystic Fibrosis Trust.
- It had been identified that in some hospitals (Northampton and Royal Berkshire), the homecare prescriptions are not verified by the pharmacist, but going directly to the homecare provider. This could pose a risk as the medication would not have been screened and validated by a pharmacist for dosing, frequency and interactions.
- Pharmacists within the network to belong to the UK CF pharmacists group and attend at least one study day on CF, whether within the network or outside.

Recommendations:

- At Oxford, the provision of pharmacist time needs to be increased so that a dedicated pharmacist is able to provide all the services recommended in the Cystic Fibrosis Trust's 'Standards of Care'. The shortfall in pharmacist input at Oxford has been recognised and will hopefully result in increased pharmacist time for CF paediatric services, particularly with regards to annual reviews.
- At Northampton and Royal Berkshire hospitals there is a need to increase pharmacy staffing to allow checking of homecare prescriptions. It is recommended that business cases be put together to support this increase in pharmacist time, allowing screening of homecare prescriptions, attendance to ward rounds and MDT meetings.
- At Wexham Park, a dedicated pharmacist allocated solely to paediatrics is advised, rather than sharing the position as clinical services manager/paediatric pharmacist – there are sufficient numbers of paediatric patients to warrant this.
- At High Wycombe/Stoke Mandeville hospital, the lead pharmacist may require additional support to cover for leave and absences and attendance to ward rounds and MDT meetings.
- In order to support medicines reconciliation processes, utilisation of a medicines management technician could be considered.
- Additionally, to strengthen and improve cohesiveness within the network, pharmacists could meet each other to share ideas and experience.

Psychology

At the centre, there is an enthusiastic and committed psychologist who has made good links with the nurse specialists, and has plans for the development of the psychology service. By the time of peer review, it was good to see that the 0.2 WTE Band 7 had increased to 0.6 WTE. However, it was not clear that the Band 8a funding was available to the psychologist at the time of peer review.

There is variable availability within the network, with Northampton having 0.2 WTE per week provided by another enthusiastic and hardworking psychologist. However, there is either a session per month or a session every two months for some of the other network clinics. Although this may allow for some psychology availability at the time of some clinics, it is hard to see how follow-up can happen or preparation for processes such as transition can be available for patients in these network clinics. It is also not clear how the more fragmented posts are able to keep up-to-date with CF-related CPD, because this work represents such a small part of these posts. It may be worth considering if this is the best use of the available resource. Two potential strategies for managing this may be to develop centre-led pathways of psychological care that can be shared across the network, thus ensuring equity for patients, or increasing the resource at the centre and offering more telephone support to the network patients.

In summary, the psychology service in the Oxford CF service seems somewhat complex with some dedicated service that is developing and available within the centre, and pockets of service available to the network.

Social work

There is currently no social worker in the Paediatric Oxford CF centre. There are nurses and a psychologist who take on some of the roles of a social worker in addition to their own roles. However, this work would best be undertaken by a social worker with experience of and good links to local services, and knowledge and experience of funding-related tribunals for patients.

5. User feedback

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

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	23	13	3	2
From the ward staff	12	9	3	2
From the hospital	14	17	6	1

Areas of excellence:

1 Accessibility of the team

2 Communication

3 Outpatient cleanliness

Areas for improvement:

1 Outpatient waiting times

2 Inpatient food

3 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

John Radcliffe Hospital

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	The action plan, sent to the families, and the full annual review report, sent to network consultant, need to be better disseminated amongst the network MDT.

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	Amber	Psychologist only saw 50% of children at annual review. Outreach clinics attended by centre dietitian only 30–40% of the time.
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	Need more dietitian, psychology and pharmacy time. Also, review panel felt that role of social worker is not best achieved by nursing staff.
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	**Excellent Mychox website.**
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	The number of patients with CFRD appears to be low/under-diagnosed.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Amber	Amber	There are few ensuite rooms, but measures are in place to minimise cross-infection.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red: sent away results take 48 hours	Red	It has been agreed that in-house levels will be in place by 2015.
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%	Red: no discussions noted	Red/unclear	Inadequate documentation available.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red	No comment	This standard for age 10 is controversial and has little evidence base. Network aim is to scan >14year

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	Summary is generated at point of discharge.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Amber	CNS is available, but doesn't see every child (85–90%).
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	Physio is available, but doesn't see every child (85-90%).
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	Dietitian is available, but doesn't see every child (85%).
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Red Insufficient dietetic time	Red	Only 39% admissions had twice-weekly dietetic review. We understand the shortfall in staffing is being addressed.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red: insufficient psychology time	Red	Not available at routine clinics, and only 50% of annual reviews.
	% availability of a clinical psychologist for inpatients	100%	Red	Red	Estimate is only 50% availability. We understand the shortfall in staffing is being addressed.
	% availability of a social worker at clinic	100%	Red: no social worker	Red	It is inappropriate that this is done by nurse.
	% availability of a social worker for inpatients	100%	Red	Red	It is inappropriate that this is done by nurse.
	% availability of pharmacist at clinic	100%	Red: no specific CF pharmacist	Red	We understand this is being addressed.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Red	Red	Last survey was in 2008 – part of peer review.
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	John Radcliffe Hospital 58 full care 132 shared care total 190
Consultant 1	0.5	1	1	0.5 WTE
Consultant 2	0.3	0.5	1	0.5 WTE
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	0.3 WTE
Specialist nurse	2	3	4	Band 7 1 x 1.0 WTE Band 6 1 x 1.0 WTE
Physiotherapist	2	3	4	Band 7 1 x 1.0 WTE Band 6 1 x 1.0 WTE
Dietitian	0.5	1	1.5	Band 7 1 x 0.3 WTE Band 6 1 x 0.4 WTE
Clinical psychologist	0.5	1	1.5	Band 8a 1 x 0.2 WTE
Social worker	0.5	1	1	0 WTE
Pharmacist	0.5	1	1	0.2 WTE
Secretary	0.5	1	2	0.3 WTE
Database coordinator	0.4	0.8	1	
Data Clerk				Band 4 1 x 0.15 WTE

Appendix 3

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre – John Radcliffe Hospital	
Number of active patients registered (active being patients within the last two years)	171 total network
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	167 total network: Oxford 133/ Northampton 34
Median age in years of active patients	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 2013')		
Number and % in age categories	0–3 years	20 (15%)
	4–7 years	39 (29%)
	8–11 years	31 (23.5%)
	12–15 years	31 (23.5%)
	16+ years	12 (9%)

Genetics	
Number of patients and % of unknown genetics	23 (17%)

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2013')	
Patients with a BMI percentile <10th centile on supplementary feeding	n=21; 9 (43%)

FEV$_1$ (ref: 1.14 'Annual Data Report 2013')			
		Male	Female
Number and medium (range) FEV$_1$ %n predicted by age range and sex	0–3 years	0	0
	4–7 years	2 (3%)	0
	8–11 years	5 (7%)	8 (13%)
	12–15 years	13 (18%)	11 (18%)
	16+ years	5 (7%)	4 (7%)

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	20
	4–7 years	39
	8–11 years	31
	12–15 years	31
	16+ years	12
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	4
	16+ years	2

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	1 (0.75%)
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 (0.75%)

Complication (ref: 1.16 'Annual Data Report 2013')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	9 (7%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	4 (3%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (0.75%) with PH; 1 (0.75) without PH

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

IV therapy (ref: 1.21 ‘Annual Data Report 2013’)		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	62
	4–7 years	224
	8–11 years	208
	12–15 years	293
	16+ years	135
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	40
	8–11 years	114
	12–15 years	124
	16+ years	80
Total number of IV days split by age group	0–3 years	62
	4–7 years	264
	8–11 years	322
	12–15 years	417
	16+ years	215

Chronic DNase therapy (ref: 1.22 ‘Annual Data Report 2013’)	
DNase (Pulmozyme)	
Percentage of patients aged 5–15 years on DNase	n=92; 43 (47%)
If not on DNase, % on hypertonic saline	1 (1%)

Chronic antibiotic therapy (ref: 1.22 ‘Annual Data Report 2013’)	
Number and % of patients with chronic PA infection	7 (5%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	7 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	4 (57%) with chronic PA; 17 (14%) without chronic PA

Appendix 4

Patient survey

John Radcliffe Hospital

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	23	18	5	1
Communication	24	14	9	1
Out-of-hours access	10	4	3	3
Homecare/community support	11	2	3	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	20	23	2	3
Waiting times	11	18	11	5
Cross-infection/segregation	19	21	4	2
Cleanliness	22	21	5	0
Annual review process	17	19	2	2
Transition	2	2	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	5	12	2	0
Cleanliness	5	8	5	2
Cross-infection/segregation	8	6	3	1
Food	2	5	6	5
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	10	7	1	1
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	6	5	4	3

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	5	1	1	0
Availability of equipment	10	10	4	0
Car parking	2	12	13	9

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	23	13	3	2
Of the ward staff	12	9	3	2
Of the hospital	14	17	6	1

