In partnership with

Peer review report

Royal Victoria Infirmary Adult Cystic Fibrosis Centre

19 March 2015

Contents

1. Executive summary

Overview of the service

This is a flourishing service run by a dedicated, enthusiastic team. Parts of the multidisciplinary team (MDT) are seriously under-resourced and require urgent expansion. The inpatient and outpatient facilities are reaching capacity and expansion of the facilities needs to be considered. There are well established outreach services for this large geographical region.

Good practice examples:

- Consultant delivered care with excellent continuity of care.
- There is a very well developed outreach service to Teeside and Cumbria.
- The hospital pharmacy team run an innovative pre-packaged home intravenous antibiotic service, enabling all cystic fibrosis (CF) patients to access home-delivered, pre-mixed antibiotic treatment.

Key recommendations:

- There are critical staff shortages within many areas of the MDT. These need to be addressed urgently, with consideration to succession planning for several disciplines.
- The MDT needs to be enhanced to allow further support to the majority of patients receiving treatment at home. Currently not all patients are seen at the end of a course of treatment in clinic and not all patients on treatment receive a home visit. This is an issue when most patients receive outpatient antibiotic treatment rather than an admission to hospital.
- Annual review is carried out within clinic time. In view of the pressure on clinic slots it would be sensible to review the process.

Areas for further consideration:

- Both the inpatient and outpatient areas are close to, or at, capacity. With predictable growth in the adult population at Newcastle, expansion of these areas is required.
- Patients would benefit from space for exercise as inpatients.
- Patients would benefit from internet access in their rooms in order to facilitate study/work.
- Clerical support is required. Currently clinicians are both collecting and inputting PORT CF data.
- Patients would benefit from fully joint clinics for CF diabetes for convenience (ie full CF team attendance to enable CF care at the same clinic visit as diabetes review). Currently, the dietitians are the only MDT members able to attend these clinics.

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

Models of care

Summary

More than 95% have an annual review and discussion with their named consultant.

Multidisciplinary care

Summary

Although care is safe and effective, each area of MDT is under significant pressure with numbers of patients/workload.

Principles of care

Summary

Most aspects of care are delivered effectively. Ultrasound scan, bone mineral density (DEXA) scan screening and Oral Glucose Tolerance Test monitoring all fall below guidelines.

Delivery of care

Summary

Outpatient care is delivered according to guidelines, apart from the lack of psychology and pharmacy input in clinic. There are several deficits in inpatient MDT care due to under-resourcing within the physiotherapy, nursing, pharmacy and dietetic teams.

Commissioning

Summary

The Adult CF service at the Royal Victoria Infirmary (RVI) is a well-established service with a cohort of 267 patients.

Band	Cohort	∑
1	40	14.98%
1A	10	3.75%
2	50	18.73%
2A	90	33.71%
3	51	19.10%
4	18	6.74%
5	8	3.00%
∑	267	100.00%

The service is funded via the national year of care tariff, and the total income to the Trust in 2014/15 will be £3.67 million.

As with most CF services, the level of dedication and skill of the clinical staff and supporting staff is impressive, although there are significant concerns about staffing levels which fall below the standards set out in the national service specification.

Areas of good commissioning practice:

- The service is funded via national payment-by-results year of care tariffs.
- Good working relationship with local specialised commissioner.
- Business proposal has been submitted to the Trust Board to address the staffing shortages.

Areas for improvement:

- Shortfall in recommended staffing levels.
- Although the key performance indicators used for the derogation self-assessment did not reference staffing levels, it was regrettable that the Hospital Trust assessed the adult CF service to be fully compliant, when they must have realised that there were significant staff shortages.
- Not unusually, the understanding between the service and the Trust's management team did not appear to be particularly strong. There is no doubt that the service and management teams talk and discuss the service, however, there was, for example, no inkling that the service understood the level of income and the difference between income and budget, and didn't appear to appreciate that changes in the size of the cohort or case mix should produce sufficient income to meet changes in staffing requirements.

Recommendations

- The Trust must decide whether or not to approve the business case as quickly as possible. The year of care tariff funds the service to full staffing levels. There should have been no need to consider a business proposal, as the funding effectively sets the staffing establishment.
- The service needs to seriously reconsider its assertion that it is fully compliant with the service specification, and it is the opinion of the commissioner that the Trust should complete a derogation action plan to be agreed and monitored by the commissioner. The action plan to include progress with regard to the business proposal.
- The Trust should involve the service in contract matters, and conversely the service needs to ensure the management team understand where any service shortfalls are to ensure commissioners are not only advised of non-compliance during peer reviews. The Trust need to accept year of care tariffs fund a fully compliant service, and there is no discretion about staffing levels and other key performance indicators.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	248

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		N/A	N/A
	Number and median(range) FEV_1 % pred by age range and sex	16–19 years	12; 72.92 (54.28–114.74)	11; 78.91 (16.96–125.38)
		20–23 years	37; 80.5 (30.12–124.35)	17; 69.77 (21.05–116.49)
		24–27 years	23; 58.94 (14.68–125.32)	20; 57.91 (25.91–108.1)
		28–31 years	20; 67.09 (15.67–98.04)	17; 51.04 (20.18–117.85)
		32–35 years	16; 46.45 (12.62–106.95)	17; 75.28 (23.03–113.01)
		36–39 years	7; 59.71 (18.05–96.82)	8; 62.94 (34.94–91.66)
		40–44 years	7; 59.75 (45.12–99.77)	11; 54.59 (17.39–107.76)
		45–49 years	7; 57.68 (25.25–111.63)	3; 108.71 (74.38–118.23)
		50+ years	7; 53.95 (36.98–112.27)	8; 51 (32.39–81.25)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	n=136; 54 (40%)	n=112; 47 (42%)
	Number of patients and % with BMI <19 split by sex	19 (14%)	20 (18%)

***Pseudomonas aeruginosa* chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	114 (46%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	89 (78%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	93 (82%)
	Number and % of patients on chronic macrolide without chronic PA infection	58 (43%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

Staffing: 0.9 whole time equivalent (WTE) consultants. This falls far below the recommended national standard (1.6 WTE shortfall), which is exacerbated by the lack of junior doctors (no CF fellow and only 0.1 WTE of an Specialist Registrar – shared with the respiratory teams).

Patients are kept under the care of a named consultant. SB (centre director) tends to have 3–4 inpatients at any one time and the other consultants may have 1–2 inpatients. AG inserts all the vascuports, which gives continuity and also a wealth of expertise. Consultants cover the CF unit as part of an unofficial consultant rota and come in most weekends to clerk patients or are telephoned with queries. There is no formal respiratory cover out-of-hours. There appears to be little pressure on the beds with no delay before admission, which is surprising in view of the number of patients being cared for at the centre. There is an advanced outreach system for patients from Tyneside. The MDT delivers outreach clinics approximately alternate Fridays.

