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Cystic Fibrosis why we're here

British Thoracic Society

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Peer review report

North West Midlands
Cystic Fibrosis Centre
Adult
20 March 2013

1. Executive summary

1.1 Overview of the service

The Adult CF service in The North West Midlands (NWM) is a crucial resource for a large region that includes areas of social deprivation. NWM adult service resources are fragmented such that no one single hospital in the region can deliver exemplary cystic fibrosis care. Diseconomies of scale mean that an adequate multidisciplinary team (MDT) with the range of staff required to guarantee excellence is difficult until patient numbers reach around 100. Over past years the lack of resources has on occasions resulted in periods of inadequate care. The 2013 tariff and the recommendation that adult care be provided from CF centres provides a timely opportunity to establish a critical mass of resource that will allow the NWM to build a CF MDT which is capable of delivering truly excellent care. We recommend that steps are taken to concentrate a critical mass of expertise in Stoke to produce a resilient and excellent service.

1.2 Good practice examples

1. A highly committed adult team with a close working relationship with the paediatric team, all within the same hospital, with monthly joint adult/paediatric meetings that support seamless transition and build expertise.
2. A willingness from the senior clinicians within the adult and paediatric teams to work towards a flexible service with the aspiration of developing a service capable of delivering exemplary care.
3. Excellent inpatient facilities and a commitment to develop the ward further to build on this.

1.3 Key recommendations

1. There is an immediate need to increase medical support for the Stoke service. A service for 50 patients requires 2 consultants with 5 programmed activities (PAs) (1/2 day each). Currently there is only 1 consultant with around 2 PAs. A further consultant needs to be appointed as soon as possible and there is an immediate need for job plans within the respiratory department to be reviewed, to release Dr Thomas to have 5 PAs of protected time for CF until she is joined by a second colleague.
2. There is an immediate need to address the fact that there is no junior medical support to the CF service and none likely to be available in the future. We would recommend the immediate appointment of a WTE Band 7 Clinical Nurse Specialist using the resource that would normally be invested in junior medical staff.
3. There is an immediate need to remedy staff shortage in adult physiotherapy. There is an immediate need for a Band 6 physiotherapist in paediatrics that will reduce the need for cross-cover and 0.3 whole time equivalent (WTE) increase in adult physiotherapy.

1.4 Areas for further consideration

1. In the next 6–12 months, plans will need to be drawn up to provide increased depth and resilience in the MDT and this may well require the service to be resourced over and above the tariff because of problems of diseconomies of scale, since critical mass will not be achieved in the short term.
2. Once staff are in place there are some important early process measures that can be measured to ensure that quality is improving, such as benchmarking intravenous (IV) days against national figures and ensuring that all patients receive an end-of-IV review.
3. Work should start to support the transfer of adult patients from Shrewsbury to Stoke in order to reduce the fragmentation of resources. This process should be supported by a clear description of the advantages of excellence that is currently being traded off against convenience.
4. We would recommend that an individual with mastery of the details of the service is adequately resourced to provide continuity and lead developments over the next 5 years, which will be a crucial period for the NWM service.

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

2.1 Models of care

Summary

100% of patients have an annual review and this is discussed with the patient by the consultant and the data is captured on the UK CF Registry. Very few patients are receiving end-of-IV reviews in Stoke. In Stoke the team is spread very thinly and sickness or leave is difficult to cover. In Shrewsbury there is a lack of critical mass of patients for team members to keep up skills or gain them if they have joined without learning about cystic fibrosis in a unit with over 100 patients.

2.2 Multidisciplinary care

Summary

The Stoke risk matrix signifies that staffing levels do not provide for safe and effective care. Stoke has a committed MDT that is unable to reach its full potential because of an inadequate critical mass. This is in part because part of the funding for the patients looked after within the NWM is invested in Shrewsbury. In Shrewsbury there are too few patients for MDT members to maintain skills and develop expertise in all the complexity that adult CF care necessarily involves. This means that the MDT in Stoke is mainly involved in fire-fighting and rescue with little spare capacity to invest in the all important preventative interventions that lie at the heart of good CF care, such as measuring and supporting adherence. In addition there is only one CF consultant, with inadequate sessions, when there should be two. We feel that concentrating resources for NWM in Stoke and appointing another consultant in CF, along with increasing all components of the CF MDT, will lay the foundations for excellence.

2.3 Principles of care

Summary

Clinics are organised to avoid cross-infection. The unit was aware of the identities of the adults who were not colonised with pseudomonas and there was recognition of the need to eradicate first pseudomonas isolates with the risk matrix, indicating that 100% are eradicated. CF diabetes screening, liver ultrasound and DEXA scanning were all slightly below target but we feel that the changes planned by the Stoke unit to increase resources should allow these areas to improve. A particular problem is an almost complete lack of junior doctor support and not enough consultant time. There are plans in place to replace the junior doctor role with an additional specialist nurse and it is felt that this post will allow a marked improvement in the ability to organise and schedule tests.

2.4 Delivery of care

Summary

The lack of MDT resource meant that physiotherapists were unable to cover clinics.There were problems with home IVs with people with cystic fibrosis not getting mid-course monitoring and very few got end-of-IV reviews. There was an awareness that this must change and these problems again highlight the need to centralise the NWM service in order to concentrate resources and increase the ability of the MDT to deliver high-quality care. The new inpatient facilities provide high-quality dedicated side rooms and careful thought has been directed towards increasing CF expertise on the respiratory ward, with the intention to divide the ward into two to create a CF area that will concentrate expertise.

2.5 Commissioning

Summary

We met with the CEO of the hospital trust who highlighted his commitment to making the NWM CF service an excellent service. We highlighted that there were significant problems with resourcing the CF service because of critical mass. We suggested a number of solutions, which might for example involve charging lower overheads on the tariff income until the CF service reached a size that meant it was not undermined by diseconomies of scale. The local commissioner attended the peer review and is committed to working with NWM to reduce fragmentation of the service in a way that supports all patients to receive the high standards of care that can be obtained at the bigger centres in the UK.

