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Cystic Fibrosis why we're here

British Thoracic Society

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Peer review report

Northern General Hospital, Sheffield
Cystic Fibrosis Centre
Adult
22 November 2013

1. Executive summary

1.1 Overview of the service

The service provides care for 170 adults with cystic fibrosis. The service has an enthusiastic and skilled specialist multidisciplinary team (MDT), but there is serious under-resourcing in parts of the MDT. The centre has excellent, purpose-built, modern inpatient facilities. The clinics have recently been relocated to a new modern outpatient facility. The team has demonstrated its ability to analyse and improve its service. It has instituted a microsystems approach to continually evaluate performance and improve efficiency. It has also begun an innovative research programme to address one of the most crucial areas in CF clinical care, the issue of adherence to therapy. The long term sustainability of the service requires the hospital trust to commit to a step-change so it is able to provide a robust 24/7 service. The hospital trust should work with commissioners to review the strategy for this service and its future role within the region, including critical mass.

1.2 Good practice examples

1. Dedicated and skilled multidisciplinary team with considerable experience in CF clinical care.
2. Purpose-built CF ward with 12 en suite rooms and two clinic rooms.
3. The team has embraced a microsystems approach to evaluate and improve the efficiency and quality of the service.

1.3 Key recommendations

1. There is an urgent need to address staffing levels within the CF MDT, in particular physiotherapy, medical staffing, pharmacy and psychology.
2. The shortfall in staffing in some key areas is further exacerbated by cross-cover arrangements within the division – some specialist CF team members are frequently drawn into providing cover, with considerable negative impact on the delivery of CF clinical care. It is imperative that the specialist CF MDT should be protected, to allow them to focus on delivery of quality specialist CF care.
3. The provision of greater secretarial and administrative support would considerably improve the efficient working of many MDT staff and allow personnel to more efficiently utilise their specialist skills. The CF team has clearly demonstrated that it is innovative, devoted to improving its clinical service and enhancing efficiencies in practice; it should have greater managerial autonomy to run its service.

1.4 Areas for further consideration

1. The current structure of the annual review should be re-evaluated to allow potential access to all members of the CF MDT on a proactive basis. The mechanism of feedback should also be reviewed as the consultants struggle to write feedback summaries to patients due to time pressures.
2. To improve the facilities for inpatients with CF who are housed outside the main CF ward due to cross-infection control measures.
3. To provide facilities for CF MDT team members to engage in telephone consultations with CF patients with appropriate privacy.
4. The current service for patients with CF-related diabetes (CFRD) is insufficient for the needs of these patients; the cystic fibrosis and diabetes MDTs have instituted an appropriate plan to reconfigure this service – this should continue to be supported.
5. There is a plan to introduce a cystic fibrosis specific real-time electronic patient record (EMIS CF ePR) – this should continue to be supported.
6. The unit should develop a plan for a further future expansion of outpatient space to enable it to accommodate additional patients – the patient numbers continue to steadily increase by approximately 10–14 patients per year.

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

2.1 Models of care

Summary

The unit has worked hard to improve efficiency in the CF outpatient clinics with continuous review of the process through a microsystems approach to delivery of care.

The CFRD service requires attention, as there are insufficient outpatient appointments available for regular review of CFRD patients. The service however has developed an appropriate plan to improve the CFRD service, including improved integration between the hospital diabetes team and members of the CF MDT.

The annual review process needs revision to enable proactive access for patients to all disciplines of the MDT, and to ensure appropriate resources for timely feedback of the results to the patients.

2.2 Multidisciplinary care

Summary

The unit has an experienced and committed MDT, although there are shortfalls in staffing in some key disciplines, notably medical, physiotherapy, pharmacy and psychology.

There is insufficient administrative support for the CF MDT.

2.3 Principles of care

Summary

The unit has a good standard of infection control.

The service is unable to have all members of the MDT available at each outpatient clinic.

Many inpatients do not have an assessment or treatment by a physiotherapist, particularly at weekends.

2.4 Delivery of care

Summary

The unit receives excellent feedback from its patients.

The unit requires further investment in pharmacy staffing to allow it to achieve current standards and to meet the requirements for the repatriation of high-cost medications to the specialist centre next year.

The lack of availability of key experienced members of the specialist CF MDT at outpatient clinics is a significant concern.

2.5 Commissioning

Summary

Service strategy: The respiratory service provided a strategy with various SWOT analyses. These provide a good overview of issues facing the division overall, including cystic fibrosis. However, it is difficult to determine the hospital trust's commitment to cystic fibrosis as there is no specific statement clarifying this point. It would be helpful to have a better understanding of the strategic priorities for the hospital trust and where specialised services including cystic fibrosis fit. The CF-specific SWOT accurately reflects the service and views of the MDT, except in regard to implications of the MDT gaps and, more importantly, some significant changes in the service model are required for the service to be sustainable in the long term.

Compliance with the service specification: This was discussed with the service specialist within the area team. All hospital trusts have been asked to complete assessment of specialised services against "key requirements" drawn from service specifications. The hospital trust submitted in the first round that it was fully compliant with all CF key requirements; the centre directors take responsibility for the incorrect submission and attribute this to misunderstanding. The Service Manager clarified that their interpretation of the key requirements was that these were met, but they recognised they were not compliant with the whole specification. Due to the nature of the national process, commissioners have not verified full compliance statements at this point; only those where services were notified by hospital trusts as not compliant. This issue has been raised with the area team as the service is not compliant with key requirement one, due to the significant issues with patient access to core MDT members. It is therefore suggested commissioners should discuss a derogation with hospital trust management.