In addition to their CF workload, CF consultants also have other responsibilities for respiratory inpatients (20 inpatients per firm) and general medical on call but with specialty based ward care. SD leads lung cancer and AG has Intensive Therapy Unit commitments.

The current respiratory cover depends on the goodwill of consultants working out of hours for free. Although this is commendable and the patients clearly value their consultant-delivered service, this approach may be unsustainable.

One WTE uplift in consultant time has been agreed from the business case and it is intended to increase the programmed activity (PA) time for SB and SD in order to support the service. There is good cover for annual and study leave.

Impression: Very dedicated consultants severely under-resourced in terms of time and junior doctor support. This service is almost entirely consultant delivered.

Areas of good practice:

- Consultant-delivered, innovative service.
- Excellent integrated palliative care service.
- Excellent outreach service.

Areas for Improvement:

- Annual reviews need to be removed from clinics as these are already busy for one clinician (10–15 patients per clinic).
- Medical cover out-of-hours needs to be reconsidered long term because consultants attending most weekends to clerk patients is unsustainable and will make recruitment and retention more challenging.
- Sufficient clinic time is required to allow a prompt review of patients post outpatient intravenous antibiotic treatment (they are currently seen routinely after four weeks and do not all receive a home visit).

Recommendations:

- Increase in consultant staffing.
- Appoint a CF fellow.
- Data collection and uploading of PORT CF data should be carried out by clerical staff not clinicians.

Specialist nursing

270–280 patients – recommended 5.5 WTE nurses as per the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

Currently 3.6 WTE employed as respiratory nurse specialist with interest in CF.

Actual hours staffing for CF care 2.6 WTE.

Have had approval to employ another respiratory nurse Band 6 (1.0 WTE), have not been allowed to recruit for this post or advertise for replacement of member of staff who is leaving (both posts held until after April), as a review is to be undertaken as to staffing requirements for the chest clinic.

The 8a clinical nurse specialist (CNS) has returned after retirement & predominately offers support to CF for an outreach clinic & cross cover when Band 7 at university.

The Band 7 works 1.0 WTE, but includes the chest clinic manager role. He is responsible for the data entry to PORT CF as well as the repatriation of high cost drugs in CF. He said he did not feel able to delegate these jobs, but did say he often has to work extended hours/come in at weekends to complete the work.

All the nurses are cognitive behavioural therapy (CBT) trained and support CBT clinics within respiratory outpatients.

All of the nurses are working extended hours to complete the outpatient work. They do not have the time to visit or support inpatients unless there is an absolute need. This means they are unable to meet the standard for care.

The nurse leaving the service is doing so because of the lack of recognition as specialist nurse due to the need to support other respiratory clinics in the department.

Ten to fifteen patients are taking home IVs per week. The hospital pharmacy compounding department reconstitutes IV medicines into syringes & intermate devices & arranges home delivery, which aims to deliver within 48 hours of the prescription. Patients generally warn team they need IVs, so that the drugs can be prepared.

The patients attend RVI for line access; all peripherally inserted central catheter (PICC) lines, subclavian lines & portacaths are inserted by Dr Gascoigne. Occasionally they use cannulae.

Because of the wide geographical catchment area and lack of staff, the nurses are unable to provide domiciliary visits to most of their patients during their course of treatment, but triage those who require visits, asking support from GP services for blood tests. There is a reliance on the patients reporting non-response to treatment, otherwise they are seen approximately four weeks after treatment is completed.

The nurses felt the service has outgrown the inpatient and clinic capacity, (nine consultation rooms and a procedure room). Patients starting treatment in scheduled clinic will overrun the 30 minutes allocated to their appointment time. Outside CF clinics, pressures on rooms from other respiratory services as well as providing planned treatment and urgent reviews whilst adhering to infection control measures.

The patient feedback is largely positive regarding the clinic experience and the nursing team.

The CF inpatient area is six beds outside the end of ward 52, which is the respiratory ward with ICU step down beds for 35 patients. The CF ward beds are at one end of the ward through the double doors and are isolated from the ward activity, so the staff allocated to care for CF beds are often stretched by helping colleagues on ward 52, where there is currently a high vacancy rate. There is little or no education regarding CF for the ward staff. They are unable to attend the weekly MDT meeting and the CNS are unable to attend ward rounds. It is felt the CF ward should be separate from the respiratory ward with its own ward staff, as patients often feel isolated at end of corridor away from the ward activity.

All nurses are members of UK Cystic Fibrosis Nursing Association (CFNA) and attend local meetings.

One hundred percent nursing attendance at MDT meetings, but not ward rounds.

Cross-cover is provided within the respiratory nursing team.

Nursing staff attend regional meetings & study days to maintain continuous professional development (CPD).

Nurses provide support for research within the unit and have presented results at the European Cystic Fibrosis Conference in last three years.

Areas of good practice:

- All nurses Cognitive Behaviour Therapy trained.
- 79% of IV antibiotic courses are done at home.
- Outreach MDT clinics.

Areas for improvement:

- Recognition of CNS CF role.
- Nurse involvement in CF-related diabetes (CFRD) care.
- Improve the availability of home visits.
- Time for development of team members and inpatient staff allowing for the development of clinical skills, education, protocols, audits, research and development.

Recommendations:

- Acknowledgment and review of job description/title to CF CNS role – not respiratory nurse specialist with interest in role. Review current staff and roles within respiratory clinic and CF to allow for a more visible presence on the wards and an increase in the number of domiciliary visits for those undergoing treatment as per the Cystic Fibrosis Trust's Standards of Care.
- Use of data clerk and pharmacist to undertake roles being maintained by Band 7.
- Development of CFRD in nursing staff to work alongside dietician and liaise with diabetologist and attend diabetes clinics.
- Work towards developing joint clinics to reduce multiple patient attendances to RVI.

Physiotherapy

Staffing consists of 4.1 WTE (1.9 shortfall); 1.0 WTE Band 7, mix of full-and-part-time, static and rotational Band 6s including one new 1.0 WTE. All physiotherapists are Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) members with good attendance on regional, national and international conferences. They have carried 1.6 WTE maternity/sick long-term with minimal back fill. Additionally, for most of 2014, the team provided cover for the respiratory team maternity and sick leave meaning the treatment of unwell general medical respiratory patients has often needed to be prioritised over exercise, exercise testing, musculoskeletal intervention and continence for CF patients.