Comments about CF team/hospital

“Shortly after receiving this we were advised that our daughter was to be admitted for two weeks of IV treatment: this would be our first inpatient stay on Drayson/Bellhouse. Inpatient comments: overall the ward facilities were excellent and being assigned an air-locked ensuite cubicle made a remarkable difference to the quality of the stay. My daughter can be shy and self-conscious so the ability to use her own bathroom helped her immensely and the airlock made for a quiet night with the associated rest benefits. Accommodation, room cleanliness was slightly below what I would expect, especially as the room had received a terminal clean five minutes prior to our occupation. A roof tile directly over the bed had what looked like baby food stuck to it and a small patch of what looked like either water staining or brown mould. Window blinds were stained with an unknown spotted substance and some of the slats were missing. The shower drain was blocked and upon investigation by me I found a very large build-up of hair, soap scum and other assorted items with a significant build-up of black mould, which was visible on the top of the drain cover plus the associated foul smell. I cleared this blockage myself, but I would have expected that as this hospital is managed by third-party, FM company Carillion that planned preventative maintenance and defect rectification would have been more effective; drains need to be checked and cleared on a more frequent basis. To my knowledge the room and ensuite bathroom were cleaned only twice during our two week stay; maybe this is standard policy within the NHS, but I would expect a more frequent cleaning cycle. My daughter’s bed linen was not changed during the two-week stay, again perhaps this is standard policy, I however would expect a weekly change of bed linen. Ward facilities and staff: the ward facilities were excellent, the play area, in particular the all-weather outside area is a fantastic addition to the wards and was key in my daughter’s happiness during the stay. The play assistants do a wonderful job and played a key role in helping my daughter come to terms with her stay, I can’t praise them enough. It surprised me that the play area is not only funded by charity, but that the charity is not allowed to advertise for donations on site due to hospital policy? The clinical staff on the ward, although stretched were wonderful; they were all knowledgeable and sympathetic to the particular needs of CF patients and acutely aware of the cross-infection risks and subsequent segregation requirements, cross-infection and segregation knowledge also extended to both the play assistants and the ward school teaching staff. Without fail all staff disinfected their hands and gloved prior to entering the room and cleanliness of the IV lines was maintained throughout the stay, resulting in only one line having to be used for the full course. My daughter’s time tabling was established very quickly to avoid any cross-infection risks with another CF patient on the ward and for the majority of the stay there were only two CF patients on the ward which made for good access to both the school and the play area. When a third patient with CF joined the ward both school and play were restricted quite heavily due to the constraints, however this only lasted 24hrs, which demonstrates that Oxford is maintaining where possible a minimum of CF patients on one ward at any one time where practicable. Education continuity: The school staff are very good at managing priorities and time and were well versed in infection control and cross-contamination risks between in particular CF patients. The teaching staff liaised with my daughter's school to ensure that my daughter's current syllabus was taught and feedback was given. Overall the team does a good job of juggling teaching with patients' care routines and segregation timetables; in some cases the teacher actually sat with my daughter during her IV session and conducted one to one teaching her. Equipment-wise the school seemed well funded and my daughter was lucky enough to receive a laptop on loan from the school for the duration of her stay. Whilst we understand that clinical care comes first, it is very frustrating for both the patient and teacher if 10 minutes into a one hour session the patient is pulled for a physiotherapy session or because the IV is early that day, more co-ordination between the teams is required and additionally see my points below regarding the overstretching of the physiotherapists. For the duration of the stay my daughter was scheduled to have two hours schooling per day, in reality I estimate she received less than half that amount due to the demands of clinical care and segregation etc. Whilst at the young age she is and the infrequency of her stays to date this will have little or no impact on her overall education, there needs to be some holistic thinking to figure out a way to give CF patients greater access to education as the stays become more frequent, for example video conferencing the patient into the classroom using a laptop and webcam. CF team: access to the CF team was good overall, but it was very apparent that they are stretched as a resource, we saw the dietitian once during our stay and only after chasing from the ward staff that needed the dietitian to raise an order for a cooked breakfast for my daughter. We were asked by the dietitian to complete a food diary, but as we didn't see the dietitian again this will have to wait until the next clinic to be recorded. Physiotherapy I would describe as the most stretched CF resource. During our stay my daughter only received two gym sessions due to availability of either a physio or the gym itself. Physio was inconsistent in its timing, duration and intensity depending on the workload of the therapist and them being bleeped to a more urgent task was not uncommon. Whilst both my wife and I are more than happy to carry out physio, however we were expressly told that the hospital CF physios would take over this role during the stay. Timings of the physio were also varied which could have an impact on drug administration due to the need to clear the airways prior to administering Colomycin and DNase. There was one conflicting piece of advice we received from the physio team in relation to the administering of Colomycin and DNase and a requirement for minimum two-hour time delay between each one. This caused my wife some distress as she then believed she had been inadvertently making the Colomycin/DNase ineffective by administering them back to back. However the doctor took the position that there was no evidence to suggest interaction between the two as did the lead physio, which is the stance we now follow. Clear processes should be in place to prevent differing opinions, in particular those related to drug administration being conveyed to parents. On a positive note, we learnt an awful lot from the physios with regards to airway clearance and the options available to us and we were provided with both practical and theoretical training to help us improve and become more efficient. Although the comments in the paragraph seem quite negative, it must be stressed that like most of the staff we encountered during our stay, they never seemed to stop and were constantly having to prioritise their time. Despite this, in conjunction with other members of the team they worked to secure us an 'iNeb' machine which we are hopeful will reduce the time taken to administer nebulised medication. Access to the consultants and the registrars was very good, in particular over the weekends. During our stay we saw a doctor on both Saturday and Sunday mornings on the ward. Outpatient care overall is very good, cross-infection risk is managed very well during clinic with clean rooms for each patient and staggered arrival and departure times. Unlike our experience of Southampton, outpatient's clinics are booked autonomously at Oxford, which reduces the need to wait in a queue at the reception desk potentially with other CF patients to get an appointment booked for follow up. Waiting times within clinic are fairly low and in general we see all members of the team. Communication with the team however can be problematic and it is not uncommon for calls to remain not responded to and subsequent chasing can be frustrating. Email has gone someway to improving this, but sometimes we need to speak to a person to allay our concerns or have an important query answered. I compare this directly to our time with the CF team under Southampton between 2007-2012. Communication there was excellent and in general the CF secretary was excellent in ensuring any requests for a call back were fulfilled that day; this was coupled with a close bond with the team in particular the CF specialist nurse. Overall though we are both confident and happy with our CF team and the care they and the hospital provide, as with all CF teams they are a finite resource that does a wonderful job. Our inpatient stay has both made us feel closer to our CF team and given us full confidence in the hospital to provide; care for our daughter. Conclusions: the inpatient care at John Radcliffe Children's hospital was very good as were the facilities. All staff are well versed in CF care and access to the CF team was for the majority of the time was good. Cross-infection risks were managed well by all areas of the ward including the school and play areas. Cleanliness of the communal areas appeared good but cleanliness and attention to detail in the cubicle was below par. The play area and play assistants are an essential part of the inpatient care and the hospital is lucky to have the resources it has in this area. Education is good if the patient can access it. More thinking and coordination is required to ensure education is not degraded if stays become more frequent. Outpatient care is very good but communications could be improved."

"I have rated the overall care from our CF team as excellent even though only scored them good on specific questions because I think the most important things is their knowledge and determination to do all they can to help which I value more highly than things such as accessibility – I trust that if we were in great need of their care we'd get it and I don't want to take that away from helping others when their need is greater."

"My CF team are very good with my son. I do think we should get more help for me and my other kids to stay in JR hospital when my son is in for IVs, but we get turned away and I haven't got the money to keep going up every day."

"Only thing that makes things hard is the parking/finding a space as most use it as a park and ride and the cost for us parents to eat and generally stay with our children."

"We are very pleased with the CF team, they are always there to advise and understand."

"JR team outstanding."

"The CF team at the John Radcliffe are excellent. We've been with this team for the past seven years and are always impressed with how they deal with us. They treat us with respect and consideration, but always with our daughter's best as their priority. The team are accessible at all times. The support offered is very strong."

"The hospital and staff are excellent. We moved to John Radcliffe from another area of the UK and the increase in quality of care is outstanding. The staff respond to questions and medication requests very efficiently and we have access to prescriptions within 24 hours to our local surgery (often within hours via fax)."

“Had an incident when we were not informed of another CF patient in inpatients that arrived the Sunday evening. We were not given a playroom timetable until approx. 3pm on the Monday. At 10:30am Monday morning both CF patients were playing unaware right next to each other. Also they were put in the room right next door to ours. Also I am not sure if the mother of the other CF child was aware of the seriousness, but the door to their room was kept open, and she and the child were constantly wandering around the corridor outside our room/kitchen/toilet. Also I had to point out to staff that no one had told us if our allocated toilet had changed (they had not even considered this). I raised my concerns with the staff, and CF team. They apologised but I don’t feel it was really adequate. No precautionary cough swab was taken. I feel that CF patients should be kept right apart - including using toilets at opposite ends of the corridor. Also staff should ensure that parents/carers understand why they are segregated, as on this occasion I feel staff assumed the parent understood/cared about the seriousness. I really feel the policy needs to be reviewed.”

“Consultant, nurses are brilliant. Hospital a lot better. Teenage ward was in the past rather dirty but much better now. Big bone of contention is people smoke in the covered entrance to the children’s ward, we have written to CEO to no avail.”

“I find our CF team leave everything to the last minute. Sometimes I feel like they feel I’m going on all the time but all I want is for my child to receive the best. Don’t like admitting for IVs.”

“The CF team are excellent and my daughter receives the best care I could ask for.”

“Better communication with other disciplines would be good eg when dealing with gastro team for constipation how the CF might be a contributing factor. Multi team meetings could actually save time and heart ache.”

“Vital test forgotten about so correct treatment not given causing health issues. I find the team hard to talk to and unwilling to listen to concerns. Patients treated according to team’s view of parents. Doctors have to be questioned as often get things wrong. Discharge papers have had wrong details and date for past two years; repeatedly told team but told it doesn’t matter. Contact is improving now there is a second CF nurse but clinic results such as sputum results are not given until next clinic appointment. Often left waiting in clinic for up to 1.5 hours before seeing the team. Annual review been forgotten many times in the past despite me reminding (three years in a row). Can I also add that although the closing date for this form was Oct 20th no parents received theirs until 18th which gives no time – probably to stop us having our say! Consultant often walks out mid-conversation if he is questioned or parent disagrees. Team unwilling to provide social worker or outside help.”

