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Peer review report
North West Midlands
Cystic Fibrosis Centre
Paediatrics
20 March 2013

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1. Executive summary

1.1 Overview of the service

The paediatric CF service is relatively small with approximately 100 full and shared care patients. It serves a large geographical area with significant socioeconomic deprivation and challenging transport links. The number of patients is unlikely to change significantly in the short to medium term. There is a minimum critical mass of multidisciplinary team (MDT) members needed in a service to offer resilience at times of leave or sickness. The service has not previously been adequately resourced, resulting in poor resilience and gaps in service provision. Specialist review of shared care patients does not comply with current standards for MDT care, and will require increased staffing. Some outcome variables are of concern, and there is a reliance on home treatment even for young patients. Improved funding through the national tariff is imperative to increase staffing and improve resilience.

1.2 Good practice examples

1. Excellent team working across the network with committed and enthusiastic MDTs at each clinic, with clear and effective communication between members of individual clinic MDTs. Good communication within the network, with regular, well-attended network meetings. Each MDT is highly regarded and valued by patients – every patient rated them either excellent or good.
2. There is vertical integration between the paediatric and adult services at University Hospital North Staffordshire (UHNS). There is evidence of joint working, and there is further scope for sharing of resources and expertise. Good communication between the paediatric network MDTs and the UHNS adult MDT.
3. Staff are active and proactive within the wider CF community in the UK. Most are members of specialist organisations, there is attendance at regional and national meetings, and an active research programme across the MDT. There are clear guidelines in use across the network.

1.3 Key recommendations

1. There is an urgent need for additional 1.2 whole time equivalent (WTE) paediatric physiotherapy provision. Current provision for full care patients is inadequate and it is impossible to see how the centre could offer the required input to the network clinics.
2. Increased consultant provision is required at UHNS. Current calculations suggest the need for a minimum of five sessions of CF care. There is often no specialist registrar availability. There is a need for a staff grade/Clinical Nurse Specialist/further consultant sessions to cover this shortfall, particularly for inpatient care.
3. There is a need for increased psychology, social work and pharmacy support. This support could be in conjunction with adult services.
4. Burton is a very small CF service with only five shared care patients with UHNS. Some Burton residents receive full care from UHNS. All Burton patients who require inpatient care should receive that at UHNS. However, Burton is an economically challenged community and therefore all possibilities should be explored including the community element of the Burton service.

1.4 Areas for further consideration

1. Consideration should be given to commercial home intravenous (IV) antibiotics provision. This would allow both pre-drawing and delivery and presumably there will be cost savings based on VAT.
2. The standard and quality of food offered to patients at UHNS needs to be improved. The Cook Chill food system scores very poorly on patient satisfaction. Consideration should be given to subsidised access to other eating facilities/snack cupboards etc.
3. There is a shortage of en suite facilities for patients at Shrewsbury and Telford Hospital (SaTH), which hopefully will be resolved under the new build.

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

2.1 Models of care

Summary

The network consists of three units: the CF centre at the University Hospital of North Staffordshire (UHNS), a large network clinic that runs between Shrewsbury and Telford Hospitals (SaTH), and a much smaller network clinic in Burton Hospital

The network model has previously met the standards of care (seen annually for assessment), but does not comply with the new standards and will not do so without significant investment.

All patients are currently seen once a year by members of the specialist CF centre multidisciplinary team (MDT), although not all patients see the full MDT. The network enters data on a commendably very high proportion of their patients to the UK CF Registry.

2.2 Multidisciplinary care

Summary

University Hospital North Staffordshire NHS Trust (UHNS)

There is a failure to meet standards for multidisciplinary care, particularly for physiotherapy. There is a shortfall in physiotherapy provision, compounded by cross-covering arrangements between paediatric and adult physiotherapists. The Cystic Fibrosis Trust guidelines would suggest that there is a need for an additional 1.2 WTE paediatric physiotherapy provision. Although all full care patients are unsurprisingly reviewed at least twice a year by the full centre MDT, there is recognition that the service is neither effective nor safe.

The panel was impressed with the commitment of the specialist nurses across the network, although there are numerous imposed inefficiencies on the nurses' working practices. All patients on home intravenous antibiotics undergo assessment including lung function before, during and at the end of a course of antibiotics. Dietetic provision was considered adequate, as was outpatient psychology, although inpatient provision was limited. There is no social work support for the service.

At a medical level the service is primarily consultant delivered, and there is a shortfall in consultant provision. Provision of CF centre MDT care for shared care patients is described as sporadic by patients and under-resourced by health professionals. The current MDT provision struggles to review shared care patients once a year – without significant investment the standard of twice-yearly review seems unachievable. Although dietetic provision appears adequate, this should be reconsidered once the Cystic Fibrosis Trust's 'Standards of Care (2011)' are implemented.

Shrewsbury & Telford Hospital NHS Trust (SaTH)

There is a well-established MDT that cares for approximately 30 patients. All members of the team have considerable experience in the management of cystic fibrosis, and the service is highly valued by users. Provision of MDT was thought to be adequate. At a medical level the service is primarily consultant delivered.

Burton Hospitals NHS Foundation Trust

The service is very small, and the majority of care offered at home. Generally provision of MDT was thought to be adequate. At a medical level the service is primarily consultant delivered.

2.3 Principles of care

Summary

The principles of care are generally of a very high standard within the funding constraints. There are minor deficiencies in attaining some process standards – CF-related diabetes screening, liver ultrasound, bone densitometry and discussion of infertility. There is generally good provision of care. There appears a deficiency in the provision of single en suite rooms at SaTH.

There were concerns that the majority of intravenous antibiotics were delivered at home, and that there were often insufficient staff to monitor patients who are regularly on intravenous antibiotics. Home intravenous antibiotics at UHNS are pre-drawn by pharmacy, but there is no system for delivery. Due to families' difficulties with parking, this often entails considerable workload for the Specialist Nurses. Review by UHNS Specialist Nurses at home is limited, as once they leave the hospital it is practically impossible to return because of difficult parking.

There were similar concerns over review of patients receiving home intravenous antibiotics at both SaTH and Burton

There needs to be a culture shift within the paediatric services across the whole network to emphasise that once they reach adulthood, patients must expect to travel to the adult CF centre to receive optimal care, and that failure to travel to the centre will result in significantly reduced levels of care.

2.4 Delivery of care

Summary

Delivery of care is restricted by service constraints. The previously documented shortfall in physiotherapy availability is reflected in only a third of patients being reviewed in clinic. Dietetic provision was adequate; a dietitian was available at all clinics to review patients as required. There are, however, constraints on psychology, social work and pharmacy availability in all three clinics.

There are concerns over some outcomes of the paediatric services. The network median BMI percentile is at approximately the mean for paediatric services within the UK. However the median FEV¹ predicted was the second lowest for paediatric centres within the UK, while the proportion of patients with chronic pseudomonas was the fifth highest for paediatric centres in the UK. These results must be seen in the context of an economically and socially deprived population.

Nevertheless, given these outcomes the panel was surprised that there was not a higher uptake of some therapies. The majority of intravenous antibiotics within the network are administered at home, in marked contrast to the UK CF Registry data, particularly for children less than three years of age. Compared to the Registry data, a smaller proportion of patients were receiving nebulised DNase or regular macrolide.