3. UK CF Registry data

University Hospital of North Staffordshire NHS Trust		Male	Female
BMI	Number of patients and % attaining target BMI of 22 for females and 23 for males	14 (50%)	19 (79%)
	Number of patients and % with BMI <19 split by sex	2 (8%)	4 (14%)

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		55.2%	50.59%
	Number and median (range) FEV_1 % pred by age range and sex	16–19 years	6, 88.40% (12.96–114.22)	4, 74.9% (39.37–84.54)
		20–23 years	4, 62.32% (30.34–84.79)	4, 36.8% (19.27–50.95)
		24–27 years	3, 64.33% (18.21–77.68)	4, 49.8% (39.76–62.62)
		28–31 years	8, 28.65% (27.02–48.19)	5, 57% (49.49–71.72)
		32–35 years	3, 81.06% (70.55–99.88)	3, 68.2% (50.17–77.24)
		36–39 years	n/a	n/a
		40–44 years	2, 63.07% (55.2–70.93)	1, 50.59%
		45–49 years	n/a	1, 41.49%
		50+ years	2, 24.59% (22.75–26.42)	2, 67.7% (39.9–96.52)

Data input	Number of complete annual data sets taken from verified data set	52

Pseudomonas Chronic PA is 3+ isolates between 2 annual data sets	Number and % of patients with chronic PA infection	34 (65%)
	Number and % of patients with chronic PA infection	30 (88%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	23 (86%)
	Number and % of patients on chronic macrolide without chronic PA infection	5 (28%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

Stoke staffing

- **Consultants:** With 50 patients in Stoke there should be 0.5 WTE consultant. Ideally this should be split between two consultants to give cross-cover. There were two consultants with 0.2 WTE each, so the allocated hours were below recommended. Recently Charles Pantin has retired so instead of two consultants covering CF there is only one, which further reduces the consultant hours available. In addition Angela Thomas does two full weeks out of seven covering the acute admissions and this further reduces the effective time she can dedicate to cystic fibrosis. Lack of staffing means that patients started on IVs may not get end-of-IV reviews and never get mid-IV reviews.

  Previously the on-call was covered one in two and is now one in one. There are two ward rounds per week and one outpatient clinic. Dr Thomas is new in post but it has been recommended that she attend national and international CF conferences.
- **Junior doctor support:** The team should be supported by 0.6 WTE junior doctors, usually in the form of CF fellow hours and a CF specialist registrar hours. In fact there are no junior doctors at all dedicated to cystic fibrosis and any CF input comes from doctors who have no training in cystic fibrosis.
- **Good practice:** Dr Thomas is committed and received CF training in a 150-patient adult unit and has the potential to share ideas with the paediatric team, which will make for a coherent service.
- **Shrewsbury:** Shrewsbury has around 14 patients 'shared care' with Stoke and around 13 patients 'shared care' with Birmingham, meaning potentially that 27 patients that could increase critical mass in Stoke are currently cared for in Shrewsbury. We understand that the 14 patients are supported by 2 PAs for CF (0.2 WTE) of consultant time.

Recommendations

- There is an immediate need to increase the consultants in Stoke from one to two consultants and ensure that the PAs allocated are not reduced by acute on-call.
- We understand that there is no prospect of securing continuity of input from junior doctors and we recommend that the resources used for junior doctors should be used to fund a senior specialist nurse who can support the service, including providing a triage service for drop-ins.
- We recommend that the patients from Shrewsbury are transferred to Stoke, in order to reduce fragmentation of the service and increase the critical mass at Stoke so that there is the possibility of developing the depth and breadth of MDT to deliver high-quality care for the region. Currently there is a major lack of critical mass in both Shrewsbury and Stoke.

4.2 Specialist nursing

Stoke staffing

- 1 WTE Band 7 CF clinical nurse specialist (CNS).
- 0.4 WTE Band 6 support nurse.
- CNS, new in post recently, has joined CFNS group, supported by paediatric staff and would benefit from more shadowing of experienced staff.
- Band 6 nurse who works alongside CNS works on CF/respiratory ward. CNS attends twice weekly ward rounds, team meetings and monthly meeting with the paediatric service. 1 whole day every 3 months attends Shrewsbury adult clinic. The Stoke adult centre has 1 clinic a week on Monday afternoon with 8 patients.

Good practice

- Dedicated, hard working, motivated, enthusiastic nursing team. Developing policies and procedures and implementing teaching plans.

Recommendations

- To enable home-care service to be implemented. At present no service identified while four fifths of IV therapy is carried out at home. Liaise with pharmacy to organise home IV therapy. Not appropriate for Band 7 nurse to organise ancillaries and collect medication from pharmacy. New CF CNS should be allocated time to visit other centres and network with colleagues.

Ward staffing

- Early: six qualified/four health-care assistants.
- Late: five qualified/three health-care assistants.
- Night: four qualified/three health-care assistants.

Good practice

- Enthusiastic ward team. Ward: split ward into two areas. Designated CF area with own staff set. Adapting rooms and have ensuites and televisions in seven side rooms.

Recommendation

- IV preparation room cramped and inadequate ventilation. This should be addressed immediately.

Shrewsbury staffing

Extremely motivated enthusiastic CNS. 0.6 WTE Band 7 CNS meets the Cystic Fibrosis Trust's 'Standards of Care (2011)', for the number of patients at Shrewsbury. However cover is only provided for three days per week when not on duty, cover given via the CF consultant.

Good practice

- Dedicated CF specialist nurse. There is good liaison with community teams and there are keen ward nurses wiling to learn about cystic fibrosis. Excellent home-care service provided. Holds a mobile phone for ease of accessibility.

Recommendations

- Does not meet CF standards for CNS as only 0.6WTE.
- Does not warrant uplift as numbers low.
- Cover via CF consultant does not meet standards of availability to patients.
- Inpatient facilities are on a general respiratory ward run by keen enthusiastic staff. Side rooms with no en suite available at present. Action plan made.

4.3 Physiotherapy

Staffing

Stoke

1.0 WTE Band 7 rotational physiotherapist with plans for a static permanent post. Member of Association of Chartered Physiotherapist in Cystic Fibrosis (ACPCF) attends national and regional ACPCF Study Days. Attendance at CF MDT meetings and ward rounds is variable due to under-resourcing of staff. Cross-cover with paediatrics for both in/out-patients. Inpatients are always given priority over clinics. Due to very limited physiotherapy resource, cover is extremely variable, especially to clinic. There are insufficient resources to meet national standards in all parameters eg Commissioning for Quality and Innovation (CQUIN) for clinic visits, completion of annual review and exercise testing. There is also a lack of facilities for exercise/exercise testing.