Sustainability: It was confirmed with the service that it has a distinct population but there was some discussion about development of other sites. It is recommended that area commissioners review all centres in the region, including projected growth in patient numbers, to ensure recognised services will have sufficient future critical mass to be viable. This may suggest some further reconfiguration is required. The MDT had only recently seen budgetary information that confirmed the income from the new cystic fibrosis Payment by Results (PbR) tariff and what future income is expected to be available. It is contrary to good resource management principles for clinical leads not to have access to budgetary information that enables them to have a working understanding of the financial drivers within a service. The MDT felt supported by individuals in the management structure but there remained a lack of clarity in terms of how an individual clinical service like cystic fibrosis can get important clinical issues heard at executive level.

Service model: The service would not meet the national specification in several ways, and does not have a plan to deliver this ie a plan to develop a sustainable 24/7 service model. Although the hospital trust had responded to some of the immediate issues identified through the peer review process, however it remained unclear if it recognised the step change required to deliver a fully compliant and sustainable service. To achieve this, the trust may need to consider pump priming and will need to confirm with commissioners that they have sufficient caseload to achieve long-term sustainability.

Service monitoring: The Trust collects a range of indicators reflecting patient experience of the service including ward-based surveys, patient surveys and incidents. There is an excellent example of a patient-led survey undertaken for patients using the home service. This is an example of good practice. Patients should be seen four times a year but are not from the evidence provided. It would be helpful if these mechanisms included the action that followed where improvement was indicated, which was not clear in all of the evidence provided.

Quality: The team presented an impressive use of service improvement techniques used to improve outpatient efficiency. During the discussion about the organisation of physiotherapy services it became apparent that some CF patients were not receiving care according to guidelines. There did not appear to be an internal mechanism for raising these concerns as quality issues, as opposed to simply as an organisational matter. It is recommended that the hospital trust ensures staff are aware of such mechanisms, eg, scope of the incident reporting procedures. It is recommended that the area team should monitor the physiotherapy issue through the Clinical Quality Review (CQR) meeting with the hospital trust.

The service is clearly led and supported by a highly dedicated team who have demonstrated that they have the ability to analyse and improve the service. However, its long-term future is dependent on the hospital trust recognising the specialist nature of cystic fibrosis, ensuring that each member of the team is a CF specialist and is working with commissioners to confirm the future role of this service within the region.

3. UK CF Registry data

Northern General Hospital, Sheffield		Male	Female
Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=78) 32 (41%) BMI >23	(n=61) 24 (39%)
	Number of patients and % with BMI <19 split by sex	17 (22%)	13 (21%)

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		86.72%	94.04%
	Number and median (range) FEV_1 % pred by age range and sex	16–19 years	20; 85.3% (26.46–114.03)	10; 95.5%% (68.86–108.94)
		20–23 years	17; 68% (21.26–106.05)	19; 69.25% (27.38–102.26)
		24–27 years	12; 63.56% (15.27–102.39)	8; 65.66% (32.06–98.79)
		28–31 years	8; 65.1% (16.13–98.27)	10; 52.46% (35.07–101.17)
		32–35 years	4; 55% (45.3–100.62)	4; 71.4% (67.02–75.76)
		36–39 years	6; 58% (34.44–81.86)	1; 54.5% (54.4)
		40–44 years	4; 84% (61.42–97.61)	7; 73.9% (36.2–87.17)
		45–49 years	4; 35.04% (29.7–65.98)	1; 49.32% (49.32)
		50+ years	3; 74.6% (29.86–83.63)	1; 23.7% (23.7)

Data input	Number of complete annual data sets taken from verified data set	139

Pseudomonas Chronic PA is 3+ isolates between two annual data sets	Number and % of patients with chronic PA infection	94 (67.6%)
	Number and % of patients with chronic PA infection	73 (78%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	72 (77%)
	Number and % of patients on chronic macrolide without chronic PA infection	10 (22%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

- The service is led by two consultants. Each has an allocation of 0.5 whole-time equivalent (WTE) for cystic fibrosis work; at any one time, one is covering the CF service while the other covers general respiratory duties.
- Both consultants have considerable experience in CF clinical care; they attend CF centre directors' meetings and national/international conferences. The consultants have begun an ambitious research programme into understanding and improving adherence in cystic fibrosis, which ultimately has the potential to influence the delivery of clinical care at an international level. The consultants have received considerable support from the management to enable them to start to set up plans for this research project. The consultants have initiated an active microsystems programme to evaluate and improve the efficiency and quality of the service.
- Both consultants are working at levels significantly above their job plans and contracted hours. They also perform an unofficial weekend one-in-two on-call rota to review unwell patients. Their commitment to the service is undoubted, but their current workload is not sustainable. The current staffing levels leave the CF service particularly vulnerable without senior cover when the consultant covering cystic fibrosis is on leave or away for other reasons, particularly as there is no staff grade cover.
- Further, although the unit is also supported by a deanery trainee respiratory specialist registrar (Spr) and two junior grade doctors, recent changes in Spr training requirements and their duties have exacerbated the deficiency in medical cover for the unit. Some clinics now only function through support by research fellows, whose posts are funded by temporary income from grants. There is a senior house officer (SHO) and a Foundation year 1 (F1) on the ward but they too are vulnerable to being reallocated to support medical wards, leaving the service run by one consultant and one junior.
- The current level of senior staffing and lack of permanent middle-grade cover are both of concern and have potential issues for patient safety.

Recommendations

- To appoint another consultant in cystic fibrosis.
- To bolster the provision of support provided by middle-grade doctors, either through additional middle-grade staff or other personnel with appropriate skills to support this role.

4.2 Specialist nursing

Summary

The clinical nurse specialists (CNSs) are extremely enthusiastic and passionate about their roles and responsibilities. They know their patients well and pride themselves on providing individualised care. They provide a home IV antibiotic service, homecare service, contribute to annual review are assisting in developing the CF-related diabetes service and participate in audit and professional development.

Recommendations

- Additional administrative support five days per week to support CNS.
- Appointment of a dedicated outpatient nurse to contribute to home IV service and flush portacaths in clinic – this could be a Band 5 or 6 nurse working full-time.
- The annual review service needs more structure to enable it to run more efficiently.
- Re-establishment of full CNS compliment (seconded member of staff: 0.6 WTE of a Band 6 nurse).