2.5 Commissioning

Summary

The panel expressed concern that future modeling based on the national tariff may not take account of the Trust's revised CF 'Standards of Care'. There is insufficient consultant and MDT team provision at UHNS for effective care to either full or shared care patients, but the need for all patients within the network to be reviewed at least twice per year (including annual assessment) by the full network MDT had not been factored into service requirements.

Under the tariff for 'payment by results', there will be a significant increase in funding and staff estimate this is sufficient to increase staffing levels to achieve the critical mass necessary. This would be dependent on the full tariff (minus the 30% agreed overheads) being passed on to the CF services, but under the current financial pressures it is unclear whether a total value of the tariff could be passed on to the CF team. There is a need for frank and potentially painful discussions between organisations on the appropriate funding for service level agreements.

3. UK CF Registry data

BMI	Paediatric sites	Patients with a BMI percentile <10th centile on supplemental feeding	2 patients
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			Male	Female	
FEV ₁	Paediatric sites	Number of patients and % with FEV ₁ <85% by age group and sex	0–3 years	0	0
			4–7 years	1 (13%)	2 (7%)
			8–11 years	2 (6%)	1 (4%)
			12–15 years	5 (16%)	3 (11%)
			16–19 years	1 (3%)	1 (4%)

Data input	Number of complete annual data sets taken from verified dataset	60
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<i>Pseudomonas aeruginosa</i> (PA) Chronic PA is 3+ isolates between two annual data sets	Paediatric sites	Number and % of patients with chronic PA infection on inhaled antibiotics by age group	0–3 years	0
			4–7 years	0
			8–11 years	1 (2%)
			12–15 years	4 (7%)
			16–19 years	2 (4%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	3 (43%)
	Number and % of patients on chronic macrolide without chronic PA infection	3 (6%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

University of North Staffordshire Hospital (UHNS)

There are insufficient allocated CF sessions within the current job plans at the CF centre. Professor Warren Lenney has two clinical sessions per week, of which one is for cystic fibrosis. Dr Fran Gilchrist has five clinical sessions per week, of which two are for cystic fibrosis. Both have extensive training/experience in CF – Professor Lenney has over 30 years' experience, while Dr Gilchrist has Certificate of Completion of Training (CCT) in paediatric respiratory medicine. There is no formal out-of-hours cover for CF patients; however, in practice either Professor Lenney or Dr Gilchrist will usually be able to give telephone advice, although they may not be immediately available to see patients. One of the two will tend to cross-cover for annual leave although they do occasionally attend conferences together. The service has a specialist registrar (often grid trainee rotating in the West Midlands) and a Senior House Officer. The intermediate grade cover seems appropriate for the size of the unit, although in keeping with many units, juniors are often not present and care is increasingly consultant delivered. Professor Lenney is the clinical lead/Centre Director and both he and Dr Gilchrist regularly attend international meetings.

The Cystic Fibrosis Trust guidelines suggest that for 75 paediatric patients, the recommended consultant time is eight programmed activities (PA) per week between two consultants. Dependent on the model of care offered across the network, a minimum of 0.5 WTE additional consultant is needed, with a degree of urgency.

Shrewsbury & Telford Hospital NHS Trust (SaTH)

Dr Martin Rees is the sole respiratory paediatrician. He does not currently have any specified CF sessions though nominally he has two sessions per week. Dr Rees has a CCT in paediatric respiratory medicine and thus has extensive training and experience in cystic fibrosis. All patients at SaTH are admitted to Shrewsbury hospital. There is no formal specialist CF out-of-hours cover, although if there are problems, Dr Rees is usually contacted out of hours. If he is unable to be contacted, the default would then be Professor Lenney or Dr Gilchrist.

Burton Hospitals NHS Foundation Trust

The Burton CF service is very small and Dr Chavi Goel has 0.5 sessions for CF care per week, which she feels is sufficient. She was a trainee with respiratory interest and therefore has appropriate training.

4.2 Specialist nursing

University Hospital North Staffordshire NHS Trust (UHNS) staffing

Cystic Fibrosis Nurse Specialist (CFNS) Band 7 and CF support nurse Band 6 are members of UK Cystic Fibrosis Nurses Association (CFNA) and attend meetings, MDT and annual review meetings. The CF support nurse is responsible for inpatient and home intravenous antibiotics (IVAB) service and attends ward rounds. They cover each other and Band 7 covers adult colleagues. They have not recently attended the European CF Conference. Band 7 attends a regional meeting biannually. Both attend a quarterly meeting with shared care colleagues. They have completed the TIDES study and have recruited for the TORPEDO trial. CFNS is involved with F1 audits. Evidence provided for recent service improvement. Band 7 is involved at all key stages following diagnosis.

Good practice

Nurses committed to an accessible service. A comprehensive document is available for the administration of IVAB. A Personal Handheld Record and age-related clinics have been introduced.

Areas of improvement

Young person's clinic fragmented, therefore a clinic is planned every two months, coordinated by CFNS. Provision of education for staff at Burton Hospital to ensure an equitable service.

Burton Community Nursing team

Service provided from 9am-5pm, hours seven days a week. Service based on demand and the availability of resources. Caseload six patients. Follow detailed home IVAB guidelines. Have access to North Staffordshire guidelines if a problem arises. Attend quarterly meetings with North Staffordshire. The CF lead has attended CF study days and conferences.

Good Practice

The Community Nursing team is committed and provides a good service which is easily accessible. There is good communication between the nursing staff and the Consultant and Registrar. The nursing team is in a position to empower the parents.

Areas of improvement

The patients are not routinely reviewed during the course of home IVAB. If the service was available after 5pm the families could have support with the evening IVAB.

Outpatients clinic at Burton

Monday to Friday outpatient service provided, Five patients attend the clinic. One patient has full care from Leicester, but has contact with the local team. Designated monthly CF clinic but also review the patients as required. Adhere to cross-infection policy. Clinic Sister has contact with the patients when they are admitted to the ward, attends MDT meetings and is very involved with the care of the patients. She attends quarterly meetings at UHNS and the regional meeting biannually, and has recently attended the CF Medical Trust Conference and national meeting.

Areas of good practice

Works as part of a committed and accessible MDT. Good communication between Consultant and Clinic Sister.

Areas of improvement

Patients to be segregated and attend either a colonised or non-colonised clinic.

Shrewsbury Community Nursing team

Service provided Monday to Friday 8am-6pm. The nurses are funded for hospital cover in addition to their community work so can assist with the insertion of lines and administering the first dose of the IVAB. Caseload of 32 patients (19 in Shrewsbury and 13 in Telford). The majority of patients have planned home IVAB (one patient always admitted for social reasons. The team follows detailed home IVAB guidelines. Both nurses attend quarterly meetings with UHNS, and the West Midlands meeting twice a year. Both are members of the UK CFNA and attend regular meetings.

Areas of good practice

The Community Nursing team provides an efficient service which is easily accessible. There is good communication between the nursing team and the Consultant. The nursing team provides invaluable support to the families and is in a position to administer the IVAB at the patients' school.

Areas of Improvement

The patients are not routinely reviewed for the duration of the treatment.

Telford Nursing team (inpatient and outpatient)

Service available Monday-Friday 8am-5pm. The post is 0.29 WTE (equivalent to 11 hours a week of nursing hours for the CF patients). Service provided for both inpatients and outpatients. Caseload of 12 patients (one is shared care with Birmingham but has nursing input from Telford). Majority of patients have home IVAB. The younger patients or those with an exacerbation are admitted. Follow CF Centre (UHNS) guidelines for the administration of home IVAB. Nursing staff prescribe the IVAB following a discussion with the consultant. Reviewed at home by the nurse +/- the physiotherapist. Consultant review at the end of the course. Attends quarterly shared care meetings and regional meeting biannually. Member of the UK CFNA and attend the meetings.