Appendix 5

Parent/patient interviews

Parent A's child attends JRH for full care. She described segregation at outpatient clinic as good, she sees all the of the CF team, has seen as clinical psychologist when needed, but does not think there is social work support. Parent A feels that any decision made about her daughter's treatment is a joint decision with her full involvement. She feels that hygiene levels at clinic are very good – ie use of hand gels and wiping down of equipment between patients. She does not experience difficulties in using hospital pharmacy after outpatient clinic appointments as most prescriptions are provided for her to take to her local pharmacy, or if urgent, the CF team arranges prescriptions direct with hospital pharmacy.

Inpatient care: Her daughter's last admission – only had two admissions – was an admission without delay. Parent A feel that hygiene on the ward has improved over the years since her daughter's last admission, adding 'it's fantastic now'. She is happy with the ward nursing staff's knowledge of CF and treating of her daughter, including timing of medications. Parent A added that 'the team are good at doing IVs at a time not disruptive to sleep at night' and they are accommodating at the weekend in providing treatments at times which allow her daughter time off the ward. Parent A feels the food on the ward is sometimes alright, but sometimes they have to use the canteen. She added that her daughter is given a snack box, but also remarked that some of the hospital menu is age inappropriate and not very appetising – eg celery soup.

Annual review: Parent A's daughter is offered annual review each year and has had annual review recently. She saw the whole MDT available and explained that all assessments take place at the John Radcliffe. The outcome of annual review takes place in the afternoon clinic and a letter outlining the annual review is sent to the parents.

Homecare: No homecare necessary for this parent's child.

Transition/school engagement: The educational team at the hospital were in touch with the child's school during her recent inpatient stay to get school work provided for the child. Parent A explained that the CF team have had initial conversations with the child/mother about transition and mother is happy that the CF team currently have transition in hand.

Good practice/positive comments:

- Superb consultant – very knowledgeable and inclusive of my daughter.
- Very supportive CF team – good communication and an open-door policy.
- Bright and cheery, clean hospital.

Areas for improvement/less positive comments:

- Tricky to get hold of CF nurses by phone.
- Hospital Trust management need to do more to stop smoking at the hospital entrance from the car park. Mother, daughter and CF consultant have all written on this matter, but mother feels nothing has been done to address this issue ('enclosed, covered area where smoking continues to take place and daughter has to walk through it on way to clinic – NHS staff smoking too).'

Parent B's child/children attend JRH for full care. He explained that they go straight to a clinic side room on arrival at outpatient clinic and stay in that room for spirometry and to see the whole CF multi-disciplinary team (MDT). He described the decision making procession regarding treatments as a 'joint decision – we tell the doctor what we need and they oblige'. Parent B added that hygiene standards at outpatient clinic are fine – eg use and encouragement to use hand gels and wiping down of equipment.

Parent B felt that the pharmacy system for getting prescriptions should be better – they currently have to take their white prescription form to their GP which can take anything up to a week to be processed. His previous experience at other hospitals involved nurse faxing through the prescription for faster processing/reduction in delays.

Inpatient care: His child's recent admission was not a trouble-free admission. The suggestion was for the child to be accommodated in a bay which parent B would not accept and so admission was delayed 48 hours for a side room to become vacant. He referred to 'pretty poor' inpatient care and understanding/knowledge of ward nurses – ie wife constantly having to explain/chase up treatments, unhappy with timing of medications and level of cleanliness which he described as 'terrible'. He added that there appeared 'general cluelessness' with parents reading out instructions to nurses and having to explain basics. He described staff forgetting to start an impaction regime for his child. Father described the hospital food as 'pretty bad' and so they took food into the hospital for their child.

Annual review: Annual review is offered each year to parent B's child, the next one due shortly around birthday. They see the whole MDT available at annual review, though see the psychologist separately. Parent B is unaware of specialist social welfare support and so said he would probably contact the CF nurse on such matters. Annual review outcome is reported back to parent B in a two-page document report and a separate discussion with the team. He added that communication with the CF team is good and that he gets a response with two hours to telephone messages.

Homecare: No homecare is currently necessary for this child according to the father.

Good practice/positive comments:

- We see a consultant every time (not a registrar).
- The physiotherapists are exceptional.
- Ease of contact with CNSs.

Areas for improvement/less positive comments:

- Prescription process is too slow; needs improvement.
- Need ward side rooms to be available rather than offering bays for CF patients.
- Car parking situation needs improving – 'it's horrendous'.
- Hygiene on the ward needs to be improved – ie ward communal bathroom was appalling, worse than previous four hospitals experienced, parent questioned level of cleaning between patients' use in ward side rooms, play area described by parents as 'filthy' covered area/half external, and containing mould in the play area.

Parent C feels that segregation measures at outpatient clinic are very good and have improved drastically, keeping children separated and no longer having toys in rooms. Parent C is not sure that rooms are deep cleaned between patients. However, she sees good use of hand gels, spirometry filters removed from packaging freshly for immediate use (aseptic technique). Parent C's child sees all the CF multi-disciplinary team at clinic – access to psychologist, but no social worker. She feels that she's fully consulted and involved in decisions made regarding changes to her child's treatments. She does not use hospital pharmacy.

Inpatient care: Her child's recent hospital admission was planned and admission was delayed by just 24 hours. Her child was admitted to a side room on the ward, with a toilet assigned to her child and other non-CF patients only. Parent C explained that there had been some concern about inadequate segregation of children with CF on the ward, but explained that this incident was being investigated. Parent C described the food on the ward for her child as 'alright… a cooked breakfast provided every day'. She added that she takes in a couple of bags of snacks to supplement the menu, but her child enjoys being in the hospital, due to the care and attention received.

Parent C described the physiotherapy coverage on the ward during the week as ‘great’. The physiotherapist comes early morning, supports PEP/bubble PEP treatment, lots of breathing exercises, introduction to hypertonic saline; in the afternoon the physio takes her child to the gym or out with the scooter. She described weekend physiotherapy coverage as ‘not up to the standard of weekday physio, not so specialised, but perfectly adequate.’

Annual review: Parent C’s child is offered annual review each year, the last annual review took place whilst her child was an inpatient on the ward. They see the whole MDT at annual review – the psychologist only when needed – but no social worker. However, she feels it would be useful to have social worker support. Parent C explained that annual review is reported back by letter within a week or two; blood tests for vitamin levels taking longer. She added that communication is generally very good from the CF team. She mostly leaves a voicemail message but also has the work email addresses for the CF nurse specialists.

Homecare: Not currently applicable for this child.

Good practice/positive comments:

- ‘We have a fantastic CF team’.
- A great side room on the ward.
- ‘Nurses on the ward are incredible – my child loves going to hospital; it’s credit to those at the hospital’.

Areas for improvement/less positive comments:

- Inpatient segregation needs improving
- CF ward rooms need to be as far apart as possible
- Contact procedures for urgent messages/enquiries could be easier.
- Need for fewer doctors to be involved in the care of one patient – parent worries that communication might break down with more heads involved.

Parent D explained that children go straight to designated side rooms on arrival at outpatient clinic, after weight and height is measured. She added that ‘there’s no opportunity to mix with any other children.’ They stay in the same side room to see each member of the CF MDT and to have spirometry. Parent D felt that the CF team are really good at involving her in decisions made about her child’s treatments. She added that the team contact her regularly to give updates/follow up progress. Parent D felt that there is good use of hand gels and wiping down of equipment between patients – ‘they’re always washing hands and making it obvious before taking cough swabs or using stethoscope.’

Inpatient care: Not applicable currently for this child.

Annual Review: Annual review is offered each year and has been recently. Parent D described the annual review process as ‘quite efficient’, adding that they’re given a timetable, given time out to go to the park during annual review and that the outcome is reported back by letter and discussed at outpatient clinic. Additionally, the CF team contact her if anything needs urgent action or flagging up.

Homecare: Not applicable yet for this child. Parent D mentioned that she has been informed that if needed, a physiotherapist would make a home visit.

Good points/positive comments:

- Cleanliness at the hospital.
- Annual review – ‘amazing nurses team dealing with taking of bloods which can be traumatic for child’.
- ‘CF team are very good at following up my child’s progress.’

Area to improve/less positive comment:

- Outpatient clinic appointment times are only afternoon slots – could be more flexible so that husband can attend too.

Parent E felt that segregation measures at outpatient clinic at the John Radcliffe CF unit are excellent. She explained they are directed straight to a consultation room where they stay for the clinic appointment. She explained that the team use the hand gels, encourage patients/parents to and wipe down equipment between patients. Parent E felt that she and her child were always consulted about changes to treatments and in the decision making. Her child sees every member of the multi-disciplinary team (MDT) available, although she did not know if there was a social worker in post. She described pharmacy as ‘smooth running’; doctors provide prescription for her to take to local pharmacy.

Inpatient care: Parent E described her daughter’s last admission as a ‘planned visit’, to a side room for part of the inpatient stay, then sharing a bay with non-CF patients. She was very impressed by ‘really good’ ward staff and punctual timing of treatments/medications whilst on the ward. Parent E added that physiotherapy was provided both weekend days – ‘not the normal physio, but the same standard as the physio each week day. Food on the ward was described by parent E as ‘o.k., good variety’.

Annual Review: Parent E referred to annual review being offered each year. Her child has had annual review this year, with all assessments at the John Radcliffe. The annual review outcome if reported back to parent by letter shortly after the clinic appointment and the CF team go over the annual review with the parent at next clinic. If unexpected outcomes occur, the CF team ring the parent. X-rays and scans in the annual review are shown to parent same day.

Homecare: None required currently, although parent described how she had a home visit for initial IV course for her child.

Good practice/positive comments:

- ‘CF team know us as a family’
- ‘I’m impressed by the consultant’s knowledge’.
- ‘Physiotherapy is super’.
- ‘There’s more I could add that’s positive about the service. I can’t fault it and I know of other CF services I can compare it with’.