CNS service

There are currently four members of the CNS team looking after 173 adult patients and who are meeting standards of care. There is one nurse prescriber. All CNSs are members of the Cystic Fibrosis Nurses Association (CFNA) and attend meetings when staffing allows. The CF team regularly takes part in clinical audit, eg, currently aseptic technique, infection control and diabetes.

Clinical

CNS provide a home IV service starting at an average of six patients per week, receiving help Monday to Wednesday from a charge nurse. A specialist nurse-led clinic runs alongside the main clinic to review patients ending home IVs. The CNSs run a homecare service with an average of five home visits per week; the secondment of one of the team to Chronic Obstructive Pulmonary Disease (COPD) limits this. The CNSs see an average of seven annual review patients per week.

Non-clinical administrative/secretarial

The CNSs perform an administrative service for consultants by pulling out all blood and sputum results generated post clinic for review. The specialist nurses spend a lot of time dealing with all prescription queries in the community and faxing all requests for medication to GPs. An additional CNS (prescriber) has streamlined this process. The specialist nurses follow up clinic non-attenders and rebook cancellations; this can be very time consuming.

Areas of good practice:

- CNSs have good relationships with the patients.
- CNSs are currently working on developing the diabetes service, including the development of an appropriate database.
- CNSs attend the CF team Service Improvement Meeting once a week, working closely alongside the rest of the MDT.
- Each CNS has an area of expertise including diabetes, transition and transplant.

Areas of concern:

- Not up to full establishment (COPD cover).
- There are only 19 hours of administrative support a week which leaves CNSs with a vast amount of clerical duties.
- Currently the CNS team shares an office with many other members of the MDT and feels this is not an environment conducive with efficient work. There are currently two computers that are shared between the team.

Ward nursing service:

12 beds staffed with two qualified nurses and one support worker. Patients with *Burkholderia cepacia* complex are nursed on another ward. Staff sickness can be an issue and cover at short notice can be difficult. At times the ward can be left with one qualified nurse on duty. This requires nurses from the other wards who may not be familiar with cystic fibrosis to come and help check IVs etc. This is not safe practice. The charge nurse is currently helping with CF outpatients' IVs three days a week. The knock-on effect of this is a reduction in ward management, education and time to develop new staff. Ward staff spend a lot of their time chasing medical notes, answering phones and booking appointments. CNS support worker helps out on the CF ward and other wards by covering kitchen duties and seeing to patients' extra nutritional needs. However, there are hopes to create a housekeeper role for these duties, freeing time to work on clinical/patient focused duties.

Discussion with the specialist nurses and the ward nurses provided some solutions:

The team suggested cystic fibrosis training and education for staff from other wards enabling them to cover the CF ward when short-staffed and help with patients who are nursed off the dedicated CF ward. The appointment of a full-time Band 5 nurse to the CF ward (bringing the daily number of qualified staff to three) will improve patient safety.

Wish list:

To renovate rooms for *Burkholderia cepacia* patients to CF unit standard. Protected clinical supervision time. A housekeeper role to free support worker from kitchen duty.

4.3 Physiotherapy

Staffing

The physiotherapy service provides for 2.3 WTE qualified physiotherapists; 1.0 WTE Band 7 clinical specialist, 0.5 WTE Band 6, 0.3 WTE rotational Band 6 and 0.5 WTE Band 5, with the part time posts split between respiratory medicine. In addition, there is funding for technical instructor posts; 0.5 WTE Band 3 and 0.4 WTE Band 2. At the time of review, there were staff vacancies which had left the establishment at 2.0 WTE qualified physiotherapists, supported by 0.5 WTE Band 3. The funded staffing falls well below the recommended 4.3 WTE for the 165 patients. This significant shortfall is further compounded by the management structure which requires the CF physiotherapy team to triage patients through a prioritisation system across respiratory medicine. A recent audit of clinical activity demonstrated that at least 20% of CF physiotherapy time was spent delivering care to other patient groups. This staffing is inadequate and evidenced by the failure to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

Inpatients

Only 10% of patients had been identified as receiving twice daily physiotherapy. Furthermore, as patients are prioritised on acuity and dependence on assistance for airway clearance, this may be as little as 2–3 times per week; this is a significant shortfall in service delivery. Exercise provision for inpatients also falls well below recommendation averaging 0–3 times per week. Weekend provision is a seven-day working model but also fails to meet standards as CF patients are often required to carry out their own treatment. The seven-day working model also impacts significantly on weekday provision, imposing further strain on the service. This is due to the requirement to cover staff absences when time is taken in lieu for weekend working. The clinical specialist, where possible, attends weekly MDT meetings, but is unable to attend ward rounds.

Outpatients

Less than 32% of patients have access to a physiotherapist in clinic. Recent measures to address this, by protecting clinic time for clinical specialist and Band 3 failed due to the need to prioritise inpatient care. Newly diagnosed and transition patients are prioritised and reviewed as appropriate. There is no process to provide physiotherapy clinic cover for staff leave or absence. There is inadequate staffing to provide support for patients on home IVs with no dedicated homecare service; however, patients are prioritised if attending clinic. There is potential for up to six annual reviews per week. These are undertaken by the clinical specialist but current staffing means that not all patients have access to full physiotherapy review. When staffing allows, all areas are addressed, including posture and continence. There are appropriate pathways in place for referring to other services as indicated. There are currently no facilities to undertake exercise testing – this is under review.

Professional development

The clinical specialist is a member of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and has attended and presented at international conferences. Continued professional development (CPD) has been difficult to maintain due to staffing, with attendance at regional and national meetings falling below recommendation. Membership of the ACPCF is mandatory for attendance at national meetings, therefore limiting non-ACPCF team members from attending. It had been identified at appointment that for mentorship the clinical specialist should have dedicated time for peer support at other CF centres. This has not taken place. As the horizontal line management structure stands, the clinical specialist is appraised and supervised by a Band 7 on respiratory medicine, which has the potential to adversely impact her CPD.