Areas of good practice

Work as part of a committed and static MDT. Good communication between Consultant and members of the MDT.

4.3 Physiotherapy

UHNS, Stoke (64 patients)

- Funded for 0.5 WTE works 0.7 WTE (0.2 from general paed.); two long and two short days.
- Responsible for CF inpatient treatments, outpatient clinics, home visits, school visits and shared care clinics.
- No additional cover to allow attendance at clinic as inpatients take priority.
- Paediatric and adult physiotherapists expected to cross-cover inpatient work when on leave. Clinics at same time, cross-cover difficult.
- No exercise facilities for annual review, when inpatients use outdoor play area.
- No capacity to see patients when on home IV. Home visits and school visits ad hoc, as time allows.
- Difficulty attending shared care clinics due to time constraints.
- Adult and paediatric physiotherapy – on call alternate months. Weekend work followed by two days off. Have to cross-cover.
- Patients seen at weekends or late shift by on-call staff.
- New diagnosis come to clinic weekly, seen by physio on second and third visit.

- Association of Chartered Physiotherapist in Cystic Fibrosis (ACPCF) member, attends annual study days, attends network meetings, good relationship with shared care physios, most communication via email.
- Attended one European meeting, has to alternate with adult physio, which is a rotational post, possibly always competing with different physio.
- Good knowledge of ACPCF standards.

Burton (five patients)

- Three hours per week for cystic fibrosis. Plans own diary so some weeks will do more.
- Inpatients seen twice a day during the week and once a day at weekend. Patients have access to twilight service.
- Respiratory team covers for ward patients, but there is no cover for clinic. Any patients missed in clinic seen at a later date.
- No physiotherapist input to those on home IVs.
- On-call and twilight adult physiotherapists, regular teaching sessions.
- Not had a new diagnosis.
- No exercise facilities.
- ACPCF member but no funding to attend meetings. Able to attend network meeting.
- Knows patients well, flexible, close links with UHNS.

Shrewsbury and Telford

- 0.3 WTE CF of 0.5 WTE community. Clinics, home visits and annual review.
- Inpatients seen by respiratory team, within reach visit from CF physiotherapist. Treated daily plus treated by parents. Most have home IVs minimum one home visit.
- Annual review seen in community clinics, able to exercise test.
- No gym facilities, however new hospital 2014.
- New diagnosis, physio introduced at first appointment, followed up at home.

4.4 Dietetics

Staffing – all hospitals slightly above recommendations. UHNS (64 patients): actual staffing 0.5 WTE Band 7, recommended 0.42 WTE. Burton (5 patients): actual staffing 0.1 WTE Band 7, recommended 0.04 WTE. SaTH (28 patients): actual staffing 0.22 WTE Band 6, recommended 0.19 WTE.

- 1) UHNS has an experienced dietitian of approximately 20 years. Active member of UK Dietitians CF Interest Group attends one meeting, annually. Dietitians at Burton and SaTH are not members of the UK Dietitians CF Interest Group (UKDCFIG), but are in process of applying.
- 2) The dietitians all attend all clinic meetings. The UHNS dietitian attends the MDT ward round. Due to small patient numbers Burton and SaTH do not have a dedicated CF ward round. The UHNS dietitian is involved in MDT annual review in all hospitals. The SaTH and Burton dietitians are also involved.
- 3) At UHNS, during leave, there is cover provided by three Band 7 dietitians. The paediatric

dietitian at UHNS also provides cover for the adult dietitian at Stoke. At SaTH a Band 6 dietitian provides ward cover and outpatient clinic cover, if requested, is provided by the dietitian from Stoke (Band 4). The dietitian at SATH goes on maternity leave later this year. During this period the outpatient cover will be provided by the dietitian from UHNS and inpatient cover will be provided by a Band 6 dietitian. At Burton urgent inpatients are covered by a Band 5 dietitian. There is no routine outpatient cover at Burton, although the dietitian from UHNS does attend Burton outpatient clinics relatively frequently.

- 4) The UHNS dietitian attended European and North American CF conferences in the past, however has not attended in five years. The other two dietitians have not attended the European or North American conferences. All regularly attend the Midlands CF Club meetings. The SaTH dietitian completed the Masters module in CF dietetics last year. All dietitians have no problems with study leave being granted.
- 5) The UHNS dietitian has been involved in a number of nutrition-related audits, eg lipase intake, vitamin D levels and supplementation. The dietitian at SaTH completed a CF-related nutrition audit last year. No dietitians have been involved in research. There have been significant service improvements in all hospitals over the last five years. All have had increases in staffing levels, enabling greater patient contact, development of patient literature and improved contact between individuals. The UHNS dietitian reported that improved staffing levels now enable home and school visits, to see patients more frequently and improve service to the shared care hospitals. In addition, in UHNS the appointment of a psychologist has given the opportunity for joint working, to address issues such as feeding behaviour and adherence.
- 6) The UHNS dietitian had full involvement with patients at key life stages. There is a comprehensive nutrition element to the transition documentation used by all hospitals. There was limited experience of end-of-life issues and transplantation in SaTH and Burton, due to low patient numbers.

Good practice

- Very good shared care working and communication between all paediatric and adult dietitians in UHNS.
- Comprehensive patient information literature developed by the UHNS dietitian, used by all.
- Good MDT working at all hospitals.
- Good support given by the very experienced dietitian at UHNS to other dietitians.
- All dietitians actively involve patients in education regarding their condition rather than aiming the education at the parents and carers. This is enabled by the educational literature and a learning checklist produced in UHNS.

Areas for improvement

- The Burton dietitian requires more experience to enable her to gain more confidence in managing different clinical situations, eg newly diagnosed infants. This could be achieved by shadowing the UHNS dietitian.
- The dietitian at SaTH would like to develop the service to patients with CF-related diabetes and to develop more general nutrition educational information, in addition to that focusing on energy, fat and lipase.
- Both the Burton and the SaTH dietitians should be members of the UK Dietitians' CF Interest Group. The dietitian at SaTH also said that she would like to attend more national CF meetings.

- The catering provision in UHNS is Cook Freeze. The dietitian reported that there are frequent complaints from the patients regarding limited choice and the standard of the food. Both SaTH and Burton have in-house catering which is generally liked. All hospitals have the provision of additional snacks, but limited availability of hot meals out of hours.

4.5 Pharmacy

There are no CF specialist pharmacists; cover is from general paediatric pharmacists. All pharmacists Band 8a or above: SaTH (0.05 WTE), Burton 0.05 WTE 2 hrs/week, Stoke 0.05 FTE 2 hrs/week. Covered by rotating Band 7 at SaTH, part-time Band 8a at Burton and rotating Band 6 or 7 at Stoke. There is on-call pharmacy service on all sites. Staffing deficiency: Stoke 0.4 WTE recommended, 0.4 WTE deficient. SaTH 0.19 WTE recommended, 0.19 WTE deficient, Burton 0.04 WTE recommended, 0.04 WTE deficient.