Clinics, including out-reach and transition are well covered. Time spent with each patient can be a problem, with frequent interruptions and pressure for quick reviews to enable the patient to be moved on, assessment of all physiotherapy needs is difficult. Outpatient appointments are offered as indicated and it is felt this works well, however finding an available room is often difficult.
Home care provision is limited to high priority patients, however the new Band 6 post will be community based, aiming to expand and offer all patients on IV treatment a home visit.
Exercise is offered in the main physiotherapy or pulmonary rehab gym, however availability is extremely limited, with no protected time for CF. Equipment is available for exercise in individual rooms, which are fairly small for this purpose. A lack of dedicated CF gym and rooms which can be used for physiotherapy reviews are going to be major barriers to expanding the physiotherapy input that can be offered to patients with CF as staffing improves.

Funding for airway clearance, nebulisation and non-invasive ventilation equipment can be a problem, with restrictions on how much can be ordered in a given month.

The team is working hard to provide the best service for their CF adults within the limits of both their own staffing and that of the general respiratory team. As staffing improves, they seem to be keen to improve their service and are very aware of the areas for development.

Areas of excellence/good practice:

- Clinic cover
- Annual review
- Enthusiasm and dedication of team

Areas for improvement:

- Exercise and exercise testing.
- Homecare provision, particularly to the large numbers of patients receiving home IVs.
- Postural screening and management of musculoskeletal problems.

Recommendations:

- Physiotherapy management should be made aware of the service specification for CF and ensure staffing is protected in order to enable the specification to be met. Consider writing local physiotherapy service standards, based upon the national service specification and evidence based clinical guidelines, outlining the expected clinical input patients with CF should receive.
- Investigate protected gym time for CF patients in the short term and aim for a dedicated CF gym and space for physiotherapy reviews/intervention in the longer term.
- Monthly funding restrictions on equipment should be stopped and managers made aware that the service specification and tariff received includes provision of equipment, including airway clearance devices and nebulisation equipment.

Dietetics

Based on 280 adult patients, the Cystic Fibrosis Trust's Standards of Care recommend 2.24 WTE dietitians. The table below shows the breakdown of the current staffing and the new structure that takes effect from May 2015. The new structure is a consequence of extra funding and the retirement of the lead dietitian in March 2015.

	Total Staffing (WTE)	Band 7 Dietitian (WTE)	Band 6 Dietitian (WTE)	Band 3 Support Worker (WTE)
Current	1.6	0.6 (Lead, 25yrs CF experience) 0.9 (Six years CF experience)	n/a	0.1
From May 15	2.2	0.9 (Lead, six years CF experience)	1.0 (No CF experience)	0.3

Although staffing levels are appropriate, they are not ring fenced for CF. Over the past three years, the CF dietitians have been expected to cover for absence in other clinical areas of the hospital without reciprocal arrangements. It is estimated the actual dietetic service provided has been 1.0 WTE which has had a detrimental effect on the service provided. Even when taking into account the additional unpaid hours worked by the dietitans, it is becoming increasingly difficult to meet the appropriate standards of care for reviewing inpatients, outpatients and annuals.

The service is provided by experienced CF dietitians. In addition to outpatient clinics (hospital and outreach) and inpatient services they also provide home visits to patients.

The dietitians provide a CF team link role with other specialties in the hospital namely the gastroenterology, gastrostomy and diabetes services. The lead dietitian provides an extended dietetic role within the CFRD service, teaching blood glucose monitoring, commencing patients on insulin and insulin dose adjustment.

There is excellent liaison at transition, with the adult and paediatric CF dietitians holding joint consultations.

The dietitians attend the weekly MDT meeting.

The dietitians are involved in audit and research. They are members of the UK CF Dietitians Interest Group. They have attended and presented at local, regional and international CF meetings. The new lead dietitian has completed the MSc module in CF nutrition.

An inpatient CF-specific menu and snack menu was developed approximately 18 months ago in consultation with patients and the catering department. There are no facilities for patients to store their own food as all patient fridges have been removed from the hospital as a result of the hospital's infection control policy. As a consequence of staffing problems, the dietitians have been unable to review the inpatient catering service.

Areas of good practice:

- Highly experienced and dedicated dietitians providing good nutritional care to patients.
- Excellent liaison with diabetes, gastroenterology, gastrostomy and paediatric services.
- Provision of a domiciliary CF dietetic service.
- Commitment to continuing professional development and involvement in audit and research.

Areas for improvement/recommendations:

- To immediately ring fence CF dietetic staffing, particularly in light of the recent changes to the dietetic structure and the need for training of the new band 6 dietitian.
- Ensure funding for courses is available to allow adequate training of the new dietitian.

- In the new dietetic structure there is a need to review the dietetic role within the CFRD service. This would need to be done as part of a whole review of the CFRD service with some consideration for joint clinics.
- Review the inpatient catering service.
- Given the predicted growth in patient numbers and scarcity of dietetic training posts for CF, some consideration is needed for future succession planning.

Pharmacy

Funded CF pharmacist provision is 0.2 WTE at Band 7

The Cystic Fibrosis Trust's Standards of Care provision for a 280-patient clinic would be 1.0 WTE pharmacist.

- Pharmacist has previously attended national specialist interest group meetings but does not do so regularly.
- Cystic fibrosis MDT meeting attended approximately once per month. Ward rounds not attended.
- Non-specialist ward cover (Band 6/7) and non-specialist screening of homecare prescriptions.
- Not recently attended any European Conferences or national CF study days.
- No CF team audits or research noted.
- Minimal input. The pharmacist's involvement in the care of patients with CF is limited to ward based review.

Areas of excellence/good practice:

- High quality service provided by pharmacy sterile manufacturing service, including cross-regional home delivery.
- Homecare prescriptions screened by specialist pharmacist with support of pharmacy homecare team.
- Cystic fibrosis pharmacist a member of the specialist group.

Areas of improvement:

- Staffing level is inadequate for patient numbers therefore unable to provide Cystic Fibrosis Trust's Standards of Care.
- Minimal CF pharmacist input into patient care other than those patients admitted for inpatient care.
- As well as having inadequate pharmacist resource available, it is inevitably under pressure from elsewhere in the pharmacy clinical service (to the acute medical directorate).

Recommendations:

- Funding and provision of a dedicated, appropriately-supported and resourced cystic fibrosis pharmacist at 1.0 WTE minimum.
- Support from both pharmacy department and CF service to empower the CF pharmacist to develop the clinical pharmacy service to people with CF to the commissioned level.
- As the CF service provides a majority of the clinical care outside of the inpatient beds these patients must receive a pharmacy service appropriate to their needs. The CF and pharmacy services should consider the best ways of delivering pharmaceutical care to these patients and ensuring equity of access to pharmacy expertise and support.