Research and audit

There is a strong commitment to research and audit.

Areas of good practice

- Experienced and dedicated team led by a clinical specialist who is insightful regarding shortcomings of the service, passionate and committed to improving physiotherapy care.
- Highly skilled Band 3 technical instructor providing a significant role supporting the service. Strong MDT involvement and support. Proactive approach to addressing adherence with team members skilled in practising motivational interviewing. Active involvement in research and audit.

Recommendations for service development

Physiotherapy Clinical Services and Operational Managers recognise the urgent need to respond to areas of concern highlighted regarding physiotherapy staffing establishment and structure. Short - and medium-term action plans has been identified aimed at addressing shortfalls. It is essential this plan should address the following recommendations:

- An immediate change to cystic fibrosis management structure to provide clinical specialist with operational responsibility for the CF service. This must include team leader responsibilities for day-to-day management of the service, mirroring other specialist CF services.
- It is essential that there is protection of CF clinical time to ensure CF physiotherapy staff are not providing support to other clinical areas.
- The proposed physiotherapy structure for qualified staff must meet the Cystic Fibrosis Trust's 'Standards of Care (2011)' recommendations (4.3 WTE) with a longer term plan in place to address projected growth in the service.
- The skill mix should address the need to develop and maintain expertise within the team, ensuring appropriately skilled cover for the clinical specialist during periods of leave.
- Review of weekend provision to improve quality of physiotherapy care across the seven day week.
- Review of the role and responsibilities of Band 3 technical instructor against current banding of post.
- Protected time for professional development, to allow regular attendance at regional, national and international conferences.
- All qualified staff working regularly with the CF team should be members of the ACPCF.

4.4 Dietetics

The dietetic service is covered by three dietitians (two WTE) experienced in cystic fibrosis. Led by a Band 8a (0.2 WTE) with 0.8 permanent Band 6 (0.8 WTE) and 1 WTE rotating Band 6 = 2 WTE in all.

This means there is usually cover available from a dietitian with CF experience during periods of leave.

Patients have good access to the dietetic service and are reviewed regularly during inpatient admissions, at outpatient clinics and have a full dietetic assessment at annual review. The dietitians are based in the main dietetic department a considerable walk away from where the CF service is delivered. There is good liaison at transition, with adult and paediatric dietitians holding joint consultations. The dietitians attend the quarterly diabetes clinics and manage the booking of these clinics. They have good links with the diabetes nursing service.

The dietetic team regularly takes part in research and audit. The lead dietitians are members of UK CF Dietitians Interest Group. They regularly attend conferences and present. The lead dietitian is principal investigator on a forthcoming study into behaviour change and a web-based home coaching programme for weight gain.

Patients are provided with a flexible food service with main meals supplied from the staff canteen and additional meals and snacks prepared by the housekeeper in the ward kitchen. In addition, between meals, hot and cold snacks are available during the day and evening served by the housekeeper and ward staff. However, as the housekeeper is only on duty three evenings per week this service may not always be available if nursing staff are busy with other duties. The patient rooms have the facility for patients to make hot drinks and a refrigerator in which to store food. The majority of patients surveyed are satisfied with the food service.

Good practice

- Well-staffed, experienced team, incorporating a rotational post that ensures cover is available at all times from a dietitian experienced in cystic fibrosis.
- Dietitians have a lead role in centre research and adherence programme.
- Flexible food service.

Areas of improvement/future developments

- The food service would benefit from additional housekeeper hours to ensure the evening service can continue throughout the week.
- The dietitians may benefit from office space nearer the CF service.
- The dietitians are keen to continue to develop the CF-related diabetes (CFRD) service with the new diabetologist.

4.5 Pharmacy

Staffing

The pharmacy team comprises of a Band 8a respiratory pharmacist who works four days a week with responsibility for the 12-bed CF inpatient ward and the 28-bed respiratory ward, and a Band 8d clinical pharmacy services manager, providing the service one day a week. This is approx. 0.6 WTE and a deficit of 0.4 WTE. They are supported by 0.5 WTE Medicines Management Technician (MMT). Cover is provided in the pharmacists' absence by a rotational Band 7 respiratory pharmacist. No cover provided for the MMT in their absence so their workload falls to the pharmacist.

Despite the deficit, the pharmacy team is very experienced, well integrated into the MDT and both are active members of the CF Pharmacists group. One has recently stepped down from the CF Pharmacists steering group, her position taken by her colleague. As such she has been involved in organising and speaking at national and international conferences. Both provide local training to pharmacy colleagues and the MDT, and have written guidelines and been involved in audits. The pharmacy department has seven-day working in place with on-call after 4pm at weekends and 7pm in the evenings, ensuring IV antibiotics can be started any time when appropriate. Outpatient services are provided locally and also by Boots chemist on site.

Aseptic services make up desensitisation regimes for patients who have options to make up their own IVs for bolus doses or have prefilled devices for certain antibiotics via a homecare service provided by BUPA. Other homecare is limited to a small number of patients on ivacaftor. Medicines information queries are handled by the pharmacists. All have had appraisals within the last 12 months and appropriate service objectives developed.

Good practice

- Highly experienced team providing good service to ward.
- Infection control guidelines well enforced by instigating air tube transport of outpatient prescriptions to ensure patients do not mix in pharmacy.
- The utilisation of the MMT, not just on the wards but also in audit work looking at prescription waiting times for CF patients, is a great example of the constant efforts directly designed to improve patient experience.