All sites have an IV homecare service and few inpatients. Burton patients are mostly outpatients; therefore drug histories are not taken. There is only one inpatient, prescriptions are computerized, and new prescriptions are seen daily. SaTH and UHNS take drug histories on admission and review medicines on a daily basis. Medication counseling is carried out ad hoc for new medicines prescribed. No pharmacists attend CF clinics nor carry out medication reviews; however they are contactable via bleep. SaTH pharmacist attends MDT six-monthly meetings. UHNS – only as required; Burton does not. No pharmacists involved in key life stages. Burton and UHNS do not have CF guidelines. Only SaTH pharmacist attends general paediatric pharmacy conferences and is part of CF special interest pharmacy group. No pharmacist attends CF specific conferences/study days. Burton and UHNS are not part of the special interest group, SaTH is recruiting for TORPEDO study, the pharmacist has written a procedure for clinical check and supplying medication. Burton and UHNS are not undertaking research/audit projects.

Good practice

- Good MDT working and relationships. SaTH have CF guidelines and pharmacist involved in updating and proof-reading guidelines. Service improvements at SaTH: pharmacist developed home IV service two years ago.
- UHNS developed pre-printed prescriptions for antibiotics to reduce errors and is currently working on a Centralised Intravenous Additive Service (CIVAS) project for all antibiotics to save time and costs by vial sharing.

Recommendations

- Additional resource required 0.34 WTE. Ensure adequate training in paediatric cystic fibrosis. Access specific CF formularies/guidelines for less experienced pharmacists. Pharmacists should attend study days/conferences and join CF special interest group. Pharmacists should be involved with medication reviews at clinic.

4.6 Psychology

UHNS and Burton Hospital clinics

UK Psychologists in CF Group (UKPPCF) meetings attended yearly and UKPPCF List-serv used. CF MDT meetings not attended for discussion of inpatients, but strong verbal/email communication takes place and there is 100% attendance at outpatient discussions. No clinical psychologist cover for absence however there is cover for continuous absence, for example maternity leave. Annual leave is not routinely covered, although the adult psychotherapist is available on her working days should anyone

require consultation. No European CF meetings have been attended, which will be addressed. National medical conference attended. adherence training and solution-focused training.

Service Developments

Development of Burton Clinical Psychologist CF service in last three years; development of Shrewsbury & Telford Clinical Psychologist service three years ago; Cystic Fibrosis Quality of life questionnaire (CFQ) routine integration of CFQ (standardised quality of life measure) into annual review; transition/CF education documentation.

Research/audit

Collaboration on national/international TIDES study. Local i-neb audit. Good involvement at all key life stages.

Good practice

- Joint working and liaison, consultation and training to other members of the CF team and network.
- Integration of CFQ into annual review.
- Strong working relationships between clinical psychologists (CP) at CF centre and network clinics.

Areas for improvement

- Recommend investment in greater clinical psychology resources in order to increase time for 1:1 therapy and inpatient work.
- Exploration of end-of-life/palliative care and transplant pathways and training for team.
- Further exploration of more formal supervision/reflective practice arrangements for team.
- Note: Loss of Assistant Psychologist post has decreased flexibility to deliver intensive interventions and support the qualified CP.

Telford and Shrewsbury clinics

UKPPCF meetings and local network events attended and list-serv used. All CF MDT meetings attended for discussion of inpatients and outpatients. No cover when absent.

Service Developments

Development of Shrewsbury & Telford CP service three years ago; CFQ routine integration into annual review.

Research/audit

Collaboration on national/international TIDES study. Good involvement at all key life stages.

Good practice

- Joint working, liaison, consultation and training to other members of the CF team and network.
- Integration of CFQ into annual review.
- Strong psychology presence in team and clinics.

Areas for improvement

- Recommend need for appropriate and equitable access to clinical space for clinical psychology appointments with team and managers.

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. 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 Adviser 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 Adviser 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)			
	0-5	6-10	11-15	16+
Male	10	6	7	2
Female	9	1	6	3

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	31	6	0	0
From the ward staff	23	8	2	3
From the hospital	23	10	2	1

Areas of excellence

1. CF team – accessibility, communication
2. Outpatient – cross-infection
3. Overall care – from CF team

Areas for improvement

1. Food
2. Waiting times
3. Car parking

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 the Cystic Fibrosis Trust's 'Standards of Care (2011)'
- Amber** = Failing to meet all the Cystic Fibrosis Trust's 'Standards of Care (2011)' with improvements required
- Red** = Failing to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)' with urgent action required

Hospital name

University Hospital of North Staffordshire (UHNS) 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	
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	N	N	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	
	Are there local operational guidelines/policies for CF care?	100%	Amber	Amber	
	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	
	% patients with CFRD reviewed at a joint CF/diabetes clinic	100%	Green	Green	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of 1st isolates <i>Pseudomonas aeruginosa</i> in the previous 12 months	100%	Green	Green	
	% 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 CF-related diabetes (CFRD)	% patients >12 years of age screened annually for CFRD	100%	Amber	Amber	
3.5 Liver disease	% patients >5 years of age with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded bone mineral density (DEXA) scan in the last three years	100%	Amber	Amber	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% 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 clinical nurse specialist (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%	Red	Red	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% 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	
	% availability of social worker for inpatients and at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients and at clinic.	100%	Red	Red	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% 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%	1	1	
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 (SLAs) in place for all shared care services	100%	Red	Red	

Hospital name

Shrewsbury and Telford Hospitals (SaTH) 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	
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%	Red	Red	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Y	Y	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile(PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	N/a	N/a	
	Are there local operational guidelines/policies for CF care?	100%	Amber	Amber	
	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	
	% patients with CFRD reviewed at a joint CF/diabetes clinic	100%	Red	Red	

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	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of 1st isolates <i>Pseudomonas aeruginosa</i> in the previous 12 months	100%	Green	Green	
	% 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 CF-related diabetes (CFRD)	% patients >12 years of age screened annually for CFRD	100%	Amber	Amber	
3.5 Liver disease	% patients >5 years of age with a recorded abdominal ultrasound in the last three years	100%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded bone density (DEXA) scan in the last three years	100%	Red	Red	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% 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 clinical nurse specialist (CNS) at each clinic visit	100%	Unknown	Unknown	
	% patients with access to a CF CNS during admission (excluding weekends)	100%	Unknown	Unknown	
4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist physiotherapist at each clinic visit	100%	Green	Green	
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Unknown	Unknown	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Unknown	Unknown	
	% availability of clinical psychology for inpatients and at clinic	100%	Unknown	Unknown	
	% availability of social worker for inpatients and at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients and at clinic	100%	Unknown	Unknown	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Unknown	Unknown	

4.4 End-of-life care	% patients receiving advice from the palliative care team at end of life	75%	N/a	N/a	
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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%	1	1	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements (SLAs) in place for all shared care services	100%	Red	Red	

Hospital name

Burton Hospitals NHS Foundation 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	
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	N	N	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	N/a	N/a	
	Are there local operational guidelines/policies for CF care?	100%	Amber	Amber	
	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	
	% patients with CFRD reviewed at a joint CF/diabetes clinic	100%	Red	Red	