Shrewsbury

0.2 WTE Band 7, funding identified, however not in the therapy budget. Shrewsbury has ACPCF departmental membership. No opportunity to attend national and regional ACPCF Study Days to date, however both have attended international conferences. There are rarely inpatients, clinics are attended. A Band 6 is identified to cover for the CF patients. This service is in its infancy. They provide cover to the bi-weekly clinic and see patients who attend the unit for IVs if requested.

One Band 7 physiotherapist has had the opportunity to attend an international conference and there are plans for the other to attend. Neither has had an opportunity to be involved in research and audit.

Stoke is severely under-resourced, physiotherapy is ‘fire-fighting’, providing input to those patients in greatest clinical need, although all inpatients will be seen daily during the week for assessment and treatment. Inpatients always take priority over clinics. The physiotherapists perform nebuliser challenges, however waiting times for challenges are unacceptable due to under-resourcing.

Good practice

- Active members of ACPCF.
- The physiotherapists are fully aware of the national standards of care and of shortfalls in service provision. They have a clear sense of the direction in which service development can be achieved.
- The physiotherapists, in spite of the restraints of service provision, remain committed and demonstrate a clear enthusiasm for working with CF patients.

Recommendations for service development

- Urgently address shortfall in physiotherapy staffing to go some way towards addressing the shortfall in service provision and the failure to achieve nationally set standards, eg CQUIN for outpatients, annual review etc.

- Separate adult and paediatric services for physiotherapy provision.
- Band 7 posts need to become static not rotational.
- The Shrewsbury service is in its infancy. CF guidelines do not support shared care. This requires consideration in the wider context of the MDT review.

4.4 Dietetics

Staffing – both hospitals slightly above recommendations.

Stoke (48 patients – adults) actual staffing 0.5WTE, band 7, recommendation 0.32 WTE

Shrewsbury (14 patients) actual staffing 0.2 WTE, band 7, recommendation 0.09 WTE.

Good practice

- **Stoke:** Good level of specialist care, good channels of communication between paediatric and adult team. Good provision for cross-cover and leave-cover between the two teams. Good MDT working and support provided for Shrewsbury dietitian. Involvement in MDT audit projects and involvement in key life stages eg transition, pregnancy.
- **Shrewsbury:** Dietitian reports good level of support from Stoke.

Areas of improvement

- **Stoke:** Catering, meal provision fair. Problems with availability of snacks for patients, Sodexo only supplies standard snacks. Patients frustrated by catering difficulties and are vocal about this. During the visit, made suggestions about providing a wider range of higher calorie, age-appropriate snacks.
- **Shrewsbury:** The dietitian should be a member of the CF Dietitians Interest Group. The dietitian has limited CF experience, covers two sites and a number of specialties and has a team leader role. Has attended Stoke for shadowing experience and feels there is adequate support for help from the specialist centre. No development work in CF, no audit, no service improvement projects, no inpatients. The dietetic service is over-funded, under providing and is not a specialist service. The skills and expertise are not provided at the same level as at Stoke. Discussed the need for a framework of training/shadowing/support.
- **Stoke:** UK CF Interest Group meeting, paediatric or adult dietitian try to attend one each per year, circulate minutes to the other team members.
- **Shrewsbury:** not a member of CF Interest Group, reports to be in the process of joining, no evidence.
- **Stoke:** Joint paediatric/adult meeting once a month, NW Midlands meeting every three months. Attend all MDT meetings and ward rounds, able to see all inpatients 2–3 times a week, attends all team meetings and clinics.
- **Shrewsbury:** shared care, one clinic every two weeks, 4–5 patients per clinic, every 2–3 months a clinic run with Stoke for annual reviews. Rarely have inpatients and only one clinic every other week. The dietitian covers two sites and various specialties, including a team leader's role.
- **Stoke:** The dietitian provides leave-cover for paediatric colleagues, cross-cover for paediatrics and adults. The adult dietitian covers adolescent patients, while paediatric colleagues cover younger children.
- **Shrewsbury:** No leave-cover, if post holder absent, no cover.

- **Stoke:** European Cystic Fibrosis Conference (ECFC) – no attendance recently due to maternity leave, circumstantial. Support is available from the Trust/CF team for attendance.
- **Shrewsbury:** Dietitian attended ECFC 2012.
- **Stoke:** Audit/research involvement in team projects including diabetes, bone health. No specific dietetic-driven projects. Service improvement projects in the Trust, no evidence of service improvement in CF dietetics. No active research involvement.
- **Shrewsbury:** no development, audits or research, no service improvement.
- **Stoke:** Transition, just commenced clinics, and set up transition document. No formal transplant or end-of-life documentation, regular MDT meetings and individual plan for patients. Family planning, pre-conception counselling provided, if aware of planned pregnancy.

4.5 Pharmacy

Staffing

0.35 WTE Band 8a CF pharmacists. The current post holder started at Stoke January 2013. The remaining 0.65 WTE of the post is respiratory. There is no specialist pharmacist cover for Shrewsbury, where the pharmacist who covers the respiratory ward sees CF inpatients. This pharmacist changes daily.

The CF pharmacist is available in an advisery capacity via the telephone, although has never been contacted. The Cystic Fibrosis Trust's 'Standards of Care (2011)' recommend that for 75 patients, there should be 0.5 WTE pharmacists. For approximately 60 patients, there should be 0.4 WTE pharmacists. 0.35 WTE falls below the recommended level. For the past 12 months the post holders have been unable to attend the specialist CF pharmacist meetings due to maternity leave and lack of funding for attendance. The pharmacist plans to join the CF pharmacists' group and attend their meetings going forward. There is a twice weekly MDT ward round and these are attended by the pharmacist. During absence, inpatients are seen by a Band 6/7/8a pharmacist from the cardiothoracic team. The paediatric CF/respiratory pharmacist (part time) is available for queries.

Out of hours, there is an on-call pharmacy service provided by Band 6 and 7 pharmacists. They have access to a 'Common CF queries' document produced by the previous post holder.

The last national CF conference attended by the CF pharmacist was 2009, but receives feedback from others attending.