Psychology

Newcastle Adult CF Service has a 0.4 WTE clinical psychologist (CP). For 270 patients, the Cystic Fibrosis Trust's Standards of Care recommend 2.0 WTE meaning the CP service is dramatically understaffed at only 20% of what is recommended and the lack of adequate CP provision has been noted in the patient interviews. Leave cover is available for urgent matters. The CP is a UK Psychosocial in CF (UKPP-CF) member and has attended local and national CPD events with plans to attend the UKPP-CF study day, but is yet to attend an international conference after two years in the post.

Areas of good practice:

- Psychological working is well disseminated, with other members of the team having completed CBT training. The CP is highly trained, having gained an additional qualification in cognitive analytic therapy.
- The CP attends all inpatient and outpatient discussions (although not routinely covered when on leave) and is able to respond flexibly to referrals.
- Despite being under-resourced, the CP is dedicated to safeguarding time for research and service development and is currently undertaking some work around the area of transition.

Areas for improvement:

- Due to lack of staffing, the current provision can only be reactive and the resources do not exist to provide CP support embedded at different life stages (e.g. transition, new diagnosis, planning for parenthood).
- There is lack of equitability, with no CP service available to those attending Teeside or Cumbria outreach clinics.
- Clinical psychologist has not previously been involved in the annual review. The Hospital Anxiety and Depression Scale was administered but this will only screen for anxiety and depression rather than the diverse range of other difficulties that the CP can support. Input into the annual review is currently being reviewed and will hopefully help to raise awareness of the role of the CP.

Recommendations:

- Increased CP staffing (additional 1.6 WTE) is crucial in order to meet the Cystic Fibrosis Trust's Standards of Care. This additional resource would enable the CP to be more embedded within the team providing further joint working, outreach work, standardised involvement at key life stages (in particular transition), further involvement in the annual review process and increased input into research and service development.
- Providing increased CP resources would also support other members of the team in the psychological support they are currently providing and enable the development of a comprehensive, proactive and preventative approach to patients' psychological needs.

Social work

Newcastle has one very experienced social worker in post with a vast amount of knowledge and experience. He is very highly thought of by all the professionals within the MDT and by the ward staff. He works 0.5 WTE for adults which is not meeting the required standards of 1.5 WTE. His post is funded by the Trust and Barnardos and he is based in a Barnados service a short distance from the hospital. The positives of this are he has the guidance and support on a daily basis from a social work team. This enables him to see patients outside the hospital settings and they are able to see more patients within their own homes. There is a good referral system by email or telephone contact and are able to respond in a timely manner.

The priority is to see patients due to the demands on their service. He is able to offer both practical support, in the form of advice on benefits/employment/housing/form filling and emotional support. Paul has seen the benefits of having the support from psychologist, now in post.

The social worker is not able to attend annual reviews but has produced a specific questionnaire and has leaflets to advertise their service. It will be important to review the effectiveness of this. A lot of support is being offered but the full interaction of CF social work into the wider team and the amount of work done is inevitably hampered by the fact that only 0.5 WTE is currently provided, compared with 2 WTE required under the Cystic Fibrosis Trust's Standards of Care for a service of this size.

Areas of good practice:

- A committed and experienced social worker who knows the families well and has a wide knowledge of cystic fibrosis.
- The social worker seeks appropriate support from the safeguarding children teams and local resources in the appropriate areas.
- Very good social work outreach support, home visits and transition, as he works for paediatric CF team.

Identified areas for development or improvement:

- The work needs to be properly resourced as there is currently only 25% of the necessary social provision which has a negative impact on the interaction into the wider work of the team, eg MDT attendance which is currently 1–2 a month.
- Concerns about the work pressure due to covering adults and paediatrics. Also at some point thought will need to be given to succession planning as worker moves towards retirement. This will be helped by proper provision of social work time.
- When the team change over to electronic notes the possibility to be explored that social work team can assess and write on notes remotely

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	3	1	15	9	3	2	0
Female	2	2	21	11	4	2	2

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	60	13	0	0
From the ward staff	28	12	3	1
From the hospital	42	26	2	1

Areas of excellence:

1. Team accessibility
2. Availability of team members
3. Outpatient cleanliness

Areas for improvement:

1. Food
2. Lack of psychology support
3. Car parking

6. Appendices

Appendix 1

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

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

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

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

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

Hospital name

Royal Victoria Infirmary

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review	90%	Green	95	Consultant delivered service.
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	97	Data input by consultant team.
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	95	Good continuity provided by the consultants.

2 Multidisciplinary care

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

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Red	This refers to the CF dietitian attending a diabetes clinic at another hospital rather than a fully joint clinic, which would reduce appointments for the patient.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	Good access both in and out of hours.

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	This ranges between home Blood sugar monitoring, continuous glucose monitoring and oral glucose tolerance testing.
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Red 25% underwent ultrasound scan	Red	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red 20% underwent DEXA	Red	DEXA scans only available at the Freeman hospital.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	Red. Limited visits	Green	This refers to access to CNS not visit frequency.
	% of patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends	100%	Red. Cover by respiratory physio team	Red	
	% availability of a CF specialist dietitian at clinic	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Red	Red	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Red Access by referral	Red	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Green	Green	
	% availability of a social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Red Available by request	Red Available by request	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	1	1	
5.2	Number of clinical incidents reported within the past 12 months	<1%	Not available	Not available	
5.3	User survey undertaken a minimum of every three years	100%	Amber	Amber	

Appendix 2

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Royal Victoria Infirmary 270 patients
Consultant 1	0.5	1	1	0.5 WTE
Consultant 2	0.3	0.5	1	0.2 WTE
Consultant 3			0.5	0.2 WTE
Staff grade/fellow	0.5	1	1	N/A
Specialist registrar	0.4	0.8	1	0.2 WTE
Specialist nurse	2	3	5	3.6 WTE (1 WTE approved 2015)
Physiotherapist	2	4	6	3.1 WTE (1 WTE approved, recruiting)
Dietitian	0.5	1	2	1.5 WTE (0.5 WTE approved recruiting)
Clinical psychologist	0.5	1	2	0.4 WTE
Social worker	0.5	1	2	0.5 WTE
Pharmacist	0.5	1	1	0.2 WTE
Secretary	0.5	1	2	1 WTE
Database coordinator	0.4	0.8	1	Ad hoc

Appendix 3

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre – Royal Victoria Infirmary	
Number of active patients registered (active being patients within the last two years)	255
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	248
Median age in years of active patients	28
Number of deaths in reporting year	6
Median age at death in reporting year	33

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	23 (9%)
	20–23 years	54 (23%)
	24–27 years	43 (17%)
	28–31 years	37 (15%)
	32–35 years	33 (13%)
	36–39 years	15 (6%)
	40–44 years	18 (7%)
	45–49 years	10 (4%)
	50+ years	15 (6%)