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Red	Red	
3.2 Monitoring of disease	% attempted eradication of 1st isolates <i>Pseudomonas aeruginosa</i> in the previous 12 months	100%	Green	Green	
	% 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 CF-related diabetes (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%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/a	N/a	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% patients seen by a CF consultant a minimum of twice a week whilst inpatient	100%	N/A	N/A	
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 clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% patients with access to a CF CNS during admission (excluding weekends)	100%	N/A	N/A	
4.2 Inpatients/ outpatients	% patients reviewed by a CF specialist physiotherapist at each clinic visit	100%	Green	Green	
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	N/A	N/A	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay	100%	N/a	N/a	
	% availability of clinical psychology for inpatients and at clinic	100%	Red	Red	
	% availability of social worker for inpatients and at clinic	100%	Red	Red	
	% availability of pharmacist for inpatients and at clinic	100%	Red	Red	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	

4.4 End-of-life care	% patients receiving advice from the palliative care team at end of life	75%	N/A	N/A	
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5 Commissioning

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

Appendix 2

Staffing levels (whole time equivalent (WTE) or otherwise stated programmed activities (PA))

	75 patients	150 patients	250 patients	University Hospital of North Staffordshire NHS Trust
Consultant 1	0.5	1	1	0.1 (PA)
Consultant 2	0.3	0.5	1	0.3 (PA)
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	1.4
Physiotherapist	2	3	4	0.5
Physiotherapy assistant				
Dietitian	0.5	1	1.5	0.5
Clinical psychologist	0.5	1	1.5	0.3
Social worker	0.5	1	1	Social welfare adviser 0.5
Pharmacist	0.5	1	1	0
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 (whole time equivalent (WTE) or otherwise stated programmed activities (PA))

	75 patients	150 patients	250 patients	Shrewsbury and Telford Hospitals NHS Trust
Consultant 1	0.5	1	1	0.2 (PA)
Consultant 2	0.3	0.5	1	0
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	1.1
Physiotherapist	2	3	4	0.3
Physiotherapy assistant				
Dietitian	0.5	1	1.5	0.22
Clinical psychologist	0.5	1	1.5	0.1
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Clinician's assistant				
Secretary	0.5	1	2	0.1
Admin assistant				
Database coordinator	0.4	0.8	1	0
CF unit manager				

Staffing levels (whole time equivalent (WTE) or otherwise stated programmed activities (PA))

	75 patients	150 patients	250 patients	Burton Hospitals NHS Foundation Trust
Consultant 1	0.5	1	1	0.05 (PA)
Consultant 2	0.3	0.5	1	0
Consultant 3			0.5	0
Staff grade/Fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	0.4
Physiotherapist	2	3	4	0.1
Physiotherapy assistant				
Dietitian	0.5	1	1.5	0.1
Clinical psychologist	0.5	1	1.5	0.1
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Clinician's assistant				
Secretary	0.5	1	2	0.1
Admin assistant				
Database coordinator	0.4	0.8	1	0
CF unit manager				

Appendix 3

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	61
Number of complete annual data sets taken from verified data set (used for production of the 'Annual Data Report 2011')	60
Median age in years of active patients	4.5 years
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 and % in age categories	0–3 years	27 (45%)
	4–7 years	12 (20%)
	8–11 years	5 (8%)
	12–15 years	13 (22%)
	16–19 years	3 (5%)

Genetics	
Number of patients and % of unknown genetics	56 patients with 2 mutations 1 patient with 1 missing mutation 3 patients with 2 missing mutations

Body mass index (BMI) (Ref: 1.13 'Annual Data Report 2011')	
Patients with BMI percentile <10th centile on supplemental feeding	2 patients

FEV ₁ (Ref: Figure 1.14 'Annual Data Report 2011')			
Number of patients and % with FEV ₁ <85% by age group and sex		Male	Female
	0–3 years	0	0
	4–7 years	1 (3%)	2 (7%)
	8–11 years	2 (6%)	1 (4%)
	12–15 years	5 (16%)	3 (11%)
	16–19 years	1 (3%)	1 (4%)

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic <i>Pseudomonas aeruginosa</i> (PA)		
Number of patients in each age band	0–3 years	27
	4–7 years	12
	8–11 years	5
	12–15 years	13
	16–19 years	3
Number of patients with chronic PA by age band	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	4
	16–19 years	2
<i>Burkholderia cepacia</i> (BC)		
Number and % of total cohort with chronic infection with BC complex	0	
Number and % of cenocepacia	0	
Meticillin-resistant staphylococcus aureus (MRSA)		
Number and % of total cohort with chronic infection with MRSA	1 (2%)	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	1 (2%)	

Complications (Ref: 1.16 'Annual Data Report 2011')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	2 (4%)
CF-related diabetes	
Number and % of total cohort requiring chronic insulin therapy	6 (10%)
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 portal hypertension	0

Transplantation (Ref: 1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	1
Number of patients referred for transplant assessment in previous three years	5
Number of patients receiving lung, liver, kidney transplants in last three years	1

IV therapy (Ref: 1.21 'Annual Data Report 2011')		
Number of days of hospital IV therapy in reporting year split by age groups	0–3 years	12
	4–7 years	108
	8–11 years	73
	12–15 years	288
	16–19 years	28
Number of days of home IV therapy in reporting year split by age groups	0–3 years	138
	4–7 years	141
	8–11 years	53
	12–15 years	285
	16–19 years	28
Total number of IV days split by age groups	0–3 years	150
	4–7 years	249
	8–11 years	126
	12–15 years	573
	16–19 years	56

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	18 (30%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	7 (12%)
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	3 (43%) with chronic PA; 3 (6%) without chronic PA

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: Shrewsbury and Telford Hospitals NHS Trust	
Number of active patients(active being patients with data within the last two years) registered	28
Number of complete annual data sets taken from verified. Data set (used for production of 'Annual Data Report 2011')	28
Median age in years of active patients	7.5
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (Ref: 1.6 'Annual Data Report 2011')		
Number and % in age categories	0–3 years	10 (36%)
	4–7 years	4 (14%)
	8–11 years	8 (29%)
	12–15 years	6 (21%)
	16–19 years	0

Genetics	
Number of patients and % of unknown genetics	28 with 2 mutations 0 with any missing mutations

Body mass index (BMI) (Ref: 1.13 'Annual Data Report 2011')	
Patients with a BMI percentile <10th centile on supplemental feeding	0

FEV ₁ (Ref: Figure 1.14 'Annual Data Report 2011')			
Number of patients and % with FEV ₁ <85% by sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	2 (15%)	2 (13%)
	12–15 years	4 (30%)	1 (7%)
	16–19 years	0	0

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic <i>Pseudomonas aeruginosa</i> (PA)		
Number of patients in each age band	0–3 years	10
	4–7 years	4
	8–11 years	8
	12–15 years	6
	16–19 years	0
Number of patients with chronic PA by age band	0–3 years	0
	4–7 years	1
	8–11 years	1
	12–15 years	3
	16–19 years	0
<i>Burkholderia cepacia</i> (BC)		
Number and % of total cohort with chronic infection with BC complex	1	
Number and % of cenocepacia	0	
Meticillin-resistant staphylococcus aureus (MRSA)		
Number and % of total cohort with chronic infection with MRSA	0	
Non-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	0	

Complications (Ref: 1.16 'Annual Data Report 2011')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	2 (7%)
CF-related diabetes	
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 with no portal hypertension	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 3 years	0
Number of patients receiving lung, liver, kidney transplants in last 3 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	0–3 years	71
	4–7 years	15
	8–11 years	14
	12–15 years	0
	16–19 years	0
Number of days of home IV therapy in reporting year split by age groups	0–3 years	0
	4–7 years	41
	8–11 years	126
	12–15 years	196
	16–19 years	0
Total number of IV days split by age groups	0–3 years	71
	4–7 years	56
	8–11 years	140
	12–15 years	196
	16–19 years	0