Areas for improvement/less positive comments:

- None mentioned.

Parent F's child attends the Royal Berkshire Hospital (Reading) every two months; she explained the specialist centre team come down from Oxford every three months which she finds useful. She takes her child to the John Radcliffe specialist centre once a year for annual review. She felt 'there's a lot of hanging around for ultra sound, x-ray etc.'

At the Royal Berkshire Hospital, which Parent F described as very good, children stay in the clinic consultation rooms throughout the appointment – spirometry takes place there too. Parent F felt that decisions made on her child's treatments were very much a two-way conversation with the consultant. She added, 'he's very good at listening.' Parent F was confident about the team's use of hand gel at clinic.

Annual Review: All assessments take place same day and parent added that a written report/letter is sent to her 'a while later'. There was a slight breakdown of communication between her local clinic at Royal Berkshire and the specialist centre over one treatment for her daughter, but it was soon rectified with an explanation. Parent F did not consider it a significant problem. Her average wait for pharmacy is 45 minutes.

Inpatient care: It was easy for Parent F's child to be admitted to the ward at Royal Berkshire Hospital as it was a planned admission, described as 'very good'. She described the ward staff's knowledge of CF and her daughter's care as 'fine' – she had her own room and bathroom, food vouchers for a second breakfast as treatments sometimes interfered with initial breakfast round. Physiotherapy at Royal Berkshire Hospital is twice daily, parent and child were taught autogenic drainage technique.

Homecare: Not applicable currently. When on home IVs, parent takes her child to the Royal Berkshire Hospital for Tobramycin levels.

Good practice/positive comments:

- Good support at the end of the phone.
- Accessibility of the consultant – 'he listens and is helpful'.

Area for improvement/less positive comments:

- None given.

Parent G is happy with segregation measures at John Radcliffe's paediatric CF centre outpatient clinic. She did not see sufficient evidence of use of hand gel and wiping down of equipment between patients by staff. Parent G felt fully involved in decisions made to treatments for her child when these decisions were discussed with the consultant, but she felt that she is not involved in decision-making when trainee doctors make decisions. Parent G said she rarely saw a dietitian at outpatient clinic and has not seen one for some time even though her child has been losing weight. She was told 'there is no dietitian available' and so she has emailed the dietitian, but explained she has received no reply.

Parent G does not have any issues with pharmacy arrangements/medication collection at hospital as she is given a prescription for processing at her local pharmacy.

Inpatient care: Parent G's felt that it's not always easy to get her child to be admitted to hospital – eg waiting two weeks for admission following Pseudomonas growth. She feels that staff nurses' knowledge and understanding of her child's CF needs on the ward have been good and bad – eg put in an open ward bay with other children coughing next to her child. Food on the ward Parent G described as 'terrible', but she felt that it's good if the dietitian can arrange extra meals for her child. She felt that it would be better if children were asked what food they'd prefer on admission, so that they eat the food and increase weight.

Parent G described the twice daily physiotherapy support as 'good'.

Annual Review: Parent G's child is offered annual review each year and has had annual review for this year. Parent G explained that the outcome of annual review is reported back as the day goes on and discussed at clinic (eg grading of lungs, where the child is with their CF etc) and then parent waits for a few weeks for the blood test result which team report back to her. Parent G's child sees all of the MDT available at annual review apart from a social worker. She added that a psychologist's review has been introduced to the annual review process in the last year.

Homecare: Parent G administers her child's home IVs. She has had to bring her parental responsibility and lack of support up with her child's school. Parent G has had one home visit in six years by her CNS. Her child had been having home IVs over the last two years and lives a short distance from the hospital. She takes her child to the hospital for Tobramycin levels and other aspects of her child's care during IVs.

Good practice/positive comments:

- Good at returning cough swabs – ie taken on Tuesday, results back Friday.
- CF team/nurse will see her child at short notice on the day ward or an alternative clinic appointment arranged at short notice.
- CNS is good at helping with schooling issues.

Areas for improvement/less positive comments:

- 'I feel that the CF team can make me feel awkward/silly at times, when I ask questions'.
- 'Frustrating to see a trainee doctor at a worrying time. A trainee should be supervised by a consultant to reduce unnecessary/irrelevant questions at a worrying enough time already.'

Parent H attends Milton Keynes Hospital and John Radcliffe Specialist Centre for her daughter's CF care. She attends Milton Keynes every three months, John Radcliffe annually, although the John Radcliffe team also hold joint clinics at Milton Keynes during the year. At Milton Keynes mother explained that only one child waits in clinic at one time before being put into a side room for consultation, so she is happy with segregation measures in place. She feels that most of the time the team listen to her and value her input when making decisions on future treatments, although she feels sometimes they don't. Parent H and her child see the multi-disciplinary team (though not a psychologist or social worker) at clinic at Milton Keynes. She has seen a psychologist once at John Radcliffe, though no social worker. She turns to the CF nurse at Milton Keynes for welfare related advice and support. Parent H explained that prescriptions at outpatient clinic are faxed to her local GP and take 2–3 days to process through to collection of medications locally.

Inpatient care: Parent H felt it was easy to get admitted to the ward at Milton Keynes. Her daughter is cared for in a side room, but she shares a ward bathroom and WC. She feels that staff nurses on the ward do not have a great understanding of CF and her daughter's needs and feels that some staff do not read her notes enough. She does feel that the more experienced nurses know her child better. Parent H explained that her child struggled with the food on the ward at Milton Keynes, partly due to lactose intolerance but also in terms of getting the necessary fat into the diet. Parent H was not happy with the physiotherapy support at Milton Keynes, explaining that she had a few differences with the physiotherapists – eg 'physios insisted on doing 20 minutes percussion but my daughter does bubble blowing, jumping exercises at home for physio'. Parent H added that the percussion was time wasted as it was unproductive and it happened 'first thing', before breakfast. Physio is provided twice daily at Milton Keynes, seven days a week.

Annual Review: Annual review is offered every year and Parent H's daughter has had it this year. All her assessments take place at the John Radcliffe Specialist Centre, where they see the whole MDT (except social worker). Annual review outcome is reported back in a letter to mother two months later.

Homecare: No home visits. Mother did not feel home visits were necessary, but did explain that she has a gastrostomy PEG in place and required more advice/help with this from the John Radcliffe team – ie she felt there was insufficient information about the extra care involved in flushing the PEG, preparing the feed, adding, 'it was left to the community team to give us this.'

Good practice/positive comments:

- 'CF nurse at Milton Keynes is great. I can phone her about anything and she gets back to me.'
- 'Flexible ward team at Milton Keynes – ie they allow my daughter to use the play room and leave her room when no other children with CF are on the ward.'

Areas for improvement/less positive comments:

- 'I feel left and ignored by nurses at times at the John Radcliffe' – ie more support needed.
- More information needed straight up about PEG feeding/'button' care at home.

Parent I

Parent I's child has shared care (John Radcliffe Specialist Centre and Northampton General Hospital CF clinic). At Northampton her child is allocated a side room on arrival at clinic where she stays throughout the appointment – the multi-disciplinary team rotate between patients. Mother and child see the consultant, CF nurse, physiotherapist and, if required, a dietitian occasionally and a psychologist on needs basis. Mother feels decisions on treatments are very much negotiated as part of a 'two-way partnership' (consultant and parents). An example of the negotiated decision making is child's reduced frequency of attendance at clinic with an option to change this if child's CF becomes more problematic. Child's prescriptions are faxed to her local GP surgery by CF consultant. Parent H felt both John Radcliffe and Northampton CF teams made good use of hand gel/hand hygiene and wiped down equipment between patients. Mother explained that some time is spent in the general waiting area during annual review at John Radcliffe. She felt that segregation measures were more robust at Northampton CF clinic.

Inpatient care: not applicable to this child.

Annual Review: Parent I's child is offered annual review each year and has had a review this year at JRH. Parent felt that each year they see a different member of staff in each discipline of the MDT and felt that staff do not seem to look at her child's notes sufficiently. She explained that various methods of reporting back annual review outcomes have been used; some of data not meaning much to the parent, so Northampton's CF consultant clarified points. Parent I explained further that some of the feedback is in separate letters on specific aspects of the annual review. Her child missed annual review on the last occasion at Northampton, as by chance her appointment at Northampton didn't coincide with the John Radcliffe team's visit to Northampton. Parent felt that the Oxford team's treatment/assessment is a bit 'one size fits all', but she will get to see the Oxford team in December.

Homecare: Not applicable for this child currently, although they had home visits from Northampton team around time of diagnosis. Mother felt it is easy to contact the Northampton CNS and consultant. She added that she is aware of good communication between Oxford and Northampton, but in reverse she feels communication may happen but it is not apparent, as she feels some messages do not get around the whole of the Oxford team.

Good practice/positive points:

- 'The Northampton team is consistent, available and easy to access.'
- 'The Northampton team's willingness to discuss, debate and find a way forward.'
- 'Questioning is more structured and appropriate at Northampton.'

Areas to improve/less positive points:

- At both hospitals this parent feels that teams do not accept the impact that clinic attendance has on her child's school attendance/education. Parent stressed child's only time off school is for clinic appointments as her child is well, so feels that clinic appointments should not be routine/by default. She would prefer appointment times that are less disruptive to schooling.
- Parent I feels unnecessary questioning and duplication of questions at Oxford should be reduced, adding that 'seeing the psychologist felt like being involved in a test.'
- Insufficient referral back to previous notes at Oxford. Parent I feels that previous notes should be more closely checked by the Oxford team.

Patient interviews on peer review day

Patient one

Mother of 14 year old boy with CF who has been attending Oxford since diagnosis at birth. She also has a daughter of 16 years old who does not have CF. The mother is a member of the Oxford CF fundraising group.

They live a 40-minute drive from the hospital where they attend bi-monthly outpatient appointments.