No pharmacist research completed. **Audit:** Discrepancies between medicines listed in clinic letters and patients' GP medication list. Protocol since produced for clinic use. Re-audit due. Plans to commence an audit of Therapeutic Drug Monitoring of medicines used in CF. Currently little involvement in key life stages. Plans to extend this role in future.

CF pharmacist does not see patients at annual reviews, nor attends annual review discussions.

Good practice

- Adapted desensitisation protocol from another hospital and then produced a policy for its use.
- Produced standardised prescription sheets for IV dispensing to help pharmacy dispensary staff.
- Produces a 'Common CF queries' document to help non–CF specialist pharmacists.
- Set up improved communication channels between CF team and pharmacy manufacturing unit.
- Produced a Patient Information Leaflet for patients going home on IVs.

Recommendations

- Make contact with Shrewsbury pharmacy colleagues.
- Join the CF pharmacists' group and begin to attend annual reviews/discussions where possible.

4.6 Psychology

Staffing

0.5 WTE Band 8a Arts Psychotherapist. The amount of time purchased meets the criteria set by the Cystic Fibrosis Trust standards, although the standards state that the provision should be offered by a clinical psychologist. There is no cover for the psychology input into the team if the designated psychologist is absent. The post holder is registered with the Health Professions Council (HPC) and is a member of the UK Psychosocial Professions in CF Group (UKPPCF) and has been in post four and a half years. She attended the National UKPPCF study days over the last few years, but neither the European nor international CF conferences.

Good practice

- Provision of a good psychological therapy service; informal feedback is positive. She is dedicated to her post and thoughtful of patients' experience.
- The service is very responsive to urgent referrals and tries to accommodate the needs of the CF team.
- Very active in trying to achieve community referrals for patients and seek appropriate support.
- There is ongoing, informal work with the team and ward to help reflection and manage challenging situations.

Areas of development

- Building on communication between CF team and psychological therapist.
- Working creatively to offer Psychology Annual Reviews (this may not be face to face).
- Working with higher management to ascertain how to work with the inpatient unit, both patient and staff needs.
- Audits of referrals and response times with regard to CF Standards for Psychology and more formal evaluation of the psychological therapy service and the outcomes from therapy.

Recommendation

- This post should be complemented by appointment of a clinical psychologist as per the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

4.7 Social work

There is no social worker in post in the CF team. This decision was taken due to funding pressures. There is the possibility of review under the tariff funding currently being implemented. There seems to be a misapprehension that there would be difficulty in recruiting a qualified social worker to the position. In place of a social worker, the team has employed a social welfare adviser. This has brought great benefits to the team and patients. The worker is committed and will take on anything asked of her. She attends local meetings twice yearly but is not eligible to be a member of the specialist CF Psychosocial Group. The worker attends the majority of MDT meetings,

clinics and annual review for adults, where a benefits assessment is completed. There is some involvement in the key life stages. This is largest in terms of the transition process. The worker brings invaluable benefits advice at all stages.

There are some challenges with the establishment of this role as it has not been clearly defined or managed. There is no mechanism for decisions to be made about the role in any given situation. This is crucial where a role is unqualified. Such roles have been found to be problematic at other centres and have therefore been withdrawn. One of the reasons for this is that helping people with their financial difficulties frequently leads into areas of personal/psychological functioning where professional training underpins decisions about appropriate further support or signposting. A qualified post allows more work to be done within the team in relation to support during key life stages and bereavement.

The situation here has left both the worker and patients very vulnerable. There are some plans to mitigate some of the difficulties. Monthly meetings with the psychologist (adults) have been initiated which may provide a forum where roles and boundaries within the team can be openly explored. For the worker there are plans to have social work supervision, but it is unclear whether this will provide appropriate support given the lack of role clarity.

Recommendations

- Recruitment of qualified social worker as per the Cystic Fibrosis Trust's 'Standards of Care (2011)', to contribute to development of transition, annual assessment and specialist key life stages support.
- Consultation with other centres on how to achieve this.
- In the meantime careful thought and close management needs to be given re the current post, to ensure that the worker and patients are properly supported.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	1	0	6	3	2	1	1
Female	1	1	2	0	2	1	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	13	6	3	0
From the ward staff	5	8	1	1
From the hospital	7	9	4	1

Areas of excellence

1. Cleanliness
2. Cross-infection
3. Overall care – from CF team

Areas for improvement

1. Staffing levels
2. Car parking
3. CF team – communication

6. Appendices

Appendix 1

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

Reported and actual compliance below follows a Red, Amber, Green rating defined as the following:

Green = Meeting all standards of care (2011)

Amber = Failing to meet all standards of care (2011) with improvements required

Red = Failing to meet standards of care (2011) with urgent action required

Hospital name

University Hospital of North Staffordshire NHS Trust

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% patients seen at least once a year by the specialist centre for an annual review.	90%	Green	Green	Inadequate critical mass to maintain skills in Shrewsbury.
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	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include AR).	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	No	No	Inadequate critical mass in MDT.
	% of MDT who receive an annual appraisal.	100%	Green	Green	
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	
	Are there local operational guidelines/policies for CF care?	100%	Amber	Amber	Note that few patients get end-of-IV review.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust standards.	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Green	
	% patients with CF-related diabetes (CFRD) reviewed at a joint CF/Diabetes clinic.	100%	Green	Green	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission.	100%	Green	Green	New ward with innovative care patterns planned.
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of 1st isolates *Pseudomonas aeruginosa* in the previous 12 months.	100%	Green	Green	
	% patients admitted within 7 days of the decision to admit and treat.	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours.	60%	Green	Green	
3.4 CFRD	% patients >12 years of age screened annually for CFRD.	100%	Green	Green	
3.5 Liver disease	% patients >5 years of age with a recorded abdominal ultrasound in the last three years.	100%	Amber	Amber	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Green	Green	
3.7 Reduced BMD	% patients >10 years of age with a recorded DEXA scan in the last 3 years.	100%	Amber	Amber	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% patients seen by a CF consultant a minimum of twice a week while inpatient.	100%	Green	Green	
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/shared care consultant/patient or carer, within 10 days of consultation.	100%	Green	Green	
	% dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	
	% patients reviewed by a CF CNS at each clinic visit.	100%	Green	Green	
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Green	Green	
4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Red	Red	
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	
	% availability of a CF specialist dietitian at clinic.	100%	Amber	Amber	Not all patients need to be seen as not pancreatic insufficient.
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	
	% availability of clinical psychology for inpatients and at clinic.	100%	Red	Red	Not all patients request to see the psychotherapist.
	% availability of social worker for inpatients and at clinic.	100%	Red	Red	Not all patients request to see social welfare.
	% availability of pharmacist for inpatients and at clinic.	100%	Red	Red	Available if needed.