Areas for improvement

The deficiencies in staffing mean pharmacists only see < 1/3 of patients who attend annual review. This, with the re-engineered process for outpatients, means they no longer see patients in clinic on a regular basis. This means they are unable to meet the standard of seeing all patients at least twice per year at the current time. Their skills in motivational interviewing are under-utilised and the time they spend with CF patients has decreased. The MDT and service goal is to ensure patients are in "prevention" rather than "rescue" – due to staffing pharmacist resources are aimed at "rescue". Time for research is limited. No opportunities to contribute to financial planning and management of the drugs budget, despite their will to be involved. Homecare support is limited and the service is currently not Hackett compliant. Repatriation of inhaled high-cost medicines to secondary care in the next financial year as well as managing patient access scheme drugs will produce a workload they are unlikely to cope with given the current staffing.

Recommendations

The staffing deficiency has been recognised and a bid has been put in for a 0.7 WTE Band 7 pharmacist to release the 8a pharmacist to CF full time and 0.5 WTE Band 5 Medicines Management Technician. This is essential to meet appropriate standards and growing homecare requirements. Additional technician/administrative support for homecare may also be required and workload should be monitored to anticipate this. Pharmacists should be utilised to ensure appropriate financial management of the drugs budget for the directorate. Pharmacist support for outpatients now they are no longer in clinic would benefit from being proactively explored, rather than relying on access via bleep if requested.

4.6 Psychology

Staffing

There is currently 0.4 WTE of a Band 7 clinical psychologist who is providing maternity cover for the substantive post holder (Band 8a 0.5 WTE who returns January 2014 three days/two days alternative weeks). The substantive post represents a shortfall of 0.5 WTE compared to the recommended staffing levels for 150 patients. There are no arrangements for cover during absence. The post holder is HPC registered and a member of the UK psychosocial cystic fibrosis group (UKPPCF), attending regional and national meetings.

The clinical psychologist attends weekly inpatient MDT meetings and service development meetings. She is usually able to see inpatient referrals within a week, although this can be hindered by part-time working. A waiting list for outpatients has been set up and patients wait for up to six weeks, but urgent referrals are prioritised and seen quickly. The locum clinical psychologist has not been involved in any audit or research nor is aware of any ongoing projects involving psychology. She does not have routine involvement with patients at annual review or at key life stages, although she is working with several patients at these stages within her clinical case load.

Good practice

Examples of good practice include the extent of both formal and informal contact with the MDT on a weekly basis, and the prompt response to referrals. Psychology input is valued by patients and the team, and previous teaching on motivational interviewing was well received.

Areas of development

These areas for improvement were identified, although it would be useful to clarify these with the substantive post holder on her return from maternity leave. They include establishing annual psychological screening and increasing routine involvement with transition, adult diagnosis and end-of-life care. Involvement in audit and research, and developing a forum for the MDT to discuss psychological factors in complex cases could also be beneficial. Current staffing levels are likely to preclude these all being possible and the psychologist should work with the team leadership to decide which areas to prioritise. Some practical issues should be noted such as the lack of administrative support or a dedicated phone line for the psychologist, and the impact of working in a busy shared office.

4.7 Social work

The unit has one 1.0 WTE social worker post, made up of two part-time social workers, both of whom are very experienced and are registered with the Health & Care Professions Council. Both social workers are members of the UKPPCF and attend annual meetings. They are unable to attend other CF conferences as they do not have access to hospital funding for this because they do not have NHS contracts; although essentially 'health-funded' this also affects their ability to access 'essential' reference materials (eg Disability Rights Handbook) and other resources.

The social workers attend the weekly MDT and pick up referrals from there, via self-referral (usually telephone and entered into the 'Message Book') or via referral from members of the MDT via email/ personal contact. They do not have a waiting list and strive to pick up referrals either the same day or next day, but have their own personal 'to do' list. At any given time, the social workers are working with a number of patients on various issues that may take 'priority'.

The social workers are not routinely involved in annual reviews (but have been in the past). This is partly due to the structure of the annual review process and also to the administration of the patient's clinics where the social workers are 'excluded' in order to hasten the number of patients seen – the annual review form reflecting the omission of social work also has impacted on the contact, although social workers keep their own records for both Social Services and their own CF records. They attend transition clinics throughout the year, but have not been routinely informed about new patients joining the service. They are closely involved in planning end-of-life care, ensuring that patients' wishes are adhered to where possible. They support regular audit within the wider MDT.

Good practice

Examples of good practice include their strong relationships with patients and the team, consistent attendance at the MDT, rapid response to referrals, and ability to invest time in complex cases and in planning end-of-life care. The social workers also report strong links with external services, a particularly strong record in benefit tribunals and success in resolving employment issues.

Areas for improvement

The social workers intend to become more involved in the annual review process, initially through other staff offering a social work review to the patients. They have made the wider team aware of the importance of being informed when new patients join the service, and when patients are diagnosed as adolescents or adults. The social workers are sometimes pulled away from their work in cystic fibrosis to work on safeguarding and other issues this can be disruptive to the continuity of their work. The social workers would benefit from administrative support and access to quiet, private spaces to make confidential phone calls and the provision of suitable office equipment, eg, availability of IT equipment for all staff to process their work, made more difficult by social workers working two systems, eg Citrix and NHS.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	4	3	9	3	3	1	0
Female	2	1	11	4	3	1	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	33	11	1	0
From the ward staff	26	12	2	0
From the hospital	20	20	4	1

Areas of excellence

1. Outpatients – cleanliness
2. Outpatients – cross-infection
3. CF team – accessibility

Areas for improvement

1. Outpatients – waiting times
2. Food
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

Northern General Hospital

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%	N/A	N/A	

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 annual review (AR).	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Safe – Yes Effective – No	Safe – Yes Effective – No	It is only safe at present as staff are covering well.
	% 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%	Green	Green	
	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%	Amber	Amber	

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 *Pseudomonas aeruginosa* in the previous 12 months.	100%	Red Work in progress	Red Work in progress	
	% patients admitted within seven days of the decision to admit and treat.	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours.	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% 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 Adult service	Red Adult service	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	N/A Adult service	N/A Adult service	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded BMD (DEXA) scan in the last three years.	100%	Red Adult service	Red Adult service	