Genetics	
Number of patients and % of unknown genetics	36 (15%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	n=136; 54 (40%)	n=112; 47 (42%)
Number of patients and % with BMI <19 split by sex	19 (14%)	20 (18%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	13 (68%)	13 (65%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Medium FEV_1% predicted at age 16 year split by sex		N/A	N/A
Number and medium (range) FEV_1 %n predicted by age range and sex	16–19 years	12; 72.92 (54.28–114.74)	11; 78.91 (16.96–125.38)
	20–23 years	37; 80.5 (30.12–124.35)	17; 69.77 (21.05–116.49)
	24–27 years	23; 58.94 (14.68–125.32)	20; 57.91 (25.91–108.1)
	28–31 years	20; 67.09 (15.67–98.04)	17; 51.04 (20.18–117.85)
	32–35 years	16; 46.45 (12.62–106.95)	17; 75.28 (23.03–113.01)
	36–39 years	7; 59.71 (18.05–96.82)	8; 62.94 (34.94–91.66)
	40–44 years	7; 59.75 (45.12–99.77)	11; 54.59 (17.39–107.76)
	45–49 years	7; 57.68 (25.25–111.63)	3; 108.71 (74.38–118.23)
	50+ years	7; 53.95 (36.98–112.27)	8; 51 (32.39–81.25)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	23
	20–23 years	54
	24–27 years	43
	28–31 years	37
	32–35 years	33
	36–39 years	15
	40–44 years	18
	45–49 years	10
	50+ years	15
Number of patients with chronic *P. aeruginosa* by age group	16–19 years	6
	20–23 years	26
	24–27 years	22
	28–31 years	17
	32–35 years	20
	36–39 years	8
	40–44 years	8
	45–49 years	3
	50+ years	4

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	17 (7%)
Number and % of *cenocepacia*	6 (2%)
Meticillin-resistant *Staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	12 (5%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	14 (6%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	23 (9%)
Cystic fibrosis-related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	74 (30%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	8(7%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	4 (2%) with PH; 4 (2%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	15
Number of patients referred for transplantion assessment in previous three years	53
Number of patients receiving lung, liver, kidney transplants in previous three years	12

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	99
	20–23 years	220
	24–27 years	707
	28–31 years	485
	32–35 years	161
	36–39 years	92
	40–44 years	159
	45–49 years	15
	50+ years	72
Number of days of home IV therapy in reporting year split by age group	16–19 years	596
	20–23 years	1193
	24–27 years	1160
	28–31 years	860
	32–35 years	816
	36–39 years	276
	40–44 years	383
	45–49 years	149
	50+ years	131
Total number of IV days split by age group	16–19 years	695
	20–23 years	1403
	24–27 years	1867
	28–31 years	1345
	32–35 years	977
	36–39 years	368
	40–44 years	542
	45–49 years	164
	50+ years	203

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV_1, % predicted <85% (ie below normal) on DNase	n=175; 70 (40%)
If not on DNase, % on hypertonic saline	7 (4%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	114 (46%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	89 (78%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	93 (82%) with Chronic PA; 58 (43%) without chronic PA

Appendix 4

Patient survey

Royal Victoria Infirmary

Other hospitals attended:

Carlisle Cumberland Infirmary Freemans Hospital, Newcastle Newcastle General Hospital

James Cook, Middlesborough University Hospital of Hartlepool University Hospital North Durham

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	3	1	15	9	3	2	0
Female	2	2	21	11	4	2	2

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	55	17	3	1
Communication	48	21	4	1
Out-of-hours access	33	17	2	4
Homecare/community support	30	10	4	4

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	53	19	3	1
Waiting times	32	27	6	1
Cross-infection/segregation	44	22	3	3
Cleanliness	54	18	3	1
Annual review process	47	24	3	2
Transition	33	11	1	5

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	20	12	3	2
Cleanliness	25	9	1	1
Cross-infection/segregation	21	11	2	0
Food	6	10	12	10
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	16	12	2	2
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	10	9	4	4

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	37	15	1	0
Availability of equipment	42	17	2	0
Car parking	8	17	23	14

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	60	13	0	0
Of the ward staff	28	12	3	1
Of the hospital	42	26	2	1

Comments about CF team/hospital

"Home-nurse service removed - wasn't particularly impressed with official response to this. Do get access to latest treatments but seems to be if you ask, not provided/updated on latest research/ devices as a default."

"Not happy about parking. Disabled spaces very limited and the fridges in rooms on ward were removed plus not allowed in kitchen."

"The clinic is very streamlined and organised, minimal waiting times. Helpful and efficient doctors, dietitians, physios, nurses. Outstanding care, cannot fault the department."

"I am one-and-a-half years post-transplant so now seen at Freeman Hospital and only twice a year at CF clinic. IVs are not part of treatment so answers based on pre March 2013."

"Highly disappointed to not have access to CF unit and end up out the way in a room on regular ward, old room no TV etc."

"I am an atypical patient who is very well but I am treated with as much care and as much speed as someone who is sicker. I felt extremely well looked after physically during my pregnancy and Chorionic Villus Sampling (CVS). I would have liked a little more emotional support during the CVS."

"Cystic fibrosis outpatients team very professional, caring, considerate and supportive. I can't think of any negatives at all. I had a few reservations about some aspects of nursing care on the ward, but these I am told have been taken seriously and addressed."

"The team is fantastic, the nurses, doctors and all of the team, have an amazing way of helping you, I feel like someone they know rather than a patient."

"I have nothing but praise for the CF team at the RVI. Their care is second to none. If I have a problem, I know I can turn to them for help."

"I have shared care with RVI and Durham. I am always treated very well at RVI and am very happy with the care I receive. It is good to have consistency of staff members every time for continuity of care."

"I cannot praise my team enough, nothing is ever too much for them and the care I receive is excellent. Particularly from Dr Dow, Dr Gasgoine and nurse Alan. Excellent CF team - would never go anywhere else."

"The service I receive is exceptionally well managed, organised and caring. It accommodates my needs very well and allows me flexibility to maintain commitments outside of my CF."

"Really supportive. I only use email I don't have any out-of-hours numbers. Car parking - too few disabled bays for too many people."

"I have always felt confident in the CF team and the new(ish) clinic is a vast improvement. I have not attended the CF department very long but all the doctors, nurses and support staff are like a little family."

"All the CF team are great, could not fault. The only thing I believe would help benefit more CF patients would be some kind of regular mental support."

I can't say enough about them. I know that if I call with a problem it will be dealt with quickly, for example, this week I had to ring them on Monday to say I had developed pleurisy, by Wednesday I was on IVs and Thursday home IVS were delivered.

"The staff in the outpatients department are always friendly, efficient and helpful. The ward is totally different you are left to fend for yourself. Sometimes you don't even get meals or water in rooms - very poor."