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	9 (32%)
If not on DNase % on hypertonic saline	2 (7%)

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	5 (18%)
Number and % of patients in that cohort on anti- pseudomonal antibiotics; Tobramycin solution, Colistin	5 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	2 (40%) with chronic PA; 9 (39%) without chronic PA

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: Burton Hospitals NHS Foundation Trust	
Number of active patients(active being patients with data within the last two years) registered	6
Number of complete annual data sets taken from verified. Data set (used for production of 'Annual Data Report 2011')	6
Median age in years of active patients	12.5 years
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 and % in age categories	0–3 years	0
	4–7 years	1 (17%)
	8–11 years	2 (33%)
	12–15 years	2 (33%)
	16–19 years	1 (17%)

Genetics	
Number of patients and % of unknown genetics	6 with 2 mutations; 0 with any missing mutations

Body mass index (BMI) (Ref: 1.13 'Annual Data Report 2011')	
Patients with a BMI percentile <10th centile on supplemental feeding	0

FEV ₁ (Ref: Figure 1.14 'Annual Data Report 2011')			
Number of patients and % with FEV ₁ <85% by sex		Male	Female
	0–3 years	0	0
	4–7 years	0	0
	8–11 years	0	0
	12–15 years	1 (20%)	1 (100%)
	16–19 years	1 (20%)	0

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic <i>Pseudomonas aeruginosa</i> (PA)		
Number of patients in each age band	0–3 years	0
	4–7 years	1
	8–11 years	2
	12–15 years	2
	16–19 years	1
Number of patients with chronic PA by age band	0–3 years	0
	4–7 years	0
	8–11 years	1
	12–15 years	1
	16–19 years	1
<i>Burkholderia cepacia</i> (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-Tuberculosis Mycobacterium (NTM)		
Number and % of total cohort with chronic infection with NTM	0	

Complications (Ref: 1.16 'Annual Data Report 2011')	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (17%)
CF-related diabetes	
Number and % of total cohort requiring chronic insulin therapy	1 (17%)
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 portal hypertension	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	0–3 years	0
	4–7 years	3
	8–11 years	1
	12–15 years	8
	16–19 years	4
Number of days of home IV therapy in reporting year split by age groups	0–3 years	0
	4–7 years	25
	8–11 years	13
	12–15 years	104
	16–19 years	52
Total number of IV days split by age groups	0–3 years	0
	4–7 years	28
	8–11 years	14
	12–15 years	112
	16–19 years	56

Chronic DNase therapy (Ref: 1.22 'Annual Data Report 2011')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	1 (17%)
If not on DNase % on hypertonic saline	0

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	3 (50%)
Number and % of patients in that cohort on anti- pseudomonal antibiotics; Tobramycin solution, Colistin	3 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	0 with chronic PA; 0 without chronic PA

Appendix 4

Patient/parent survey: University Hospital of North Staffordshire NHS Trust

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	10	6	7	2
Female	9	1	6	3

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	33	4	0	0	0
Communication (verbal/written)	31	6	0	0	0
Out-of-hours access (via phone or ward)	26	8	2	0	0
Homecare/community support (appointments/advice)	17	10	1	1	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	27	9	1	0	
Waiting times	19	15	1	1	2
Cross-infection/segregation	25	11	1	0	2
Cleanliness (room)	27	10	0	0	2
Annual review process	25	9	3	1	1
Transition (paediatric to adult)	6	0	0	1	29

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	20	6	1	1	9
Cleanliness (cubicle/bathroom)	19	9	1	0	7
Cross-infection/segregation	18	5	4	0	7
Food (quality/quantity)	7	8	6	7	8
Exercise (gym equipment/facilities)	4	5	3	3	19

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	19	5	1	0	12
Availability of equipment (physiotherapy aids/nebuliser parts)	24	3	1	0	0
Car parking (availability/ease of reach)	7	8	8	10	2

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	31	6	0	0	
Of the ward staff	23	8	2	3	
Of the hospital	23	10	2	1	

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	5	0	0	0	0
Communication (verbal/written)	4	1	0	0	0
Out-of-hours access (via phone or ward)	3	2	0	0	0
Homecare/community support (appointments/advice)	2	2	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	3	2	0	0	0
Waiting times	3	2	0	0	0
Cross-infection/segregation	3	2	0	0	0
Cleanliness (room)	3	2	0	0	0
Annual review process	3	2	0	0	0
Transition (paediatric to adult)	1	0	0	0	4

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	3	2	0	0	0
Cleanliness (cubicle/bathroom)	2	3	0	0	0
Cross-infection/segregation	2	1	1	0	0
Food (quality/quantity)	3	1	1	0	0
Exercise (gym equipment/facilities)	2	0	0	1	2

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	4	1	0	0	0
Availability of equipment (physiotherapy aids/nebuliser parts)	4	1	0	0	0
Car parking (availability/ease of reach)	1	2	1	0	0

How would you rate the overall care?

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

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	2	0	0	0	0
Communication (verbal/written)	2	0	0	0	0
Out-of-hours access (via phone or ward)	2	0	0	0	0
Homecare/community support (appointments/advice)	2	0	0	0	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor	N/A
Availability of team members (who you need/want to see)	2	0	0	0	0
Waiting times	2	0	0	0	0
Cross-infection/segregation	2	0	0	0	0
Cleanliness (room)	2	0	0	0	0
Annual review process	2	0	0	0	0
Transition (paediatric to adult)	0	0	0	0	2

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	2	0	0	0	0
Cleanliness (cubicle/bathroom)	2	0	0	0	0
Cross-infection/segregation	2	0	0	0	0
Food (quality/quantity)	2	0	0	0	0
Exercise (gym equipment/facilities)	0	0	0	0	2

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous antibiotic (IVs) service	2	0	0	0	0
Availability of equipment (physiotherapy aids/nebuliser parts)	2	0	0	0	0
Car parking (availability/ease of reach)	0	2	0	0	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	2	0	0	0	0
Of the ward staff	2	0	0	0	0
Of the hospital	2	0	0	0	0

Comments about CF team/hospital

University North Staffordshire Hospital NHS Trust

“Car park should be £1 for 2 hours instead of £2 for 4hrs.”

“Professor Lenny and Siobhan Davis are outstanding individuals with their care and attention that they give my daughter.”

“Very caring and loving. Feel very comfortable when in hospital.”

“All good!”

“Very friendly and approachable.”

“Excellent support.”

“Always available on the end of the phone for help and advice.”

“I dread going on the ward with my daughter for any overnight stay and try my best to get her home as soon as possible. The CF team are an extension of our family. I do not want my daughter moving to adults as the consultant does not know her or her health. We would prefer to keep the same consultant and CF nurses who have cared for her all her life and who know her!!”

“Since our last ward visit there has been a new hospital built and we are not familiar with the new facilities.”

“We are really, really pleased and grateful for all the help, support and time the CF team have put into our family. They’ve given us some light.”

“Overall excellent service. CF team wonderful. Pharmacy manufacturing process slow when returning for more IVs. Food on the ward poor.”

“Overall we are very happy with the care she receives.”

“I believe all the CF staff are dedicated to the care of the patients and give of their very best. Patients are valued and members of staff show good empathy. Occasionally there are some financial constraints.”