4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	Note: very few patients get end of IV reviews.
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life.	75%	Amber	Amber	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months.	<1%	4	4	
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	

Hospital name

Shrewsbury and Telford Hospitals NHS Trust

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% patients seen at least once a year by the specialist centre for an annual review.	90%	Green	Green	Small number of patients insufficient to maintain skills.
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 Multi–disciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT. (One consultation may include annual review).	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	Small patient numbers limit critical mass.
	% of MDT who receive an annual appraisal.	100%	Green	Green	
	% of MDT who achieved their PDP (Professional Development Profile) in the previous 12 months.	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	N/A as SaTH is a network clinic.	N/A	
	Are there local operational guidelines/policies for CF care?	100%	N/A as SaTH use Stoke policies and guidelines.	N/A	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust standards.	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Green	
	% patients with CFRD reviewed at a joint CF/ Diabetes clinic.	100%	No clinic	N/A	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission.	100%	Red	Red	Single room but not en suite. Toliet outside the room.
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of 1st isolates *Pseudomonas aeruginosa* in the previous 12 months.	100%	Green	Green	No instances.
	% patients admitted within 7 days of the decision to admit and treat.	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours.	60%	Green	Green	
3.4 CFRD	% patients >12 years of age screened annually for CFRD.	100%	Green	Green	
3.5 Liver disease	% patients >5 years of age with a recorded abdominal ultrasound in the last three years.	100%	Red	Red	Only 1 patient.
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Green	Green	
3.7 Reduced BMD	% patients >10 years of age with a recorded DEXA scan in the last three years.	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% patients seen by a CF consultant a minimum of twice a week while inpatient.	100%	Green	Green	
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/shared care consultant/patient or carer, within 10 days of consultation.	100%	Green	Green	
	% dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	
	% patients reviewed by a CF CNS at each clinic visit.	100%	Green	Green	
	% patients with access to a CF CNS during admission (excluding weekends).	100%	Green	Green	
	% patients reviewed by a CF specialist physiotherapist at each clinic visit.	100%	Red	Red	Physio limited yet crucial.
	% patients reviewed by a physiotherapist twice daily, including weekends.	100%	Red	Red	
	% availability of a CF specialist dietitian at clinic.	100%	Red	Red	Limited yet crucial.
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Red	Red	
	% availability of clinical psychology for inpatients and at clinic.	100%	Red	Red	Not all patients need psychology input.
	% availability of social worker for inpatients and at clinic.	100%	Red	Red	Not all patients need social worker input.
	% availability of pharmacist for inpatients and at clinic.	100%	Red	Red	No pharmacist

4.3 Home-care	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life.	75%	Green – no patients	Red	Patients reaching end-of-life might require transfer

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months.	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months.	<1%	2	2	Room not available to see CF outpatients – another room found
5.3	User survey undertaken a minimum of every three years.	100%	Red	Red	

Appendix 2

Staffing levels

	75 patients	150 patients	250 patients	University Hospital of North Staffordshire NHS Trust
Consultant 1	0.5	1	1	0.4 (but currently only 0.2)
Consultant 2	0.3	0.5	0.5	0
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	0
Specialist registrar	0.4	0.8	1	0
Specialist nurse	2	3	5	1.4
Physiotherapist	2	4	6	1
Physiotherapy assistant				
Dietitian	0.5	1	2	0.5
Clinical psychologist	0.5	1	2	0 – arts psychotherapist 0.5
Social worker	0.5	1	2	0 – social welfare adviser 0.5
Pharmacist	0.5	1	1	0.4
Clinician's assistant				
Secretary	0.5	1	2	0.5
Admin assistant				
Database coordinator	0.4	0.8	1	0.5
CF unit manager				

Staffing levels

	75 patients	150 patients	250 patients	Shrewsbury and Telford Hospitals NHS Trust
Consultant 1	0.5	1	1	0.2
Consultant 2	0.3	0.5	0.5	0
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	0
Specialist registrar	0.4	0.8	1	0
Specialist nurse	2	3	5	0.6
Physiotherapist	2	4	6	0.2
Physiotherapy assistant				
Dietitian	0.5	1	2	0.2
Clinical psychologist	0.5	1	2	0
Social worker	0.5	1	2	0
Pharmacist	0.5	1	1	0
Clinician's assistant				
Secretary	0.5	1	2	0.2
Admin assistant				
Database coordinator	0.4	0.8	1	0
CF unit manager				

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the 'UK CF Registry Annual Data Report 2011', available at cysticfibrosis.org.uk/registry)

CF Registry data 2011	
Demographics of centre: University Hospital of North Staffordshire NHS Trust	
Number of active patients (active being patients with data within the last two years) registered	53
Number of complete annual data sets taken from verified data set (used for production of National Report)	52
Median age in years of active patients	28
Number of deaths in reporting year	1
Median age at death in reporting year	22

Age distribution (Ref: 1.6 'Annual Data Report 2011')		
Number in age categories	16–19 years	10 (19%)
	20–23 years	8 (15%)
	24–27 years	7 (14%)
	28–31 years	13 (25%)
	32–35 years	6 (11%)
	36–39 years	0
	40–44 years	3 (6%)
	45–49 years	1 (2%)
	50+ years	4 (8%)

Genetics	
Number of patients and % of unknown genetics	3 (6%) unidentified gene on one allele

BMI (Ref: 1.13 'Annual Data Report 2011')		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	14 (50%)	19 (79%)
Number of patients and % with BMI <19 split by sex	4 (14%)	2 (8%)