"Good service - I am a six-monthly patient but was much more frequent, never any issues."

"Friendly and knowledgeable team. Hospital is easily accessible to service and is very clean."

"The CF team are always friendly, professional and willing to go the extra mile to help. I couldn't ask for better care."

"I found that my transition wasn't as smooth as I thought it could have been, more of the paediatric side. I know this was a few years ago now and things have changed."

"I have only transferred from paediatric to adult care within the last six months. On the run up to this, I was very unwell - in and out of hospital. The paediatric team decided, without any input from me or my parents, when I had to transfer over. Nobody spoke to me about this. On my last admission, I was told I had to go over as soon as the decision had been made. I felt this to be very wrong."

"Dr Bourke at RVI is an excellent CF consultant."

"Really couldn't ask for better care, definitely the best clinic I attend by far."

"They all do a fab job, wouldn't change any staff."

"Cannot praise the CF team enough!"

"I get no support from the CF team at all."

"Excellent service."

"They are a very caring and helpful team."

"I could not ask for a better team."

"I think the CF team are good and really helpful as is the RVI. Would like my medication delivered to my door."

"I live in Sunderland and have to travel through Newcastle which makes my appointments harder."

"Good team."

"Staff are really friendly, warm and informative always make you feel at ease."

"Very good to excellent service, sometimes waiting longer than normal."

"Haven't been an inpatient for quite a few years."

"The only issue would be the delivery service sometimes I am at clinic when they ring and then I haven't got my delivery until 8.45pm."

Appendix 5

Patient/parent interviews

Newcastle Royal Victoria Infirmary – adults' peer review - telephone interviews

Patient A felt segregation measures at outpatient clinic are very good, adding she doesn't sit for long before being moved into a consultancy room, where she sees each member of the CF MDT and spirometry takes place. She sees all of the MDT, is offered clinical psychologist's support, but does not know of a social worker in the team. Patient A felt clinical decisions are always discussed with her, with her views taken into consideration. She sees good use of hand gels and wiping down of equipment between patients. The CNS collects her prescriptions from pharmacy, so she has no concerns around hospital pharmacy.

Inpatient care: Not applicable. This patient does not require inpatient CF treatment currently.

Annual review: Patient A is offered annual review every year and has undergone annual review this year. She saw the whole CF MDT and all assessments took place at the RVI. She did not undergo a liver CF scan or DEXA scan. Annual review outcomes are reported to her, in a letter, a week after annual review.

Home care: Patient A has home IV antibiotic treatment, deliveries of which are arranged by RVI. She has to mix her own antibiotics. She explained RVI always ring to see if she is available to receive a delivery of the IV antibiotics. Patient A is starting to receive deliveries of Colobreathe inhaled antibiotics too. She finds it easy to contact a member of the CF team, usually the CNS, adding she can get straight through to the nurse.

Good practice:

- "CF team are easily available and I can be seen same day."
- "Good staff, consultant and clinical nurse specialist especially."
- "Hygiene and cleanliness'."

Area for improvement:

- "Car parking – can never find a space and it's extortionate. People park in the hospital car park, then go shopping." Car park is near Newcastle shopping area.

Patient B is promptly directed to a consultancy room, on arrival at outpatient clinic. She stays in the consultancy room for the duration of the clinic appointment, unless requiring a chest x-ray. She felt use of hand gels and wiping down of equipment between patients is very good. Patient B felt very much part of the decision-making process regarding her treatments.

Patient B sees all of the MDT, although has refused to see the clinical psychologist at outpatient clinic and has asked about social worker support – this is currently handled by another team.

She rarely has to use hospital pharmacy, although when she has, she has found service pretty prompt; medications are ready for when she leaves clinic.

Inpatient care: This patient does not require inpatient care currently.

Annual review: Patient B is offered annual review each year and has recently had this year's annual review. Her assessments take place at RVI, with the exception of DEXA scan at the Freeman Hospital. A copy of the clinical letter is sent to the GP. If there are other clinical changes, the dietitian gives Patient B a telephone call, or can speak face to face. Patient B has been given a contact card with all the contact details of the CF team.

Home care: Not necessary currently for this patient.

Good practice:

- "Professional manner of the CF team."
- "Minimal time at outpatient clinic."
- "Absolutely great service."

Area for improvement:

- None suggested.

Patient C has been attending RVI since 2010. She felt segregation measures had improved at outpatient clinic over the last 18 months; now whisked promptly into a side room for consultation and spirometry within a few minutes. The CF MDT rotate between patients who stay in their respective side rooms. Patient C explained clinic staff are good at using hand gels and wiping down equipment – gels attached to their belts and CF team using the sinks straight after entering the consultancy room.

Patient C sees all of the CF MDT including the CNS for port flushes. She explained the dietitian and physiotherapist work closely together, sees usually both, but they cover one another during absence from clinic. Patient C didn't see a clinical psychologist as she felt it not necessary currently. She chooses not to see a social worker, adding the Barnardos social worker has been very useful, really lovely and visited her at home, to support her comprehensively for 2 hours or more.

Patient C felt the CF team makes decisions on her care jointly with her, describing them as very good. She cited an example of how they brought a psychologist in to help patient/team deal with her needle phobia which has resulted in new procedures regarding needle usage on Patient C which the team follow. Patient C has also negotiated a six month compromise on treatment plan and more convenient clinic appointments to help her with child care. She felt the hospital pharmacy experience is 'usually pretty good', as a member of the CF team lodges her prescription with pharmacy ready for her to pick up.

Inpatient care: This patient hasn't required inpatient care in the last 12 months.

Home care: Patient C starts IV antibiotic therapy in hospital, goes home same day and then receives pre mixed IV antibiotics delivered to from hospital directly, although this service is being passed over to BUPA. Pharmacy begin delivery procedure before Patient C has got home, so she has to get away from clinic and home before delivery arrives at home. Her Tobramycin levels are checked at hospital.

Annual review: Patient C is offered annual review each year, the next one due in spring 2015. All assessments take place at the RVI, except for DEXA scan undertaken at the Freeman Hospital. Following routine outpatient appointments, Patient C receives a letter a week to 10 days later with the outcomes. Her annual review outcomes are reported back next clinic; some have it sent by post according to Patient C. She is happy with the CF team's communication more generally – i.e. she emails the physio or dietitian and receives a reply within 48 hours. For more urgent enquiries she telephones and receives a reply by 10am or same day. She rings the ward out of hours – the ward team manages urgent cases and bed situation and her medication worries out of hours. Patient C's diabetic care is managed by the General Hospital (Newcastle).

Good practice:

- "The service feels more personal. With continuity in the team, they know about me and treat me as a person and understand my background and personal life." – e.g. providing a holistic approach
- "Physiotherapist and social worker work hand in hand."