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	Only achievable if consultants do not take time off when covering the wards.
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%	Amber	Amber	
	% patients reviewed by a CF Clinical Nurse Specialist (CNS) at each clinic visit.	100%	Red	Red	
	% 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 Physio action plan.	Red Physio action plan.	
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Red Review as per clinical need.	Red Review as per clinical need.	
	% 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 Patients referred on need basis	Red Patients referred on need basis	
	% availability of social worker for inpatients and at clinic.	100%	Green	Green	
	% availability of pharmacist for inpatients and at clinic.	100%	Green	Green	

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

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received in the past 12 months.	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months.	<1%	12% 21 incidents on ward to 170 patients.	12% 21 incidents on ward to 170 patients.	
5.3	User survey undertaken a minimum of every three years.	100%	Green	Green	

Appendix 2

Staffing levels

Whole-time-equivalent (WTE)

	75 patients	150 patients	250 patients	Northern General Hospital 170 patients
Consultant 1	0.5	1	1	0.5 WTE
Consultant 2	0.3	0.5	0.5	0.5 WTE
Consultant 3			0.5	
Staff grade/Fellow	0.5	1	1	0.0 WTE
Specialist registrar	0.4	0.8	1	1.0 WTE
Specialist nurse	2	3	5	2.5 WTE
Physiotherapist	2	4	6	2.8 WTE
Physiotherapy assistant				
Dietitian	0.5	1	2	2 WTE
Clinical psychologist	0.5	1	2	0.5 WTE
Social worker	0.5	1	2	1.0 WTE
Pharmacist	0.5	1	1	0.6 WTE
Clinician's assistant				
Secretary	0.5	1	2	0.8 WTE
Admin assistant				
Database coordinator	0.4	0.8	1	0.3 WTE (data clerk)
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: Northern General Hospital, Sheffield	
Number of active patients (active being patients with data within the last two years) registered	143
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2011')	139
Median age in years of active patients	24
Number of deaths in reporting year	2
Median age at death in reporting year	28.5

Age distribution (Ref: 1.6 'Annual Data Report 2011')		
Number in age categories	16–19 years	30
	20–23 years	36
	24–27 years	20
	28–31 years	18
	32–35 years	8
	36–39 years	7
	40–44 years	11
	45–49 years	5
	50+ years	4

Genetics	
Number of patients and % of unknown genetics	7 patients with no genotype on 2 alleles; 19 patients with no genotype on 1 allele

Body mass index (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	(n=78) 32 (41%) BMI >23	(n=61) 24 (39%)
Number of patients and % with BMI <19 split by sex	17 (22%)	13 (21%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	12 (15%)	9 (15%)

FEV_1 (Ref: Figure 1.14 'Annual Data Report 2011')		
	Male	Female
Median FEV_1% pred at age 16 years split by sex	86.72%	94.04%
Number and median (range) FEV_1 % pred by age range and sex		
16–19 years	20; 85.3% (26.46–114.03)	10; 95.5%% (68.86–108.94)
20–23 years	17; 68% (21.26–106.05)	19; 69.25% (27.38–102.26)
24–27 years	12; 63.56% (15.27–102.39)	8; 65.66% (32.06–98.79)
28–31 years	8; 65.1% (16.13–98.27)	10; 52.46% (35.07–101.17)
32–35 years	4; 55% (45.3–100.62)	4; 71.4% (67.02–75.76)
36–39 years	6; 58% (34.44–81.86)	1; 54.5% (54.4)
40–44 years	4; 84% (61.42–97.61)	7; 73.9% (36.2–87.17)
45–49 years	4; 35.04% (29.7–65.98)	1; 49.32% (49.32)
50+ years	3; 74.6% (29.86–83.63)	1; 23.7% (23.7)

Lung infections (Ref: 1.15 'Annual Data Report 2011')		
Chronic *Pseudomonas Aeruginosa* (PA)		
Number of patients in each age band	16–19 years	30
	20–23 years	36
	24–27 years	20
	28–31 years	18
	32–35 years	8
	36–39 years	7
	40–44 years	11
	45–49 years	5
	50+ years	4
Number of patients with chronic PA by age band	16–19 years	17
	20–23 years	22
	24–27 years	16
	28–31 years	15
	32–35 years	7
	36–39 years	6
	40–44 years	6
	45–49 years	4
	50+ years	1

Burkholderia Cepacia (BC)	
Number and % of total cohort with chronic infection with BC complex	1 (0.7%)
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	11 (8%)
CFRD	
Number and % of total cohort requiring chronic insulin therapy	31 (22.3%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	3 (2.2%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis with no PH	With PH 1 (0.7%) without PH 1 (0.7%)

Transplantation (Ref:1.18 'Annual Data Report 2011')	
Number of patients referred for transplant assessment in reporting year	8
Number of patients referred for transplant assessment in previous three years	25
Number of patients receiving lung, liver, kidney transplants in last three years	3

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	285
	20–23 years	483
	24–27 years	488
	28–31 years	138
	32–35 years	46
	36–39 years	137
	40–44 years	72
	45–49 years	71
	50+ years	11
Number of days of home IV therapy in reporting year split by age groups	16–19 years	238
	20–23 years	758
	24–27 years	373
	28–31 years	340
	32–35 years	176
	36–39 years	190
	40–44 years	117
	45–49 years	94
	50+ years	89
Total number of IV days split by age groups	16–19 years	523
	20–23 years	1241
	24–27 years	861
	28–31 years	478
	32–35 years	222
	36–39 years	327
	40–44 years	189
	45–49 years	165
	50+ years	100

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	(n=100) >16 yrs with FEV_1<85%
If not on DNase % on hypertonic saline	5 (5%)