Patient one is healthy, was last admitted to hospital 2–3 years ago with non-CF related pneumonia. Patient one has taken an interest in research and volunteered to trial Mannitol in 2013. This meant inhaling 10 tablets daily for the duration of the trial.

Areas of excellence:

- The team are great, all are very approachable. The parent knows the consultant and has a good relationship with all.
- The consultant explained the problems around future fertility to patient A. All the team attend the outpatient appointment. They do not always see the dietitian. However, she is there if needed.
- The hospital has an excellence for research, which is a good reason to stay.
- The physiotherapist was very helpful in supplying a letter to the local gym for the patient to attend spin classes.
- No fasting prior to ultrasound.

Areas for Improvement:

- Parking ranges from difficult to horrendous.
- Annual review can be a long appointment.

Patient two

Single mother of a seven-year-old boy. She also has a daughter of 10 years who does not have CF. They live 4–5 miles from the hospital and drive to appointments.

The mother is a member of the Oxford CF fundraising group.

The patient received his annual review during his inpatient stay. There was an issue with fasting prior to ultrasound. However, fasting is no longer required.

Areas of excellence:

- Care on admission: he loves coming into hospital as he is made a fuss of and is centre of attention.
- Good contact with team. Since the CNS joined, contact has improved greatly by either calling or email. The response is fast.

- Patient likes the food. He is not a fussy eater and in any case the mother takes him home for an evening meal during his inpatient stay. She does feel that if the stay were long a patient could get bored with the food. The food is of good portion size and served hot. There are snacks available, however the mother brings in own.
- Consultant relationship is good and she feels she can ask questions.
- “The rooms are clean. It is nice to have our own space.”
- Cross-infection precautions in outpatients have improved. Used to have to sit in waiting room with a sign indicating CF patient.

Areas for improvement:

- Nightmare parking. Waiting for a space can make you late for appointment. This could be a possible risk for cross-infection.
- As an inpatient the boy had played with another CF child in the play room and they were in rooms next door to each other. This was at a weekend and the staff did not seem aware of their conditions.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	**John Radcliffe, Oxford**
	Yes/no/ number/ N/A	**Notes/comments**
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	30-minute gap left between patients using consultation rooms.
Do patients spend any time in waiting room?	Yes	Patient appointments staggered.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In a height and weight room by outpatient nursing staff.
Where are the lung function tests done for each visit?		In patients' own consultation rooms.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	There is a play specialist and toys available.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	The service currently has three patients with diabetes and they are seen in a separate diabetes clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	The service is currently looking at their transition programme.

Additional comments

- Room availability for annual review assessments is limited and the time allocated to each patient is very tight. Members of the MDT feel that the appointments are often rushed and this is due to the consultation rooms being in such high demand.

Environmental walkthrough: ward

Ward name: Melanie (Teens) Bellhouse Drayson (General Paediatrics)

Microbiology status: All

		Hospital name	**John Radcliffe 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 ward	Two wards are available and suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Melanie ward – 8 Bellhouse Drayson – 4	Melanie ward – three rooms are ensuite and negative pressure. Bellhouse Drayson ward – none of the side rooms are ensuite.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Yes	CF patients do not share bathroom facilities with other CF patients, however they may have to share their designated bathroom facilities with other non CF patients.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Lockable cupboard in each room.
Can you use mobiles?		Yes	Very poor network coverage.
If there is a television, is the service free?		Yes	Free service.
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	There is parent's accommodation elsewhere in the hospital. The seating/day bed in the side rooms is made out of a cloth material which is not wipeable or easily cleaned after each use. This may pose a cross-infection risk.
Visiting hours – are there allowances for CF patients/families out of normal hours?			Opening visiting hours.
Is there access to a fridge/microwave either in the side rooms or in the parents' kitchen?		Yes	In the parents' kitchen area.
What facilities are provided for teenagers?			Teenager room – DVDs, games, books. Only one CF patient allowed in at a time.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Two gym rooms available
What facilities are there to help with school and further studies?		There are school rooms with teachers who will liaise with patients schools when required.
Is there a relatives' room?	Yes	
What internet access is there?	Full	Free service.
What facilities are there to enable students to continue to work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	This is done in own rooms.
What facilities are provided for those with MRSA?		Barrier nursed and placed in a negative pressure room where possible.
What facilities are provided for those with *B. cepacia*?		Barrier nursed and placed in a negative pressure room where possible.
What facilities are provided for those with other complex microbiology?		Barrier nursed and placed in a negative pressure room where possible.
Are patient information leaflets readily available on ward?	Yes	Cystic Fibrosis Trust leaflets.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	**John Radcliffe, Oxford**
	Yes/no/ number/ N/A	**Notes/comments**
Car parking		
Any concessions for patients and families?	Yes	Patients and families are offered a reduced car-parking tariff – £10 per week.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	The wards are not designated CF wards.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Radiology – yes, sufficient space. Patients are never sent to the pharmacy; medication is delivered/dispensed on the wards. DEXA scan area – it is very unlikely that there would be more than one CF patient waiting in this treatment area.
Do patients have to wait at pharmacy for prescriptions?	No	See above.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

Northampton General Hospital

Overview summary

NGH is the largest of the five network clinics, and provides an excellent care service for their shared care patients.

The MDT includes a whole time CF nurse, but dietetic services are stretched. There is a recently appointed psychologist.

NGH submits their own registry data to Port CF, and the outcomes are favourable, particularly in terms of nutrition, compared with pooled data from patients either solely under JRH, or sharing care with the other four network hospitals.

There are no ensuite cubicles, the estate being quite old.

They have undertaken qualitative research on giving the diagnosis of probable CF to parents of screened patients. This was presented at the 2014 European CF conference.

Feedback from their families was very positive.

1 Models of care

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

2 Multidisciplinary care

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

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

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Amber	Single rooms, but not ensuite. Designated bathroom.
	% 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	Same day, or within three days of decision.
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	No comment	This standard for age 10 is controversial and has little evidence base. Network aim is to scan >14 year olds

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	Electronic discharge letter sent out on discharge.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	Not possible during CNS's annual leave.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	Not possible during CNS's annual leave.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Amber	80% documented.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red: no psychologist available since March 2014	?	Newly appointed psychologist.
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red: social workers available if needed	Red	Multi-agency referral for social worker, if required.
	% availability of a social worker for inpatients	100%	Green	Green	Multi-agency referral for social worker, if required.
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	Not applicable to current cohort.

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Northampton General Hospital
Consultant 1	0.5	1	1	3 PAs/0.3 WTE
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	1 WTE
Physiotherapist	2	3	4	0.3 WTE
Dietitian	0.5	1	1.5	
Clinical psychologist	0.5	1	1.5	0.1 WTE to be appointed
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	0.6 WTE
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 2013’, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2013	
Demographics of centre – Northampton General Hospital	
Number of active patients registered (active being patients within the last two years)	171 total network
Number of complete annual data sets taken from verified data set (used for production of ‘Annual Data Report 2013’)	34
Median age in years of active patients	7
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 ‘Annual Data Report 2013’)		
Number and % in age categories	0–3 years	9 (27%)
	4–7 years	10 (29%)
	8–11 years	5 (15%)
	12–15 years	7 (20%)
	16+ years	3 (9%)

Genetics	
Number of patients and % of unknown genetics	6 (18%)

Body mass index (BMI) (ref: 1.13 ‘Annual Data Report 2013’)	
Patients with a BMI percentile <10th centile on supplementary feeding	0

FEV$_1$ (ref: 1.14 ‘Annual Data Report 2013’)			
		Male	Female
Number and medium (range) FEV$_1$ %n predicted by age range and sex	0–3 years	0	0
	4–7 years	1 (6.25%)	1 (6%)
	8–11 years	0	0
	12–15 years	0	2 (11%)
	16+ years	0	0

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	9
	4–7 years	10
	8–11 years	5
	12–15 years	7
	16+ years	3
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	1
	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 2013')	
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 2013')	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

IV therapy (ref: 1.21 'Annual Data Report 2013')		
Number of days of hospital IV therapy in reporting year split by age group	0–3 years	40
	4–7 years	66
	8–11 years	9
	12–15 years	21
	16+ years	0
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	58
	8–11 years	61
	12–15 years	129
	16+ years	28
Total number of IV days split by age group	120	40
	161	124
	351	70
	653	150
	495	28

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
Percentage of patients aged 5–15 years on DNase	N=17; 9 (53%)
If not on DNase, % on hypertonic saline	1 (6%)

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2013')	
Number and % of patients with chronic PA infection	1 (3%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with Chronic PA; 8 (24%) without chronic PA

Northampton General Hospital

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	4	2	1	1
Female	3	3	2	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	10	4	1	0
Communication	11	4	0	0
Out-of-hours access	7	6	0	0
Homecare/community support	11	3	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	7	8	0	0
Waiting times	6	7	1	1
Cross-infection/segregation	7	7	1	0
Cleanliness	8	5	2	0
Annual review process	3	4	0	0
Transition	1	2	0	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	2	7	0	1
Cleanliness	2	6	2	0
Cross-infection/segregation	3	5	2	0
Food	1	1	7	1
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	5	3	0	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	2	2	3	0

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	2	2	0	0
Availability of equipment	4	7	3	0
Car parking	1	2	9	2

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	11	4	0	0
Of the ward staff	1	8	2	0
Of the hospital	2	9	2	0

Comments about CF team/hospital

"The best; caring, considerate very proactive good communication."

"NGH - am having a meeting this week to address my concerns in having enough IV trained staff during the night. Have not had IVs at home or Oxford. My daughter has had a bronchoscopy that revealed a mycobacteria infection. All staff at JR and NGH are incredibly caring and motivated. NGH not enough physios on a weekend."

"Fantastic CF team at NGH, could not wish for better care. Shared care with Oxford seems to work really well and we see the Oxford team throughout the year as well for annual review."