Areas for improvement:

- "Car parking – it's near the city centre, so it's difficult to get spaces, car park is abused by shoppers, always full. There have been more disabled spaces provided – approx.24 – but parking is limited."
- More liaising with GP service needed to make GP service more proficient in more routine treatments – e.g. port flushing, and taking Tobramycin levels.

Patient D felt segregation measures at RVI seemed alright, adding those patients growing *P. aeruginosa* wait in a different waiting area, before being transferred to individual consultancy rooms. Patient D sees all of the CF MDT at outpatient clinic and was recently referred to the clinical psychologist. She didn't know of a social worker. She felt decisions on her treatment are made jointly with her, adding "they (the CF team) usually listen to me." She gave an example where she chose to return to nebulising an antibiotic rather than use inhaled version. Patient D explained that the CNS lodges her prescription during clinic at pharmacy, to ensure a quick pick up at end of clinic.

Inpatient care: This patient has not had inpatient treatment in the last year.

Annual review: Patient D is offered annual review each year, adding parts of her annual review take place during routine outpatient appointments. She sees the whole CNS, doctor, dietitian and physiotherapist at annual review. All her annual review assessments take place at the RVI, apart from the DEXA scan, undertaken at the Freeman Hospital. She couldn't remember when she'd last had a liver CT scan. Patient D's annual review outcome is reported back at her next outpatient clinic; any urgent matters communicated to her by telephone by the CNS or dietitian.

Home care: Patient D picks up her first batch of IV medications from hospital, then takes delivery of the second batch in week two, which used to be under the BUPA service. She attends the RVI for Tobramycin levels and can have her portacath flushed at either RVI or at home, at the healthcare centre.

Good practice:

- "Really friendly staff at the CF centre."
- "Easy to get hold of the CF team."

Area for improvement:

- "It would be better if CF team could fax prescriptions to local doctor/GP for easy pick up."

Patient E felt segregation measures at outpatient clinic were generally quite good, directed into single rooms where they stay for the duration of clinic, with spirometer wheeled between rooms. He felt staff always wash their hands, although he had noticed some gel dispensers missing and is never asked to use the gel dispensers. He cannot be sure equipment is wiped down.

Patient E felt the CF team are 'not pushy' and so don't dictate treatment plans and decisions on treatments are two-way. He felt this depends though on what the team can be sure of. He has seen the clinical psychologist, but feels the psychologist should be more visible. He has heard of a social worker, but does not know about the support provided. Patient E felt those patients who are more 'pushy' like him get to know what treatments are available and where (eg. provision of eflow nebuliser), since he felt this sort of information is not offered freely. He felt changes in commissioning and funding of CF dictate what's on offer in terms of treatments and equipment and is annoyed "that money comes into it." He has to wait at pharmacy, sometimes for a few hours to Tobi Podhaler.

Inpatient care: This patient has not required inpatient treatment in the last year.

Home care: Patient E gets his portacath flushed at RVI or at the outreach clinic in Sunderland. He also gets his Tobramycin levels checked at the RVI; a service which he explained the CNS used to provide. He starts IVs at hospital and then has IV antibiotics and ancillaries delivered by BUPA. He added sometimes he experiences shortages in deliveries, but these are soon rectified by BUPA, whereas he felt RVI pharmacy were not so accommodating in rectifying home delivery errors a few years ago.

He feels communication from the CF service is good. His preference though would be for staff to email him rather than telephone him on sensitive CF medical matters whilst he is at work.

Good practice:

- "CF staff very caring and friendly."
- "General service at the CF centre very good."
- "Access to clinical trials is good."

Areas for improvement:

- "CF service should increase its focus on psychological support."
- "Increase home visiting by CF team members, to reduce hospital visits when I'm stable – e.g. port flushes, Tobramycin levels checked."
- "Provide more information/keep patients more up to date on what treatments/equipment are available – e.g. nebuliser technology."

Patient F has significant learning difficulties, in addition to her cystic fibrosis. Her carer explained this young adult's experience in accessing the CF service at RVI. Segregation was described as "fine; it works and does its job." Patient F's foster carer felt some decisions are made by the CF team rather than as joint team/patient decisions, adding "sometimes consultants think they know better." Foster mother felt the CF team do not cope well with her child's learning difficulties and she desperately needs to see a clinical psychologist. She has been asking for this but nothing has been forthcoming and from 13 January, 2015 foster mother explained no social worker support will be provided. A health nurse will deal with the learning difficulties.

Foster mother felt she and her foster child had had no support, whatsoever from the CNS, apart from to have a port flush, after what she described as "fantastic support" from the paediatric CNS as a child. She summed it up, as follows: "C. was well managed in paediatrics, but post transition has been a nightmare."

Parent F felt the hospital pharmacy experience was "straight forward; receive the prescription in minutes." She picks up the nebulised Tobramycin from hospital; the rest of the medications from the GP, with whom she has a good relationship.

Home care: No home IVs. The physiotherapist makes home visits to teach Parent F's foster child physiotherapy techniques and check spirometry, on foster mother's request.

Inpatient care: Foster parent described ward staff's understanding of CF as adequate, but with minimal understanding of her foster child's learning difficulties. She felt staff are horrified by her child's learning difficulties. She described struggling to get a physio to see her child and struggles around her routine. Foster parent has printed out a rota for the ward team to follow and phones each day to see her child has received physiotherapy. Foster mother carries out evening physiotherapy, ensuring that the physio carries out morning physiotherapy.

Foster mother described the difficulties her foster child has with the hospital menu – the same meal being ticked each night due to lack of help, she felt, in filling in the menu preferences. Her child does not eat the sandwiches provided on the ward and mother described the ward menu as "a nightmare."

Patient F has not had a diabetes assessment in a year as her scheduled assessment was postponed due to inpatient treatment and a rescheduled appointment yet to be given. She has a port flush every six weeks. Mother felt hand hygiene and wiping down of equipment between patients was good, both at outpatient clinic and on the ward.

Annual review: Patient F is offered annual review each year. Her last annual review was last autumn. She sees all of the CF MDT at annual review, with the exception of any psychosocial support. She does not receive a letter to report outcomes of annual review specifically, but receives a letter after each routine outpatient appointment. The CF team contact Patient F/her carer if there is an urgent message relating to her treatments, although foster mother will phone the CF team if her daughter develops a chest infection. All her annual review assessments take place at the RVI, except for the DEXA scan and hearing tests which are conducted at the Freeman Hospital.

Good practice:

- "CF service is flexible in providing outpatient appointments."
- "CF team are easy to contact."