“We have been so lucky. We don’t seem to have any problems.”

“We are indebted to the team for their support with our daughter’s CF. We could not speak highly enough of the team at North Staffs.”

“No problems at present.”

“Very good team always available and helpful.”

“Upon meeting the CF team at Stoke, we were immediately welcomed and he felt like he had been made a main priority. We have been offered endless amounts of support and he was well looked after when admitted.”

“The CF team is very good. No complaints at all.”

“Excellent service, great team.”

“Food is vile.”

Shrewsbury and Telford NHS Trust

“RSH always see consultant at every appointment. Always see the same dietitian/physio etc so continuity is excellent.”

“Consultant excellent, CF nurse very good. Visits from professor from North Staffs for annual review sporadic and few and far between.”

“The CF team in Shrewsbury are fantastic. Dr Rees and the team are always available to speak to you about any worries.”

“All excellent.”

“During IV antibiotic courses at home when hospital trips necessary to sort out problems waiting up to 5/6hrs at weekends to be resolved. New line/cannula – if necessary at weekends, always a long wait but always helpful, pleasant and cheerful staff. Home visiting CF team are amazing, couldn’t manage without our community nurse on all occasions she/they are marvellous.”

“They are truly wonderful – could absolutely not cope without them.”

Appendix 5

Patient/parent interviews

University North Staffordshire Hospital NHS Trust

Parent 1

- Sees CF team every two months – goes straight into waiting room.
- If needs to, contact MDT via phone or email and has open access to ward.
- If needing results e-mail and the results are sent – parent has to initiate rather than nurse.
- Hospital inpatient treatment planned admissions every six months. CFNS accesses port.
- Side room with TV but bad signal – no fridge – no physio equipment in room. No physio while an inpatient lets child do acapella (airway clearance device) and mother to do treatment.
- Food – has got better but still cold and not good with treatment times.
- Used to have CF-designated snack box – no more. Could choose cheese/biscuits/pot noodles. Child misses this.

Parent 2

- Sees CF team every two months.
- Contacts via phone usual quick in response.
- A/R just normal appointment but a bit longer for x-rays and blood tests – reports back results a month later, routine feedback no formal letter or report.
- Waiting room goes on non *Pseudomonas* clinic – walked through to room, however height and weight are done elsewhere.
- Happy with care received. Can't think of any improvements.

Parent 3

- Contact CF team through CF office on CFNS mobile. Receptionist not very good.
- Routinely seen every two months but four to six weeks port flushed.
- If concerned get to see same day via ward and on call Drs.
- Wait temporarily then into room for outpatients.
- Inpatient food a big issue major complaint with hospital doesn't work very well. Forced to use child's menus. Not enough provision made, especially if in for two weeks. Adult menu is better.
- Snack packs limited, order from emergency menu. Frozen meal from Sedexo which will take an hour before you can get it.
- Fridge and TV in room.
- Physio – acapella (airway clearance device) – doesn't fit in around home schedule so can be hard. No gym – children's ward just things for little children.
- Annual review – investigations over period of time prior to clinical visit – no formalised feedback.
- Outpatient clinics – segregated by *Pseudomonas*. Arrival – short wait in reception then into room.
- Excellent – education of staff – caring nature not just a job – empathy with children and parent improvements – food on ward and the organisation out-sourced – Wi-Fi needed for children for homework.

Patient/parent interviews

Peer Review day

University North Staffordshire Hospital NHS Trust

Parent

- Staff have a 'family feel' and give a personal service, the child is known to all the team. The child trusts all the staff.

Outpatient clinic

- The staff are fantastic, always caring and efficient.

Admission

- The only problem would be broken facilities. The TV was broken for a long period of time which is difficult if you are admitted for long stays.
- The child goes to school for one hour in the morning. There is a play therapist who brings round colouring. The stay could be improved if the play therapist were to take the child for a while giving the parent a break. The mother takes a break when the father arrives in the evening and only when the nurse takes the child for IV or the physiotherapist for therapy.
- The food is awful and wouldn't eat anything offered from the trolley, therefore it costs more to feed the child in own purchases. There is a fridge available for own use to store food.
- The staff do order in bacon as the child normally has this for breakfast everyday, they provide squash also. The parent does not ask for anything else.
- Tea is brought round at 16:45 which is too early, it would be nice if there were snacks offered in between meals for the extra calories.
- The physiotherapists come round three times daily which is a great service. There were issues with pharmacy during the move in manufacturing, when the wait was one hour, but this is now resolved.

Appendix 6

Environmental walkthrough: outpatients department Outpatients/CF clinic

University Hospital of North Staffordshire NHS Trust		
	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 taken to consultation room after height/weight measured in room.
Is there easy access to toilets?	Yes	
Where does height and weight measurements take place? Is this appropriate?		A dedicated height/weight room.
Where are lung function tests done for each visit?		Individual clinic rooms.
Are clinic rooms appropriately sized?	Yes	4 dedicated CF rooms.
For annual review patients, are any distractions provided?	Yes	There is a play therapist and toys available, patients can also bring in own.
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?	Yes	Seen in joint clinics with diabetologist.
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	All receive an appropriate pack at the age of approx 13–14 years.

Additional comments

Bright, clean, modern, appropriate facilities.

Environmental walkthrough: outpatients department
Outpatients/CF clinic

Shrewsbury and Telford Hospitals NHS Trust		
CF paediatric clinic		
	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	4 clinic rooms.
Do patients spend any time in waiting room?	No	Patients are taken directly to rooms.
Is there easy access to toilets?	Yes	
Where does height and weight measurements take place? Is this appropriate?		In individual clinic rooms. Mobile equipment.
Where are lung function tests done for each visit?		In individual rooms.
Are clinic rooms appropriately sized?	Yes/No	2 small and 2 adequate
For annual review patients, are any distractions provided?	No	Bring own equipment, eg mobiles. Patients are not left for long periods.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	?	Not required until Dec 2012, diagnosed 4 patients. CF lead who will come to paed's clinic. Diabetes care unit arrange care.
Transition patients – can they get tour of outpatient facilities?	N/A	
Transition/new patients – do they get information pack?	N/A	

Additional comments

N/A

**Environmental walkthrough: outpatients department
Outpatients/CF clinic**

Burton Hospitals Foundation NHS Trust		
Paediatric CF clinic		
	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	Appointments are staggered.
Do patients spend any time in waiting room?	No	Only 5 patients total.
Is there easy access to toilets?	Yes	
Where does height and weight measurements take place? Is this appropriate?		In clinic rooms. Two rooms have height and weight equipment.
Where are lung function tests done for each visit?		Portable spirometer.
Are clinic rooms appropriately sized?	Yes	Well equipped.
For annual review patients, are any distractions provided?	Yes	Toys available, can bring own in. Patients never left waiting for long.
If diabetics are seen outside of CF clinic, is area and facilities appropriate for CF care?		The nurse is informed and will come to clinic if concerns. Only 1 diabetic patient.
Transition patients – can they get tour of outpatient facilities?	N/a	
Transition/new patients – do they get information pack?	N/a	

Additional comments

Clean, bright and well-equipped centre and ward.

There is an information file available for patients on admittance.

There is a well-equipped play room and outside play area.