"Been to Oxford twice for annual service and was extremely disappointed by the level of care. Waiting times were very long (try to keep two-year-old without food for several hours) especially blood test (two hours). Hardly anyone there, a waste of time and money as we didn't get anything from this unit except stress and anger. Very disappointed."

"An 'out of hours' advice service run by CF specialists (people who understand the condition and its care, not specialists as in a consultant) would be useful. Our CF affected daughter always seems to get sick or we need advice Friday nights through to Sundays and we are left feeling a little helpless."

"The impression we have, as a result of the annual review and the discussions we had there but also supported by discussions with the consultant at Northampton are that the treatment/approach to CF children is a 'one size fits all' approach, and is not tailored to the needs of the specific child. It is a tickbox exercise that assumes that all CF children require and need the same level of treatment and that if the hospitals are not seen/are not able to demonstrate using this approach that they will not receive funding from the CF Trust. The comments below are very specific to this year's annual review but some areas are very typical of how we/our daughter is treated each year. 1) Contrary to normal the physio was better this year, very pragmatic and easy to talk to and discuss issues. 2) X-ray and scan was good but clearly no communication between

CF team and x-ray/scan unit. 3) Blood taking still a fiasco, with lengthy waiting times and the team having difficulty to find a vein that would give sufficient blood. 4) The whole process does not take account of distance travelled with time delays in the process 5) There was no evidence whatsoever of any benefit of going to Oxford 6) Overreaction to weight/sugar/lung functions we were always told by adenoidal team at Addenbrooke's that lung function would be affected by narrowed wind pipe (an operation she had when she was about 5 years old). The only time we have had any success was at specialist lung function unit at Churchill Hospital which was only ever done once. 7) Numerous letters were sent with no discussion of anything within them. This is not acceptable. 8) Psychology got blood-taking assessment completely wrong. 9) Oxford not a team, just a collection of experts –they don't listen, jump to conclusions and not consistent. They don't take into consideration our daughter's particular circumstances and do not read notes prior to day or during day. 10) Checklist assessment and diagnosis – very desperate to find something that needed to be actioned. 11) Obviously don't believe us eg food diary – it was more like an interrogation than a conversation. 12) Body language clearly displays that they do not believe us when we say no symptoms and that she does not produce anything, and they don't believe when we tell them about her physical exercise/activities routine. 13) Repeated questions by different people. 14) Poor process, early arrival, non-eating, delays with the blood tests etc."

"I feel that our team is excellent. My only problem is that when the nurse is away we feel abandoned as the consultant is hard to reach and they have no other nurse to cover holidays and I feel that the ward staff don't know enough about CF in or out of hours."

"I feel that we know both our CF team at Northampton and Oxford. Both teams have always helped when needed and work personally with my child and the family. My daughter is happy to go to clinic which is really important. My questions are always answered well."

"We have always found the CF team and the care they give of an excellent standard. Queries are always answered promptly and fully."

"We only attend the John Radcliffe Hospital annually and think that it has improved over the years (better structure, less waiting time). Staff are always lovely, same as with Northampton, I think the care from the team is fantastic."

"The doctor and her team have provided wonderful support and care since our daughter was diagnosed at four weeks old. We won't experience John Radcliffe until her first annual review this winter. Although when we have met the doctor from JR we have been impressed with his attitude and care."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Northampton General Hospital
	Yes/no/ number/ N/A	**Notes/comments**
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	Clinics are carefully timed using four consultation rooms.
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?		Height is measured in a corridor and weight is measured in a weight room.
Where are the lung function tests done for each visit?		In patients' own consultation rooms.
Are clinic rooms appropriately sized?		Three adequately sized rooms, one rather small.
For annual review patients, are any distractions provided?		Annual Reviews done at John Radcliffe Hospital, Oxford.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	One patient with diabetes.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Age-related information packs are given which include information about diagnosis and transition.

Environmental walkthrough: ward

Ward name: Paddington

Microbiology status: All

		Hospital name	**Northampton General Hospital**
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	General paediatric ward, suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Nine	One or two rooms dedicated to CF care where required.
Do the en suites have:	**Toilets?**		No ensuites; sinks only in rooms.
	Wash basins?	Yes	
	Bath or shower?		
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Lockable cupboard.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull-out beds.
Visiting hours – are there allowances for CF patients/families out of normal hours?			Open visiting hours for parents.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In the parent's room.
What facilities are provided for teenagers?			iPad, game consoles, DVDs.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		No hospital gym. There is a movable exercise bike which can be used in the patient's room.
What facilities are there to help with school and further studies?		There is a play leader and two hospital teachers. The teachers liaise with patients' schools when required.
Is there a relatives' room?	Yes	TV, microwave, fridge, tea and coffee available.
What internet access is there?		Free, full service.
What facilities are there to enable students to continue to work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in own room used.
What facilities are provided for those with MRSA?		Barrier nursed where required.
What facilities are provided for those with *B. cepacia*?		Barrier nursed where required.
What facilities are provided for those with other complex microbiology?		Barrier nursed where required.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

- The hospital building is very old and not suitable for a growing service.
- The side rooms are extremely hot – this is problematic when having to have room doors closed.

Environmental walkthrough: Other

	Hospital name	**Northampton General Hospital**
	Yes/no/ number/ N/A	**Notes/comments**
Car parking		
Any concessions for patients and families?	Yes	No concessions for outpatients. Inpatients pay the first £3.20 then an exemption ticket is issued for their stay.
Other hospital areas		
Clear signage to CF unit and/or ward.		The ward is clearly sign posted but not CF-specific.
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?		Adequate space in all areas.
Do patients have to wait at pharmacy for prescriptions?	No	Medicines are collected for the patients by hospital staff.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	A monthly report is received by the service.
Are there patient comment/ feedback boxes?	Yes	

Royal Berkshire Hospital

Overview summary

Royal Berkshire Hospital (Berks) provide excellent shared care for their CF patients.

In addition to the lead consultant, there is a second consultant and an associate specialist, providing good cross-cover for senior medical staff.

The motivated MDT is lacking in sufficient dietetic support, but there has been recent increased physio and nursing support. There appears to be a shortfall in the provision of a physiotherapist routinely at the weekends. There is a psychologist, but with limited sessions.

An integrated care pathway has been implemented, aiming to streamline inpatient CF admissions. The inpatient facilities are good, with most cubicles having ensuite facilities.

Transition of approximately 25% of their patients is to Frimley Park, rather than the Oxford adult service.

Parental feedback about the Berkshire CF service was generally good.

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	N/A		
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	N/A		
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Red: happens in practice but not informally documented	Red	Needs formalising and disseminating to MDT.

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes safe service; would be more effective with staffing meeting the standard.	Green	
	% of MDT who receive an annual appraisal	100%	Green	Green	Deficit: appraisal was booked.
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Amber	Dietitian did not attend educational meeting.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	N/A	N/A	

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%	N/A: no current patients with CFRD.	N/A	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Greem	Ten rooms have full ensuite facilities.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	

3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Centre data	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red: in practice, not documented	Red/unsure	Inadequate documentation available.
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 network guideline >14yrs	No comment	This standard for age 10 is controversial and has little evidence base. Network aim is to scan >14 year olds.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green: electronic discharge letters	Green	Electronic discharge letter within 48hrs of discharge.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Amber	Amber	Estimate – data not collected.
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red	Red	
	% availability of a CF specialist dietitian at clinic	100%	Red: only 50% of clinics	Red	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Red	Red	Data indicates only 4 of 14 expected reviews.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red	Red	50% availability only.
	% availability of a clinical psychologist for inpatients	100%	Red	Red	50% availability only.
	% availability of a social worker at clinic	100%	Red	Red	It is inappropriate that this is done by nurse.
	% availability of a social worker for inpatients	100%	Red	Red	It is inappropriate that this is done by nurse.
	% availability of pharmacist at clinic	100%	Green	Green	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A: no palliative patients within last five years	N/A	Not applicable to current cohort.

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Royal Berkshire Hospital
Consultant 1	0.5	1	1	1 PA/0.1 WTE
Consultant 2	0.3	0.5	1	0.35 PA/ 00.35 WTE
Consultant 3			0.5	0.35 PA
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.5 WTE
Physiotherapist	2	3	4	0.45 WTE
Dietitian	0.5	1	1.5	0.1 WTE
Clinical psychologist	0.5	1	1.5	0.05 WTE
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	Nil dedicated
Secretary	0.5	1	2	0.17 WTE
Database coordinator	0.4	0.8	1	

Royal Berkshire Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Most of our care is at the RBH in Reading. Dr Dehalpert and his team are excellent; he makes himself contactable by email and replies within 24 hours (normally within a couple of hours). No issues with the Oxford annual review – is always well organised and seems to run smoothly."

"Car park always full, park further away and walk. Only issues was last year when following annual review new treatment suggested at Oxford we didn't know until Reading phoned to say he would be starting. We felt a bit confused as to who and why prescribed but team at Reading explained it all. Felt Oxford could have communicated better in this instance."

"We only attend Oxford for the annual review although we have seen the Oxford team in clinic at Reading too. We are happy with the services provided. Our daughter has not been an inpatient at the RB since 2010. We have an excellent relationship with the team at Reading. They are readily available and communication is excellent. We have noted that cross contamination and infection control measures have improved over the time we have attended clinic. We are very happy with the service provided."