Areas for improvement:

- "CF team need to treat my foster child more holistically."
- "There need to be more distractions and entertainment options for inpatients on the ward, staying in for two weeks minimum at a time."
- "Would be helpful to provide some kind of hospital transport for patients with learning difficulties. She is vulnerable and breathless travelling across Newcastle by public transport."

Peer review day patient interview

Patient G

Thirty-six-year-old male patient. He was admitted thirteen days ago. He was assessed last September and has been on the transplant list since January 2015.

Patient G lives with his wife and five-year-old child. They live approximately a twenty minute drive from the hospital and his wife usually drives him in and visits him daily. Parking is sometimes ok depending on the time of day.

Areas of excellence:

- Staff keep him well informed.
- Has good contact with the team and knows them well.
- Free TV.

Areas for improvement:

- Wi-Fi would be beneficial to bring up to date.
- Food could be better, there are plans in place for improvement. He would like more variety as he is admitted every four weeks for a two week stay, for which he orders off the ward trolley.
- Brings in own food. It would be easier if he had a fridge in his room to access whenever he wanted.

Patient H

Twenty-six-year-old male. He is admitted once every three months for IVs although he is trying to manage these more in his own home. He lives a good distance away (in Sunderland) from the hospital so unfortunately doesn't receive many visitors. When he does have visitors they struggle to park and often find alternative parking outside of the hospital grounds.

- The TV service is free. Food is ok, as is the portion size. Access to extra snacks is available all day – sandwiches, coke, crisps etc.

Areas of excellence:

- Always admitted quickly – never has to wait more than one-and-a-half days for a bed.
- Medical staff quickly learn the preferred routine of the patient.
- Receives physiotherapy input up to three times a day.

Areas for improvement:

- Internet is expensive - £12 per week. Lack of free internet access is disappointing.
- Physiotherapists not visible at weekends.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Royal Victoria Infirmary (Adults)
	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 directed to the clinic room and the team rotate between rooms.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height can be measured in the lung function lab. Weight in clinic room.
Where are the lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	Yes	Nine clinic rooms used with further rooms available if required. All rooms are purpose built, bright and modern. All rooms can be negative pressure.
For annual review patients, are any distractions provided?	N/A	Reading material available. Patients will bring in own distractions if required.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	No	Once transitioned patients will receive details for adults.

Additional comments

Approximately 280 patients, 270 and fourteen currently transitioning.

Three clinics, held on Monday, Wednesday and Friday, one of which is an evening clinic. Clinics are segregated depending on microbiology. Patients are segregated and seen at different clinics for *Pseudomonas*, *non-Pseudomonas* and *M.Abscessus*, who are seen at end of clinic. All rooms are not reused after complex microbiology attendance and are 'Chlor' cleaned nightly. The lung function lab is located near to the clinic.

Environmental walkthrough: ward

Ward name: 52 (CF Unit is in an annex to ward 52)

Microbiology status: General Respiratory

		Hospital name	Royal Victoria Infirmary, Newcastle Adults
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		6	Also use of five further cubicles in ward 52 and three cubicles in ward 51 if required.
Do the en suites have:	**Toilets?**	6	
	Wash basins?	6	
	Bath or shower?	6	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Each cubicle has a lockable cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free on CF unit. Wall mounted TVs.
If no, are there any concessions for CF patients?			If a patient were admitted to ward 52, free use of TV service can be arranged.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Reclining chairs in cubicles.
Visiting hours – are there allowances for CF patients' families out of normal hours?		Yes	Open hours for CF patients.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	No fridges in the cubicles, patients have the use of the fridge and microwave in the ward kitchen, however they are not allowed access and have to rely on the team.
What facilities are provided for teenagers?			Wii-Fit use in cubicle, patients usually bring in own IT. Patients are also central to the town and are free to go out.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Wii-Fit, bikes, hand weights, kettle bells for use in cubicle. Also can have use of pulmonary rehab gym which has two treadmills, two bikes, trampette and hand weights, however this can be difficult to book a slot.
What facilities are there to help with school and further studies?	None	Patients can go to college or University in between treatments.
Is there a relatives' room?	No	There is use of one small counselling room, alternatively can go to one of the multiple cafes.
What internet access is there?	None	Patients can bring in own dongles as this is cheaper than paying for the hospital internet.
What facilities are there to enable students to continue to work and study?	None	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Can clean parts in sink but no facility to sterilise.
What facilities are provided for those with MRSA?		Strict infection control, isolation and barrier nursed.
What facilities are provided for those with *B. cepacia*?		Patients would be admitted to 52/51 wards. Strict infection control, isolation and barrier nursed.
What facilities are provided for those with other complex microbiology?		Patients would be admitted to 52/51 wards. Strict infection control, isolation and barrier nursed.
Are patient information leaflets readily available on ward?	Yes	General leaflets available, Cystic Fibrosis Trust leaflets and fact sheets can be requested from team.
Transition patients – can they get a tour of ward facilities?	Yes	Tour would be offered in latter part of transitioning process.

Additional comments

Situated in Leazes Wing on level six and can be accessed via lifts. The CF unit was opened in 2011 and is situated in an annex off ward 52.

Environmental walkthrough: Other

	Hospital name	Royal Victoria Infirmary, Newcastle Adults
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	No formal concession, the team can contact the porters who can waiver the charge.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	General signage, the chest and CF clinic are not clearly descriptive.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?		Radiology – Large waiting area. DEXA – patients attend the Freeman hospital. Pharmacy - there are many areas and coffee shops to sit and wait away from the pharmacy counters if needed.
Do patients have to wait at pharmacy for prescriptions?		Patient's relatives and MDT take the prescriptions to pharmacy for collection on way out from appointment. There is also a good supply of general drugs kept at the clinic for dispensing to patients.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Large office situated near to outpatient clinic entrance.
Are there patient comment/ feedback boxes?	Yes	Various surveys conducted throughout the year (transition project survey, physiotherapy) Friends and family survey/comment machines located around the hospital Patient feedback machine in outpatients.

Appendix 7

Panel members

Dr Joanna Whitehouse*	Consultant	Birmingham Heartlands Hospital
Patrick Wilson	CF Specialist Pharmacist	Glenfield Hospital, Leicester
Rachel Massey-Chase	CF Specialist Clinical Psychologist	Kings College Hospital
Lisa Priestley	CF Clinical Nurse Specialist	Churchill Hospital, Oxford
Janet Roberts	CF Specialist Dietitian	University Hospital, Manchester
Nicola Mills	CF Specialist Physiotherapist	Glenfield Hospital, Leicester
Sue Fenemore	CF Social Worker	Southampton General Hospital
Peter Dixon	Commissioning	Cumbria Northumberland T&W
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	Quality Assurance and Control Manager	Cystic Fibrosis Trust

*Clinical lead

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