FEV_1 (Ref: Figure 1.14 'Annual Data Report 2011')		
	Male	Female
Median FEV_1% pred at age 16 years split by sex	55.2%	50.59%
Number and median (range) FEV_1 % pred by age range and sex		
16–19 years	6, 88.40% (12.96–114.22)	4, 74.9% (39.37–84.54)
20–23 years	4, 62.32% (30.34–84.79)	4, 36.8% (19.27–50.95)
24–27 years	3, 64.33% (18.21–77.68)	4, 49.8% (39.76–62.62)
28–31 years	8, 28.65% (27.02–48.19)	5, 57% (49.49–71.72)
32–35 years	3, 81.06% (70.55–99.88)	3, 68.2% (50.17–77.24)
36–39 years	n/a	n/a
40–44 years	2, 63.07% (55.2–70.93)	1, 50.59%
45–49 years	n/a	1, 41.49%
50+ years	2, 24.59% (22.75–26.42)	2, 67.7% (39.9–96.52)

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas Aeruginosa* (PA)		
Number of patients in each age band	16–19 years	10
	20–23 years	8
	24–27 years	7
	28–31 years	13
	32–35 years	6
	36–39 years	0
	40–44 years	3
	45–49 years	1
	50+ years	4
Number of patients with chronic PA by age band	16–19 years	6
	20–23 years	5
	24–27 years	5
	28–31 years	12
	32–35 years	4
	36–39 years	0
	40–44 years	1
	45–49 years	1
	50+ years	0

Burkholderia Cepacia (BC)	
Number and % of total cohort with chronic infection with BC complex	1 (2%)
Number and % of cenocepacia	0
MRSA	
Number and % of total cohort with chronic infection with MRSA	1 (2%)
Non-Tuberculosis Mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complications (Ref: 1.16 'Annual Data Report 2011')	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	4 (8%)
CFRD	
Number and % of total cohort requiring chronic insulin therapy	15 (29%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	3 (6%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis with no PH	With PH 1 (2%) without PH 5 (10%)

Transplantation (Ref:1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	3
Number of patients referred for transplant assessment in previous three years	12 (2009–2011)
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (Ref:1.21 'Annual Data Report 2011')		
Number of days of hospital IV therapy in reporting year split by age groups	16–19 years	251
	20–23 years	90
	24–27 years	56
	28–31 years	59
	32–35 years	96
	36–39 years	0
	40–44 years	0
	45–49 years	18
	50+ years	73
Number of days of home IV therapy in reporting year split by age groups	16–19 years	113
	20–23 years	36
	24–27 years	195
	28–31 years	383
	32–35 years	58
	36–39 years	0
	40–44 years	14
	45–49 years	42
	50+ years	95
Total number of IV days split by age groups	16–19 years	364
	20–23 years	126
	24–27 years	251
	28–31 years	442
	32–35 years	154
	36–39 years	0
	40–44 years	14
	45–49 years	42
	50+ years	168

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1 % pred <85% (ie below normal) on DNase	25 (53%)
If not on DNase % on hypertonic saline	6 (13%)

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	34 (65%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	30 (88%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	23 (68%) with chronic PA; 5 (28%) without chronic PA

UK CF Registry data

(All references, data and figures are taken from the 'UK CF Registry Annual Data Report 2011', available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2011	
Demographics of centre: Shrewsbury and Telford Hospitals NHS Trust	
Number of active patients (active being patients with data within the last two years) registered	9
Number of complete annual data sets taken from verified data set (used for production of National Report)	9
Median age in years of active patients	22
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (Ref: 1.6 'Annual Data Report 2011')		
Number in age categories	16–19 years	3 (33%)
	20–23 years	2 (22%)
	24–27 years	1 (11%)
	28–31 years	2 (22%)
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	1 (11%)
	50+ years	0

Genetics	
Number of patients and % of unknown genetics	1 (11%) unidentified gene on one allele

BMI (Ref: 1.13 'Annual Data Report 2011')		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	0	2 (50%)
Number of patients and % with BMI <19 split by sex	3 (60%)	1 (25%)

FEV_1 (Ref: Figure 1.14 'Annual Data Report 2011')		
	Male	**Female**
Median FEV_1% pred at age 16 years split by sex	59.72% (n=5)	77.38% (n=4)
Number and median (range) FEV_1 % pred by age range and sex		
16–19 years	2, 91.07% (84.99–97.15)	1, 78.82%
20–23 years	2, 49.06% (41.59–56.53)	n/a
24–27 years	n/a	1, 33.75%
28–31 years	n/a	2, 100.23% (75.93–124.53)
32–35 years	n/a	n/a
36–39 years	n/a	n/a
40–44 years	n/a	n/a
45–49 years	1, 59.72%	n/a
50+ years	n/a	n/a

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas Aeruginosa* (PA)		
Number of patients in each age band	16–19 years	3
	20–23 years	2
	24–27 years	1
	28–31 years	2
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	1
	50+ years	0

Number of patients with chronic PA by age band	16–19 years	1
	20–23 years	2
	24–27 years	1
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
***Burkholderia Cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	0	
Number and % of cenocepacia	0	
MRSA		
Number and % of total cohort with chronic infection with MRSA	1 (11%)	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	0	

Complications (Ref: 1.16 'Annual Data Report 2011')	
ABPA	
Number and % of total cohort identified in reporting year with ABPA	0
CFRD	
Number and % of total cohort requiring chronic insulin therapy	2 (22%)
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 with no PH	0

Transplantation (Ref: 1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	0
Number of patients referred for transplant assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (Ref: 1.21 'Annual Data Report 2011')		
Number of days of hospital IV therapy in reporting year split by age groups	16–19 years	0
	20–23 years	0
	24–27 years	0
	28–31 years	14
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
Number of days of home IV therapy in reporting year split by age groups	16–19 years	0
	20–23 years	6
	24–27 years	56
	28–31 years	7
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
Total number of IV days split by age groups	16–19 years	0
	20–23 years	6
	24–27 years	56
	28–31 years	21
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1 % pred <85% (ie below normal) on DNase	1 (11%)
If not on DNase % on hypertonic saline	2 (22%)

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	4 (44%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	3 (75%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	3 (75%) with chronic PA; 0 without

Appendix 4

User survey results: University Hospital of North Staffordshire NHS Trust

Other hospitals attended

Shrewsbury and Telford Hospitals NHS Trust

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	1	0	6	3	2	1	0
Female	1	1	2	0	2	1	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/a
Accessibility (appointments/advice)	11	9	2	0	0
Communication (verbal/written)	9	8	5	0	0
Out-of-hours access (via phone or ward)	8	3	4	2	4
Home-care/community support (appointments/advice)	6	2	3	3	8