"The team at the RBH excellent. Documentation should be given for performing home IVs – this is lacking – otherwise very good team."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	**Royal Berkshire 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?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In a height and weight room.
Where are the lung function tests done for each visit?		In patient's own consultation room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		Annual reviews are done at John Radcliffe Hospital, Oxford.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Diabetics are seen in a separate diabetic clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No	

Environmental walkthrough: ward

Ward name: Dolphin and Lion (function as one ward)

Microbiology status: All

		Hospital name	**Royal Berkshire Hospital**
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	General paediatric ward but suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		12	
Do the en suites have:	**Toilets?**	Yes	Ten rooms have full ensuite facilities.
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Medication is mainly held by nursing staff.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Service provided through patient line. Service is free from 7am–7pm.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Zed beds
Visiting hours – are there allowances for CF patients/families out of normal hours?			Open visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In the family kitchen.
What facilities are provided for teenagers?			TV, Wii, PlayStation.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Movable gym equipment.
What facilities are there to help with school and further studies?		Hospital teacher.
Is there a relatives' room?	No	
What internet access is there?		Internet service provided through patient line.
What facilities are there to enable students to continue to work and study?		Hospital teacher. Patients are able to take exams in the hospital if necessary.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Use sinks in own rooms.
What facilities are provided for those with MRSA?		Barrier nursed where required.
What facilities are provided for those with *B. cepacia*?		Barrier nursed where required.
What facilities are provided for those with other complex microbiology?		Barrier nursed where required.
Are patient information leaflets readily available on ward?	No	
Transition patients – can they get a tour of ward facilities?	Yes	

	Hospital name	**Royal Berkshire Hospital**
	Yes/no/ number/ N/A	**Notes/comments**
Car parking		
Any concessions for patients and families?	Yes	Parking is free for families/main carer.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Not a specific CF ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		DEXA scans are done in a private hospital off site. The pharmacy area is fairly small so there is a possible risk of cross-infection in this area. Patients sent for x-ray are staggered.
Do patients have to wait at pharmacy for prescriptions?	Yes	As above.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Comment/feedback box on ward.

Wexham Park Hospital

Overview summary

Wexham Park is one of the smaller shared-care clinics.

The MDT is stretched – we understand that the dietitian returned to work after retiring, and there is a lack of physio time, with insufficient input at weekends, and difficulty in doing any physio home visits. There is a psychologist, but with very limited sessions.

There are very limited inpatient ensuite cubicles, so CF patients do not always get allocated to them.

It was stated that perhaps more IVs are done at home than is optimal, but the MDT would need boosting to provide the inpatient support for this, in order to improve the 'tune-ups' for exacerbations.

A possible merger with Frimley Park Hospital may benefit the CF service. There are a number of CF patients at Frimley Park, whose care is shared with the Brompton Hospital.

Transition of patients is either to Oxford or Frimley adult CF services.

There was limited feedback – from only three families.

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Red: not specifically documented in notes	Red	Needs formalising and disseminating to MDT.

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green: have access to JR guidelines	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'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	N/A: no CFRD patients	N/A	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Amber	Amber	CF patients take priority, but if the two ensuite facilities are full, bathrooms are shared.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Red: no cohorting clinic policy	Red	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red: Tobramycin levels take 48–72hrs	Red	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red	Red	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	No comment	This standard for age 10 is controversial and has little evidence base. Network aim is to scan >14 year olds.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	?	Their SWOT analysis states insufficient at weekends, ie contradicts 100%.
	% availability of a CF specialist dietitian at clinic	100%	Amber	Amber	75% availability.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Red	Red	30% reviews.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red	Red	50% availability.
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red	Red	0% availability.
	% availability of a social worker for inpatients	100%	Red	Red	0% availability.
	% availability of pharmacist at clinic	100%	Red	Red	0% availability.
	% 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	Input from GOSH palliative care team for one recent patient.

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Wexham Park Hospital
Consultant 1	0.5	1	1	0.9 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.16 WTE
Physiotherapist	2	3	4	0.16 WTE
Dietitian	0.5	1	1.5	0.08 WTE
Clinical psychologist	0.5	1	1.5	0.025 WTE
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

Patient survey

Wexham Park Hospital

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

How would you rate your CF team?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Really supportive, caring and efficient. Very knowledgeable."

"The only exposure my daughter gets to smoking is on every visit to Wexham Park Hospital, where we have to walk through a plume of smoke to get her through the door. Should be banned near hospital entrance."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	**Wexham Park Hospital**
	Yes/no/ number/ N/A	**Notes/comments**
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In a height and weight room.
Where are the lung function tests done for each visit?		In patient's own consultation room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		Annual reviews are carried out at JRH, Oxford.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		No diabetics at present. They would be seen at a separate diabetic clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No	

Environmental walkthrough: ward

Ward name: 24

Microbiology status: All

		Hospital name	**Wexham Park Hospital**
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	Ward but suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Five	
Do the en suites have:	**Toilets?**		All have a sink. Two rooms with toilets and showers. CF patients take priority of full ensuite facilities.
	Wash basins?	Yes	
	Bath or shower?		
Do CF patients have to share any bathroom facilities?		Yes	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull out beds.
Visiting hours – are there allowances for CF patients/families out of normal hours?			Opening visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In parent's room
What facilities are provided for teenagers?			Computer games.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		Physiotherapists take patients up to the gym.
What facilities are there to help with school and further studies?		School on site. Teachers visit patients on ward.
Is there a relatives' room?	Yes	
What internet access is there?		Full, free service.
What facilities are there to enable students to continue to work and study?		School on site. Teachers visit patients on ward.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Washed in own room.
What facilities are provided for those with MRSA?		Barrier nursed where required.
What facilities are provided for those with *B. cepacia*?		Barrier nursed where required.
What facilities are provided for those with other complex microbiology?		Barrier nursed where required.
Are patient information leaflets readily available on ward?	No	
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	**Wexham Park Hospital**
	Yes/no/ number/ N/A	**Notes/comments**
Car parking		
Any concessions for patients and families?	Yes	Free parking for CF patients.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Not a dedicated CF ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	Yes	Pharmacy – this is a fairly open area and it's unlikely that CF patients would ever mix here.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	No	

Buckinghamshire NHS Trust (High Wycombe and Stoke Mandeville Hospital)

Overview summary

Although one of the smaller shared care clinics, Buckingham (Bucks) has been challenged by a disproportionate number of newly diagnosed patients in the last year.

Their MDT has inadequate inpatient physio time at weekends, and insufficient dietetic time. There is no psychologist, so patients are referred to Oxford.

The outpatient clinic and a day ward is at Wycombe, with inpatient facilities at Stoke Mandeville, which involves split-site working.

Although there are a number of ensuite cubicles, CF patients were not always able to be admitted to them.

Parental feedback was positive about the team and Wycombe, but negative about Stoke Mandeville for inpatient care.

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	Amber	85% actual – four patients yet to be registered; done at annual review.
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Amber	Amber	Changeover of physio staff in Sept 2014 meant non-attendance.
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	N/A	Amber	Work in progress.

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

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Amber	Two of 13 admissions not in a cubicle.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Red: 48 hours external lab.	Red	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red: discussed - not recorded in notes	Red	Inadequate documentation available.
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red: JR protocol 1 DEXA >14yrs	No comment	This standard for age 10 is controversial and has little evidence base. Network aim is to scan >14year olds.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Amber	Two of 13 admissions were not.
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: improvement since electronic dictation	Red	Vast improvement since introduction of electronic dictation.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Amber	No typed summaries; all have handwritten summary for GP.
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Amber	90%: 31 of 146 clinic appointments – unclear if they were available, or just didn't see patient.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Amber	95%: 138 of 146 clinic appointments – unclear if they were available, or just didn't see patient.
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	64% only.
	% availability of a CF specialist dietitian at clinic	100%	Green	Amber	84%: 123 of 146 clinic appointments – unclear if they were available, or just didn't see patient.

4.2 Inpatients/ outpatients	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Red	Red	46%: 6 of 13 pts admitted were not seen twice weekly, but from separate inpatient data, two had very brief inpatient. stay.
	% availability of a clinical psychologist at clinic	100%	Red: Available via referral	Red	Available by referral in Oxford.
	% availability of a clinical psychologist for inpatients	100%	Red	Red	0% available.
	% availability of a social worker at clinic	100%	Red	Red	0% available.
	% availability of a social worker for inpatients	100%	Red	Red	0% available.
	% availability of pharmacist at clinic	100%	Red	Red	0% available.
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Buckinghamshire NHS Trust
Consultant 1	0.5	1	1	1.2 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.33 WTE
Physiotherapist	2	3	4	0.07 WTE
Community physiotherapist				Unknown
Dietitian	0.5	1	1.5	0.032 WTE
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	No dedicated CF time
Secretary	0.5	1	2	Unknown
Database coordinator	0.4	0.8	1	

Patient survey

Wycombe Hospital and Stoke Mandeville Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

“Given a choice we would go with John Radcliffe rather than Stoke Mandeville.”

“We have never had any reason to question our CF teams. The service provided by everyone is amazing. In the past we have been seen elsewhere so we do have a comparison.”

“I am very happy with Dr McDonald and his team and the service we receive at Wycombe hospital. Our troubles occur when we have to attend the dreaded Stoke Mandeville where the level of care seems to fail due to an ignorance of the special needs required for CF patients. More funds available for training would be very welcome to make our children’s stay and parents less stressful. Wycombe hospital could also benefit with its own CF psychology department currently there is no psychologist who attends the bi-monthly clinics and it’s just too far to travel back and forth to Oxford - not to mention the expense - living with twp children with chronic illness affects all members of the family, it’s like treading unknown waters as you never know how problems are going to manifest – one could benefit from a helping hand at times, a bit of consistency in what is sometimes a very unpredictable lifestyle.”

“My child is very sad at having to leave the hospital and staff to go to adult service. Wycombe is much slower and more convenient as well.”