Chronic antibiotic therapy (Ref: 1.22 'Annual Data Report 2011')	
Number and % of patients with chronic PA infection	94 (67.6%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics; Tobramycin solution, Colistin	73 (78%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	With chronic PA 72 (77%); without chronic PA 10 (22%)

Appendix 4

User survey results: Northern General Hospital, Sheffield

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	4	3	9	3	3	1	0
Female	2	1	11	4	3	1	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor	N/A
Accessibility (appointments/advice)	29	14	1	1	0
Communication (verbal/written)	23	16	4	1	0
Out-of-hours access (via phone or ward)	18	13	5	1	0
Homecare/community support (appointments/advice)	14	8	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)	17	18	8	2	0
Waiting times	11	13	16	1	0
Cross-infection/segregation	32	10	2	0	0
Cleanliness (room)	34	10	0	0	0
Annual review process	22	19	2	0	0
Transition (paediatric to adult)	15	11	1	0	0

How would you rate your inpatient care (ward)

	Excellent	Good	Fair	Poor	N/A
Admission waiting times	17	9	4	2	0
Cleanliness (cubicle/bathroom)	27	5	2	0	0
Cross-infection/segregation	27	6	2	0	0
Food (quality/quantity)	10	11	8	6	0
Exercise (gym equipment/facilities)	13	12	1	5	0

How would you rate:

	Excellent	Good	Fair	Poor	N/A
Home intravenous (IVs) antibiotic service	20	10	2	0	0
Availability of equipment (physiotherapy aids/nebuliser parts)	24	10	2	0	0
Car parking (availability/ease of reach)	5	16	9	6	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor	N/A
Of your CF team	33	11	1	0	0
Of the ward staff	26	12	2	0	0
Of the hospital	20	20	4	1	0

Comments about CF team/hospital

"What I rate the most is the cross-infection control/segregation which is vital. I'm not keen on the new location of the outpatient clinic though."

"The team is excellent. They provide an excellent service and great personal care."

"The CF team as a whole is fantastic, especially as we are going through rough times with transplant and basically living on the ward. The staff make it so easy; like home from home. All I will say is they are understaffed, but it's a cracking job regardless."

"Excellent staff that can't do enough for you, family-type atmosphere makes stays in hospital a whole lot better."

"Always receive great care from the team; very friendly and calming. Waiting times still quite long, but has improved over the past few years."

"The hospital food is poor, especially taking into account nutrition for people with cystic fibrosis. The CF team is fantastic and has helped me improve my health and knowledge about cystic fibrosis."

"Waiting times are several hours, and not enough parking to facilitate the usage of the services."

"The CF team provides an outstanding service. The facilities on the inpatient ward are world class and while being in a hospital environment, the service and facilities are comparable to any of the best hotels that I have stayed in. I am not, however, so impressed with the new outpatient provision."

"The CF team is all really caring and lovely, even the cleaners on the ward act like part of the care team."

"Due to autism, departments (ie X-ray) scans had to be notified so staff could use appropriate language for explaining what was going to happen. Should this be done by the unit instead of parent having to do this?"

"Without a physio for a long time but things seem to be back to normal. Also, doctors are excellent, knowledge and advice for CF patients."

"The unit is good but should let departments (ie X-ray, scans) know when young person has autism eg, DEXA scan. Nurse came, took blood with no introduction or explanation. This young person was taken ill on the unit when his routine bloods were taken."

"I have only spent three days in the new ward so not much experience, but the ward is so luxury. My CF team is excellent, never had any problems. They are always there for me – very happy with my care and all staff."

"I strongly feel that all the medical staff I see genuinely care about my welfare."

"I live approximately one hour away from hospital and the team is always willing to find ways of getting meds etc to me without me having to mess about – really helpful."

"Northern General team was extremely responsive, supportive and friendly. I am very well with my cystic fibrosis but for any favour, question or query – immediate detailed response."

"Outpatients difficult to access. Used to have dedicated CF unit; now share with other departments. This has to be a backward step."

"Car parking can be complicated – now we have disability Blue Badge; this has been made easier."

"Communication used to be excellent. Admin clerk can't book or confirm my annual review after five phone calls. Has been good when CF nurses manage it; now done by a clerk – joke! No support from original team members. I have been at Northern General, where the care I have received has been brilliant. The new outpatients service is disappointing, the service levels have gone back 20 years to a service where you are not seen by the team that has looked after you for 20 years. Feel very let down and will not attend anymore."

"Never had any problems with the team."

"Sometimes you can visit over a period of between six to nine months and not see a CF consultant – only another doctor. I know some patients ask to see a CF consultant if they didn't see one at their last visit."

"When I was admitted for IVs for two days, I had to wait eight hours after being discharged to get all the medication required for them to let me leave. I also had to wait a day to get a long line in as there were no doctors around who could do this. Outpatient care is generally ok, but care from doctors when admitted is not so good."

"Have had to use A&E to find a bed. My Cepacia makes the gym inaccessible. Friendly, supportive, informative and professional."

"As a mostly excellent team, I feel that the consultants should make more of an effort to see their patients, as I can go from one year to the next without seeing either of my consultants. So when I do see them, they don't always have the information on my health."

Appendix 5

Patient/parent interviews

Northern General Hospital, Sheffield

Patient 1

Visits team every four to six weeks at outpatient clinic. Reports to reception and then straight into own room. Height, weight and lung function are done in the room. Patient visually sees the lung function machine cleaned down after use. He sees all team members. Appointments can be from 20 minutes up to four hours duration. Inpatients – one year ago since being an inpatient. Happy with rooms en suite with fridge TV/internet/laptops/Wii fit. Bed available for friends to stay. Food: access to normal patient menu and access to canteen for anything, but long way from being nutritional and high calorie. Gym on ward: can use it as many times as wishes when vacant and physiotherapist visits once a day. Home IVs – provided by BUPA. When out of hours contact needed as line was blocked; no one available, so family member helped with taking line out until the week day when team was then contactable. Normal hours: contacts CF unit and sorted straight away. Out of hours: rings ward.