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/a
Availability of team members (who you need/want to see)	10	11	1	0	0
Waiting times	7	11	4	0	0
Cross-infection/segregation	13	6	3	0	0
Cleanliness (room)	18	4	0	0	0
Annual review process	11	8	0	0	0
Transition (paediatric to adult)	5	3	2	0	11

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/a
Admission waiting times	6	5	1	1	9
Cleanliness (cubicle/bathroom)	6	5	2	0	9
Cross-infection/segregation	7	5	1	0	9
Food (quality/quantity)	3	2	4	2	10
Exercise (gym equipment/facilities)	2	1	2	3	13

How would you rate:

	Excellent	Good	Fair	Poor	N/a
Home intravenous antibiotic (IVs) service	9	5	3	0	5
Availability of equipment (physiotherapy aids/nebuliser parts)	7	12	1	1	1
Car parking (availability/ease of reach)	1	5	4	12	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/a
Of your CF team	13	6	3	0	0
Of the ward staff	5	8	1	1	7
Of the hospital	7	9	4	1	0

Comments about CF team/hospital

"The people do their best, but processes aren't great."

"All round excellent service."

"Most of the staff seem over-worked, especially the CF nurses. I was struggling with my chest and rang to ask for a physio appointment and had to wait a week before I could see her. Not her fault but I felt it was unacceptable and I have had the CF nurse ring me from home, she's had so much to do."

"Team great. More nurses needed on ward; less agency staff."

"Location of outpatient clinic is a long walk from reception. Increase in nursery team gives better results."

"Good service last 20 years."

"A/R – problematic – too little coordination so that all tests are not performed on same day. Often no pre-made IVs available. Long walk from car park to ward levels etc; difficult to manage when unwell."

"We have just had a new CF team. I haven't met everyone yet: slightly unfair to comment."

"No problems all, brilliant."

"All good so far."

Appendix 5

Patient/parent interviews

University North Staffordshire Hospital (Adult)

Patient 1

Arrival at outpatient department you touch screen to enter details and that you have arrived, then you get directed where to go. Initially this is lung function department, CF nurses used to do that, but now we go to another department. No idea of cross-infection rules there. Then we log in a touch screen again and this directs you to waiting room to go into a room where team then float between.

Used to see the same people all the time same Dr/Nurses/physio etc but last couple of appointments seeing different people – was stable, now all changed. Continuity is needed.

- It's a two-hour–long process to see everyone.
- Annual review – one big day and then told on next clinic visit your results.
- Need to get in contact with someone – contacts CF ward.
- Visibly see cleaning hands, which is a good thing.
- Hospital provides physio adjuncts and Pari nebuliser.
- Biggest bug-bear is smokers outside main entrance.

Patient 2

The service has improved overall, the doctor is helpful. Since the move the wards are much better. The team is caring, especially the physiotherapist and the psychologist. The patient feels there are difficult team dynamics, which creates an atmosphere. The location of the ward is not ideal (third floor).

The food is of poor quality. The patient chose from the easy chew menu and was given chicken breast and jacket potato! There is not a dedicated kitchen, but staff do offer toast, although the cake offered is inadequate and small. A wider selection of cakes and crisps would be beneficial. Most patients lose weight during their stay. Larger fridges would be beneficial. Occasionally, food that is ordered does not appear at meal time.

- Outpatients – it is difficult to contact a nurse, the patient rang and left a message, the nurse rang her back two days later. There is only one overworked CF nurse.
- Longlines can take up to 2–3 days. There is a lack of trained nurses to perform longlines/IVs.
- There is access to gaming stations, a good facility.
- The parking is terrible; (the patient has a disabled badge), and informs us there are plans to charge the disabled from October. The patient has to allow extra time for appointments in order to find a parking space.
- The patient has issues with confidentiality in the team and feels private business has been disclosed. The patient has reported this issue and feels it has not been dealt with appropriately. The patient does not know who to talk to about this.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	University Hospital of North Staffordshire	
	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 taken directly to clinic rooms.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Height/weight room visited by each patient not individual clinic rooms.
Where are lung function tests done for each visit?		Spirometry room, all patients visit one room although cross-infection policies in place to minimise risk.
Are clinic rooms appropriately sized?	Yes	6 rooms.
For annual review patients, are any distractions provided?	No	Can use own equipment eg phone/games.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Patients seen in same clinic once every two months.
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Pack. Newly diagnosed also receive a pack.

Additional comments

Some staff offices have no natural light and although of good size, can be problematic for full-time staff.

Modern, clean, good-sized clinic, lack of warmth and colour throughout due to hospital rules. Lack of art-work in clinics and other areas. This is apparently due to hospital rules.

	Royal Shrewsbury 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	Normal clinic 4–6 patients maximum.
Do patients spend any time in waiting room?	No	Patients are taken straight to consultancy rooms.
Is there easy access to toilets?	Yes	Nearest is 20 yards.
Where do height and weight measurements take place? Is this appropriate?		In the weighing room.
Where are lung function tests done for each visit?		Individual rooms
Are clinic rooms appropriately sized?	Yes	6 rooms.
For annual review patients, are any distractions provided?	No	Can bring in own mobiles. Visits not long enough for requirement of distractions, patients are not left for long periods.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Patients seen in diabetic clinic in same area.
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Tailored to individual requirements.

Additional comments

Dietitian reviews patients in clinic.

Environmental walkthrough: ward
Ward name: 233 Respiratory and Adult CF Ward
Microbiology status: All microbiology

		University Hospital of North Staffordshire	
		Yes/no/ number/ n/a	**Notes/comments**
Is ward a dedicated CF ward or ward suitable for CF care?		No	Respiratory ward with dedicated CF rooms.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	7 CF–dedicated rooms allocated have a good window view.
Number of side rooms?		7	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Shower
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Locker available. Plans for larger personal lockers to store own laptops/ drugs/nebulisers and personal equipment.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free. There are plans for more larger screens.
If no, are there any concessions for CF patients?		n/a	
Are there facilities to allow parents / carers /partners to stay overnight?		Yes	The rooms have large armchairs and camp beds are available. One large room has a double sofa bed.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open access. Must adhere to protected meal time rules.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	There are fridges in rooms and microwave can be utilised by staff to heat meals in kitchen.
What facilities are provided for teenagers?			Wi-Fi, Wii fit, Xbox, playstation, iPod, music, 2 laptops for DVD viewing.