		University Hospital of North Staffordshire NHS Trust	
		Yes/no/ number/ N/a	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		No	General ward, suitable for CF patients.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?			Not a dedicated number of rooms, always for CF patients.
Do the en suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Wet rooms.
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)		N/a	
Can you use mobiles?		Yes	There is a poor signal.
If there is a television, is the service free?		Yes	Free.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Camp beds.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	Fridges in rooms. Microwave in kitchen and parents' room.
What facilities are provided for teenagers?			Adolescent room. Games station, Wii, Large TV available.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	Have Wii-fit.
What facilities are there to help with school and further studies?		Very well-equipped school room. Teacher available in the mornings.
Is there a relatives' room?	Yes	Dayroom, well equipped with sofa, furniture, TV microwave, fridge and sink.
What internet access is there?	No	Staff are trying to get this installed.
What facilities are there to enable students to continue work and study?		Teacher available, who can also perform home visits.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Clean in room and air dry on table top.
What facilities are provided for those with MRSA?		Different ward (217) in a side room.
What facilities are provided for those with <i>B.Cepacia</i> ?		Different ward (217) in a side room.
What facilities are provided for those with other complex microbiology?		Different ward (217) in a side room.
Are patient information leaflets readily available on ward?	Yes	Kept in a resource file. Also a patient list of leaflets available.
Transition patients – can they get tour of ward facilities?	Yes	Kept in office.

Additional comments

Dedicated staff working in clean, bright, modern, appropriate facility. More colour and artwork would again make the facility less clinical.

Environmental walkthrough: ward
 Ward name: Rainbow Ward (paediatric)
 Microbiology status: All microbiology

		Shrewsbury and Telford Hospitals NHS Trust	
		CF Paediatric clinic	
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		No	General children's ward.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		7	Small, basic. Have small TVs.
Do the en suites have:	Toilets?	No	Allocated dedicated toilet.
	Wash basins?	Yes	In room.
	Bath or shower?	No	
Do CF patients have to share any bathroom facilities?		Yes	Bath/shower.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Lockable cupboards on ward at bedside and in drugs room. Parents/nurses hold keys.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	TVs/DVD free.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/carers/partners to stay overnight?		Yes	Camp beds.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open.
Is there access to fridge/microwave either in the side rooms or in a patient kitchen?		Yes	Kitchen and parents have use of microwaves and fridges.
What facilities are provided for teenagers?			Xbox, Nintendo DS, DVDs

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	Not been required, have soft play area.
What facilities are there to help with school and further studies?		Tables and chairs. Teacher 9–11am.
Is there a relatives' room?	Yes	Very small and basic dayroom. No microwave.
What internet access is there?	No	Have requested Wi-Fi for 2014.
What facilities are there to enable students to continue work and study?	No	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sinks and space to store equipment.
What facilities are provided for those with MRSA?	N/A	Separate rooms and cross-infection policy would be available.
What facilities are provided for those with <i>B.Cepacia</i> ?		Separate rooms and cross-infection policy would be available.
What facilities are provided for those with other complex microbiology?	N/A	Separate rooms and cross infection policy would be available.
Are patient information leaflets readily available on ward?	Yes	In clinic rooms.
Transition patients – can they get tour of ward facilities?	Yes	

Additional comments

31 patients

New build at Telford and will move around September 2014 for all inpatients. Staff to work still over both sites, except nursing team.

Stable team.

Attend CPD, Peer Specialist Interest Groups, Courses.

No CF team social worker – social welfare adviser based at UHNS covers whole area.

Home IV funding – concerned it will not continue.

New aseptic unit but it is not licensed, once licensed will look at pharmacy staff requirements. Present pharmacist dedicated to CF.

Physiotherapist works from community team, when requested for CF patients, homecare if required, daily visits.

Home IV delivered to nearly all if required.

Every patient is seen by members of the CF team, there is good care.

Good physiotherapy care with five-day cover by specialist physiotherapist and weekend cover by on call staff. Stable team, give good service to patients/family and good team support.

Environmental walkthrough: ward
 Ward name: Childrens Ward 1 & 2
 Microbiology status: All microbiology

		Burton Hospitals NHS Foundation Trust	
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		No	General ward.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	
Number of side rooms?		4	
Do the en suites have:	Toilets?	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	Would dedicate a bathroom if required.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		N/A	Does not apply to paedcs.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free TV/DVD.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Camp beds.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open.
Is there access to fridge/ microwave either in the side rooms or in a patient kitchen?		Yes	
What facilities are provided for teenagers?		Yes	Can bring in own.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	General gym, a visit can be pre-arranged by the physiotherapist.
What facilities are there to help with school and further studies?	Yes	Play assistant liaises with school.
Is there a relatives' room?	No	
What internet access is there?	Yes	Wi-Fi
What facilities are there to enable students to continue work and study?	No	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sterilising units in rooms and an area to wash and air dry.
What facilities are provided for those with MRSA?	N/S	No patients. If there were, would follow infection control policy consulting microbiologist.
What facilities are provided for those with <i>B.Cepacia</i> ?		Side room.
What facilities are provided for those with other complex microbiology?		Side room.
Are patient information leaflets readily available on ward?	Yes	In waiting room and on wall in corridor to clinic rooms.
Transition patients – can they get tour of ward facilities?	N/S	

Additional comments

N/A

University Hospital of North Staffordshire NHS Trust		
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Separate car park for Paediatrics and also multi-storey car park. CF patients/parents can ask parking warden for a ticket to park in disabled bays, yet still have to pay. If inpatient, cost for one week is reduced to £3.40 on receipt of a letter signed by Ward Manager. If receiving benefits, can get full reimbursement with a letter from the CF Coordinator.
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	
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	On wall – ward entrance. On stand in outpatients, leaflet list available.
Are there patients' comments/ feedback boxes?	Yes	In PALS centre on ground floor.

Additional comments

N/A

Shrewsbury and Telford Hospitals NHS Trust		
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	£2 per day. No problems with parking. If on income support can be reimbursed. Disabled bays available.
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 density (DEXA) scan?	N/A	
Do patients have to wait at pharmacy for prescriptions?		Can be collected from Children's Ward.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	Parents' room.
Are there patients' comments/ feedback boxes?	Yes	Corridor.

Additional comments

N/A

Burton Hospitals NHS Foundation Trust		
	Yes/no/ number/ N/a	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	If children in ward for 1 week or longer, staff will call general office and cost will be discounted. If on income support can apply for reimbursement.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	General ward not signposted to CF.
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 density (Dexa) scan?	Yes	Large waiting area and would not be sent together.
Do patients have to wait at pharmacy for prescriptions?	Yes	Large waiting area and would not be sent together.
Patient information		
Is patient advice and liaison service (PALS) well advertised – leaflets, posters?	Yes	On wall outside ward entrance.
Are there patients' comments/ feedback boxes?	Yes	On wall outside ward entrance.

Additional comments

No parking issues – plenty of spaces, pay on exit at machine in hospital.

Appendix 7

Panel members

Iolo Doull	Consultant
Alice Lo	Pharmacist
Elizabeth Fitzpatrick	CF Specialist Psychologist
Kathryn Azzopardi	CF Clinical Nurse Specialist
Sue Wolfe	Consultant Dietitian
Kate Lindsay	CF Specialist Physiotherapist
Angela Mills	Social Worker
Kim Cox	Commissioning Yorkshire & Humber
Sophie Lewis	Patient Adviser
Lynne O'Grady	Peer Review Project Lead

Appendix 8

Other information

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