Areas of excellence: Advice, knowledge about cystic fibrosis and always supportive and there when needed.

Improvement: Food provisions.

Patient 2

Sees team monthly – goes straight to room, lung function done by auxiliary nurse. Always sees nurse and physio. Other members of the MDT – either by request or just pop in. Never get to see consultant; always get a registrar, even if requests to see consultant who is either not there or too busy. This makes it very difficult. If unwell needing IVs, usually three days as inpatient before continuing at home. Waits for a bed can be three days up to two weeks. Port accessed by specialist nurse, however flushes in between are done by patient.

Inpatient sees specialist physio twice a day during week. No input at all on weekends – not in. Self-treats with NIV machine and autogenic drainage (AD). Sees nurse and dietitian when admitted. Only some form of doctor is seen and on ward rounds, again no consultant. Good with food snacks and kitchen on ward, where staff make up meals for patients. Food from canteen not great. Home IVs – BUPA. However, some medications have to be made up by patient. Access to team in normal hours – very good. Varies as patient either has appointment first to assess or if verbally expressing feeling ill, then will wait for bed availability. Out of hours – ring ward – easy access. Annual review: all the same day. Letter then sent a few months later. If anything wrong, rings straight away. Still doesn't get to see consultant for annual review; registrar again.

Areas of excellence

- Make you feel as comfortable as possible when in ward.
- Unit nurses take on more than they should.
- Physio helped with nebulisers and educating.

Improvements

- Seeing consultant at least at clinic (monthly).
- Self-medicate – Ward had booklet referring to self-medicating. Two years on, still cannot do. Able to keep Creon and inhalers, but all other medications kept with ward staff.

Appendix 6

Environmental walkthrough: outpatients department
Outpatients/CF clinic

	Northern General Hospital, Sheffield	
	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	Once checked in all go directly to room.
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?		Appropriate, takes place in individual clinic rooms.
Where are lung function tests done for each visit?		Mobile lung function equipment x4 taken to individual rooms and cleaned appropriately.
Are clinic rooms appropriately sized?	Yes/No	Some rooms do not have a bed for examination therefore may not in some circumstances be appropriate.
For annual review patients, are any distractions provided?	Yes	Two good rooms for annual review. Large TV, bed/chair.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Same clinic (two patients).
Transition patients – can they get tour of outpatient facilities?	Yes	Joint clinic.
Transition/new patients – do they get information pack?	No	No formal pack, although good verbal induction given.

Additional comments

- Three clinics held each week
- Patient's first appointment is one hour long, where they will meet the whole team.
- Universal precautions used for cross-infection control.
- Drugs are pre-ordered so patient does not have to go to pharmacy.
- Novel approach to clinics to improve the patient waiting times and patient experience, as clinics run by CF clinic captain.

Environmental walkthrough: ward
Ward name: CF ward – Sheffield adults
Microbiology status: All microbiology

		Northern General Hospital, Sheffield	
		Yes/no/ number/ N/A	**Notes/comments**
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Other respiratory patients utilise beds if not used by cystic fibrosis.
Are there side rooms available for CF care? (if overflow facilities are required)		Yes	Excellent, spacious, clean, well decorated and well thought-out facilities.
Number of side rooms?		12	Maximum of eight to date utilised by cystic fibrosis, although 12 available if required.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Yes	One ward bath.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Can stay in rooms on 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	Access to fridges in rooms; no microwave in rooms, although available for nurses to use in general kitchen to heat meals.
What facilities are provided for teenagers?		Yes	Laptops with Wi-Fi, Wii Fit, computer games. Xbox is to be ordered in the near future.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Well equipped single patient use gym and exercise bike for rooms.
What facilities are there to help with school and further studies?	Yes	Desk and PC in rooms.
Is there a relatives' room?	Yes	Comfortable lounge.
What internet access is there?		Wi-Fi.
What facilities are there to enable students to continue work and study?	Wi-Fi, own desk. Tutor visits ward if required.	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sinks in rooms to wash and air dry nebiliser parts.
What facilities are provided for those with MRSA?		Barrier nurse.
What facilities are provided for those with *B.cepacia*?		Barrier nursed and admitted to Brearley 2 Ward. Facilities here are not of the same standard as the CF ward, however plans are to upgrade in the near future.
What facilities are provided for those with other complex microbiology?		Barrier nurse on CF ward.
Are patient information leaflets readily available on ward?	Yes	Welcome folder given to patients. Website available, although it requires updating.
Transition patients – can they get tour of ward facilities?	Yes	Most patients are from Sheffield Paediatric Hospital.

Additional comments

Facilities excellent. The CF ward is very spacious. The MDT may benefit from office space nearer to the ward; to cut down on time spent travelling, particularly from physiotherapy departments and dietetics.

	Northern General Hospital, Sheffield	
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Free parking close to CF centre, permit provided.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	In general yes. However, old signage for previous CF ward could lead to confusion.
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	Drugs are pre-ordered to avoid patients waiting at pharmacy.
Patient information		
Is Patient Advice and Liaison Service (PALS) well advertised – leaflets, posters?	Yes	Friends and family.
Are there patient comment/ feedback boxes?	Yes	Whiteboard in ward.

Appendix 7

Panel members

Dr Andrew Jones*	Consultant	University Hospital South Manchester
Clare Cox	Pharmacist	Papworth Hospital
Vanessa Shearing	CF Specialist Psychologist	Papworth Hospital
Susan Talbot	CF Clinical Nurse Specialist	Royal Brompton Hospital
Jo Barrett	CF Specialist Dietitian	Heartlands Hospital
Alison Gates	CF Specialist Physiotherapist	Churchill Hospital
Covered by Psychologist	Social Worker	
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for peer review panel

Appendix 8

Other information

cysticfibrosis.org.uk