	Yes/no/ number/ n/a	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	There are plans for portable equipment.
What facilities are there to help with school and further studies?	None	Can bring in own laptops.
Is there a relatives' room?	Yes	Dayroom not overnight accommodation.
What internet access is there?	None	Staff are hoping to arrange this.
What facilities are there to enable students to continue work and study?	Patients can use their own laptops/dongles.	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Patients can clean and air dry in their room on tabletop.
What facilities are provided for those with MRSA?		Side room segregation.
What facilities are provided for those with *B.cepacia*?		Ward 222
What facilities are provided for those with other complex microbiology?		Side room segregation.
Are patient information leaflets readily available on ward?	No	Kept in outpatients.
Transition patients – can they get tour of ward facilities?	Yes	

Additional comments

Dedicated, keen ward staff, very clean and tidy ward area with great views of local area from all CF rooms. Lack of art, lack of warmth and colour on walls throughout gives a bland, clinical appearance. Staff do have plans to improve artwork and ward appearance. However, hospital owners' rules and regulations appear to hamper efforts to give a more 'warm' atmosphere

IV preparation room has no ventilation and this may be a considerable health and safety concern. This would be alleviated by drugs being prepared in the pharmacy. This would be a great time-management move for ward nurses, allowing more time to nurse patients and also removing them from the IV room and potential health and safety concerns.

Environmental walkthrough: ward
Ward name: Shrewsbury Adults Service – Ward 27R
Microbiology status: All microbiology

		Royal Shrewsbury Hospital	
		Yes/no/ number/ n/a	**Notes/comments**
Is ward a dedicated CF ward or ward suitable for CF care? (underline which one)		Not dedicated	Shared with respiratory and gastro patients. Rarely more than one CF patient admitted at one time.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		4	Plan in action to convert two to en suite.
Do the en suites have:	**Toilets?**	No	Immediately outside side rooms and shared at present with other patient groups.
	Wash basins?	Yes	In room.
	Bath or shower?	Yes	Outside room at present and shared with other patient groups.
Do CF patients have to share any bathroom facilities?		Yes	Bath/shower/toilet
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	In room – locked cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		No	Patients can bring in their own electrical items such as TV, which are checked by electrical team.
If no, are there any concessions for CF patients?		N/a	
Are there facilities to allow parents/ carers/partners to stay overnight?		No	Only a chair in the room.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Relaxed.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		No	Ward kitchen, no microwave.
What facilities are provided for teenagers?			Patients can bring in their own laptops/ electrical equipment.

	Yes/no/ number/ n/a	Notes/comments
Is there access to a gym or exercise equipment in the rooms?		There is a gym in the hospital (cross-infection?), but it has never been used by CF patients.
What facilities are there to help with school and further studies?		Liaise with children's general ward or home tutors attend.
Is there a relatives' room?	No	
What internet access is there?	None	Can bring in and use own dongle.
What facilities are there to enable students to continue work and study?	None	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Basin in own room and locker. Surface space to air dry.
What facilities are provided for those with MRSA?		Same as for all other microbiology.
What facilities are provided for those with *B.cepacia*?		Same as for all other microbiology.
What facilities are provided for those with other complex microbiology?		Same as for all other microbiology.
Are patient information leaflets readily available on ward?		Kept in a ward file and distributed as and when required. Physiotherapy also hands out information leaflets.
Transition patients – can they get tour of ward facilities?	Yes	All facilities shown.

Additional comments

21 patients on file – 14 of these are shared care with Stoke.

There are plans for a conversion to self-contained rooms with en suite/wet rooms. Respiratory treatment room – where IVs are performed – is shared with respiratory patients. There is a locked drugs cupboard.

	University Hospital of North Staffordshire	
	Yes/no/ number/ n/a	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Multi-storey car park. CF patients ask parking warden for a ticket to park in disabled bays yet have to pay. For inpatients cost reduced to £3.40 per week on receipt of a letter signed by ward manager. If receiving benefits, with a letter from the CF Coordinator can get full reimbursement.
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, DEXA scan?	Yes	Large waiting area.
Do patients have to wait at pharmacy for prescriptions?	No	Short waiting times or CFNS collects prescriptions for some.
Patient information		
Is Patient Advice and Liaison Service (PALS) well advertised – leaflets, posters?	No	Once approved will have wall display. CF information board in ward reception.
Are there patient comment/ feedback boxes?	Yes	In PALS centre on ground floor.

Additional comments

Long distances to walk from department to department, for some. Wheelchairs available in reception main entrance, if required.

Hospital is new and clean with large waiting areas. There is some bright artwork in main reception areas yet little throughout. Lack of colour and artwork throughout give a very bland, clinical feel to this wonderful, new facility.

Good staff and visitor restaurant. Gardens and terraces outside main hospital reception provide modern attractive areas to sit or walk in clement weather.

Parking remains problematic for some patients and staff who are charged to park.

	Royal Shrewsbury Hospital	
	Yes/no/ number/ n/a	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Book of vouchers available to buy for 10 visits giving half price parking £1 instead of £2. If on benefit Income Support can be reimbursed.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	Clear signage to ward. 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, DEXA scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	No	Do not send more than one CF patient at any one time. Not excessive waiting time.
Patient information		
Is PALS well advertised – leaflets, posters?	Yes	Well advertised.
Are there patient comment/ feedback boxes?	Yes	Patients speak to staff – good relationship. Ward audited once monthly. Patient satisfaction survey.

Additional comments

Good relationships with patients, relaxed and personal environment. In last 18 months, consultant has been building the CF team.

Appendix 7

Panel members

Dr Martin Wildman	Consultant
Katrina Cox	Pharmacist
Alison Pearce	CF Specialist Psychologist
Nicky Gilday	CF Clinical Nurse Specialist
Elaine Lloyd	CF Specialist Physiotherapist
Helen Watson	CF Specialist Dietitian
Angela Mills	Social Worker
Kim Cox	Commissioner – Yorkshire & Humber
Sophie Lewis	Clinical Care Adviser
Lynne O'Grady	Peer Review project lead

Appendix 8

Other information

cysticfibrosis.org.uk