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Wycombe General Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	Patients are generally directed to the height and weight or clinic room on arrival. They could wait in the waiting area. It would be highly unlikely they would mix with other CF patients due to the staggered appointment system.
Is there easy access to toilets?	Yes	Male and female.
Where do height and weight measurements take place? Is this appropriate?	Yes	Dedicated room which is cleaned after each use.
Where are the lung function tests done for each visit?		In clinic room and cleaned between use.
Are clinic rooms appropriately sized?	Yes	All rooms are spacious, bright and clean. Well equipped for use. All toys are removed for clinic.
For annual review patients, are any distractions provided?	N/A	At Oxford John Radcliffe Hospital.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Diabetes clinic is held on Wednesday afternoon; CF in the morning. A patient with CFRD would be seen at either the end of diabetes clinic or the beginning of CF clinic. Therefore they would only have to make one visit.
Transition patients – can they get tour of outpatients' facilities?	Yes	At first appointment the parents would meet the team, be given contact information and if required, would have a tour.
Transition/new patients – do they get information pack?	Yes	Packs from Oxford John Radcliffe Hospital. Would direct to website.

Additional comments

- Twenty six patients with one or two transitioning at present.
- Clinic appointments are every half hour; seven/eight patients are seen at each clinic. There are five clinic rooms of which three or four are used for clinic. Highly infected patients are seen at the end of clinic. The team will rotate between rooms.
- All patient notes are kept at outpatients. They are in the process of setting up electronic notes

Environmental walkthrough: ward

Ward name: 3

Microbiology status: general

		Hospital name	**Stoke Mandeville Hospital**
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	Suitable.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Usual to have only one patient admitted at any one time, very occasionally two.
Number of side rooms?		12	All side rooms are modern, clean and bright, of good size and well equipped. Five rooms for CF use.
Do the en suites have:	**Toilets?**	5	All five have wet-room facility, of good size, clean and well equipped for use.
	Wash basins?	5	
	Bath or shower?	5	
Do CF patients have to share any bathroom facilities?		No	Due to low patient admittances.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		N/A	Child medications are locked away in drug room.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Each room has a wall mounted TV. There are also portable Starlight TVs with games and DVD facility.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Zed beds in rooms.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open. General visiting hours are 9am–8pm.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Fridge only located in the parent kitchen for use to store food. No microwave.
What facilities are provided for teenagers?			Adolescent room with seating, desk, TV books and games. WiFi.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	Can have use of one trampet in room.
What facilities are there to help with school and further studies?		Two 'Blueprint' Ofsted teachers to assist in school work and liaise with school. IT available, WiFi.
Is there a relatives' room?	Yes	Parents' lounge with seating and also a kitchen with tea/coffee making, fridge and toaster.
What internet access is there?	WiFi	
What facilities are there to enable students to continue to work and study?		The schoolroom teachers are informed of pre booked admissions to plan work.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in room.
What facilities are provided for those with MRSA?		Isolation and follow guidelines.
What facilities are provided for those with *B. cepacia*?		Isolation and follow guidelines.
What facilities are provided for those with other complex microbiology?		Isolation and follow guidelines. One NTM patient who receives regular treatment at Oxford.
Are patient information leaflets readily available on ward?	Yes	General information leaflets are given to patients/parents on admittance. The CNS is presently working on developing a pack for CF patients for future use.
Transition patients – can they get a tour of ward facilities?	Yes	New patients would be given a tour if required.

Additional comments

- The ward at Wycombe closed in 2009, after which patients were admitted to Stoke Mandeville Hospital.
- Each side room has a window to the corridor as well as to the outside. Outside each side room, on the wall are dispensers for gloves, aprons and hand sanitiser gels.
- A new multi-storey car park is in the process of being built and part of it is in use at the moment.

Environmental walkthrough: Other

	Hospital name	**Wycombe General Hospital**
	Yes/no/ number/ N/A	**Notes/comments**
Car parking		
Any concessions for patients and families?	No	Parking is limited at both hospitals, even though Wycombe Hospital has four car parks and Stoke Mandeville Hospital has five car parks surrounding the hospitals. Pay and display – charges at both: 1hr = £1.50; 1 – 2hr = £3.00; 2 – 3hr = £4.50; 3 – 8hr = £6.00; 8 – 12hr = £7.50; 12 – 24hr = £9.00.
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?		Wycombe Hospital Pharmacy has seating for twelve, situated in open corridor area. Radiology – planned appointments. DEXA – Churchill Hospital, planned appointment.
Do patients have to wait at pharmacy for prescriptions?	Yes	Patients are advised not to wait and can go to the coffee shop nearby. It is highly unlikely patients would mix due to staggered appointments.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Wycombe Hospital – well signed at main entrance, manned office with many general leaflets. PALS leaflets are also displayed at outpatient reception. Leaflets are displayed in the parents' kitchen.
Are there patient comment/ feedback boxes?	Yes	Day ward and also at ward at Stoke Mandeville.

Milton Keynes Hospital

Overview summary

Milton Keynes has 16 CF patients sharing care with Oxford and a few others under Royal Brompton and Great Ormond Street Hospitals. Not all of their MDT staff have managed to attend a CF educational meeting in the past year, but this is difficult as some staff work part time.

The core MDT has good availability for in- and out-patients, but there is a significant threat to the service due to the imminent semi-retirement of their very experienced CF nurse, without an adequate succession plan. There is no psychologist.

While the regular, bimonthly meetings with the lead nurse for safeguarding provide some social support and surveillance, this does not replace the role of a CF social worker.

There are currently no ensuite cubicles for inpatients.

Some patients transition to Brompton Hospital, rather than Oxford.

There was limited feedback – from only two families.

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

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Amber	Amber	No specific data, with MDT breakdown.
	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'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en-suite rooms during hospital admission	100%	Green	Amber	Single rooms, but not ensuite.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	No comment	This standard for age 10 is controversial and has little evidence base. Network aim is to scan >14year olds

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	No data: if CF consultant away, seen by paediatric consultant colleague and discussed with specialist centre as required.
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Amber	Amber	75% on a snap shot.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red: do not have psychology support	Red	0% available.
	% availability of a clinical psychologist for inpatients	100%	Red: do not have psychology support	Red	0% available.
	% availability of a social worker at clinic	100%	Red: contacted when needed	Red	0% available, but social issues discussed with lead paediatric safeguarding nurse, regular meetings, and social worker can be contacted.
	% availability of a social worker for inpatients	100%	Red: available if required	Red	0% available, but as above.
	% availability of pharmacist at clinic	100%	Red	Red	0% available.
	% 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	No such patients currently, but advice available if needed.

5 Commissioning

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

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Milton Keynes Hospital
Consultant 1	0.5	1	1	1.75 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.45 WTE
Physiotherapist	2	3	4	0.15 WTE
Dietitian	0.5	1	1.5	0.09 WTE
Clinical psychologist	0.5	1	1.5	
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	0.25 WTE
Database coordinator	0.4	0.8	1	

Patient survey

Milton Keynes Hospital

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"Poor standard of doctors able to put cannula/long line in when required. Admitted 11am – first attempt at cannula 2pm then 6pm! Food availability poor – child is also lactose intolerant – inappropriate choice. Oxford always admit onto ward instead of cubicle and really bad experiences with staff. They are not interested."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Milton Keynes
	Yes/no/ number/ N/A	**Notes/comments**
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		In a height and weight room – no time is left between patients.
Where are the lung function tests done for each visit?		In patient's own consultation room.
Are clinic rooms appropriately sized?		Three of the four are a good size and the fourth is on the small side.
For annual review patients, are any distractions provided?		Annual Reviews done at John Radcliffe or the Royal Brompton.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Seen in same clinic area.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Not currently available.

Environmental walkthrough: ward

Ward name: 5 Milton Mouse

Microbiology status: All

		Hospital name	**Milton Keynes Hospital**
		Yes/no/ number/ N/A	**Notes/comments**
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	General paediatric, suitable for CF care.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Four	
Do the en suites have:	**Toilets?**	No	
	Wash basins?	Yes	
	Bath or shower?	No	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Locker with key.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free service.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Pull out beds in rooms.
Visiting hours – are there allowances for CF patients/families out of normal hours?			Open visiting hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?			There are fridges in the rooms and a microwave is available.
What facilities are provided for teenagers?			A relaxing area; games, TV, DVDs

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	
What facilities are there to help with school and further studies?		None.
Is there a relatives' room?		Yes, but not suitable for overnight stays.
What internet access is there?		Full. Free service.
What facilities are there to enable students to continue to work and study?		None.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Specific sinks are used.
What facilities are provided for those with MRSA?		Barrier nursed if required.
What facilities are provided for those with *B. cepacia*?		Barrier nursed if required.
What facilities are provided for those with other complex microbiology?		Barrier nursed if required.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

- There are only ever 1 – 2 CF patients on the ward at any one time.
- Despite there being no full ensuite rooms, plans are in place to create ensuite facilities in two of the existing rooms

Environmental walkthrough: Other

	Hospital name	Milton Keynes Hospital
	Yes/no/ number/ N/A	**Notes/comments**
Car parking		
Any concessions for patients and families?	Yes	Inpatients receive a weekly permit at a reduced cost.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	General paediatric ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	Sufficient space in all areas.
Do patients have to wait at pharmacy for prescriptions?	No	CF patients are generally issued with a FP10 prescription so that they can collect their medicines locally.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

Panel members

Jane Clarke*	Consultant	Birmingham Children's Hospital
Sukheshi Mahecha	CF Specialist Pharmacist	Royal Brompton Hospital
Sam Phillips	CF Specialist Clinical Psychologist (also covered Social work)	Bristol Hospital
Julie Mould	CF Clinical Nurse Specialist	Hull Hospital
Claire Mott	CF Specialist Dietitian	University Hospital of Wales
Tamara Orska	CF Specialist Physiotherapist	Kings College Hospital
Sian Summers	Specialised Commissioning	Wessex
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	Quality Assurance and Control Manager	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Jacquie Ryan	Executive Assistant	Cystic Fibrosis Trust

*Clinical lead for Peer Review

cysticfibrosis.org.uk