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Peer review report

Southampton and Poole, Wessex Adult CF Service

20 March 2014

6. Appendices

1. Executive summary

1.1 Overview of the service

The Wessex Adult Cystic Fibrosis (CF) Service at Southampton and Poole cares for 226 adults. To date, the service at Poole (37 patients) has been supported by the specialist CF service in Southampton (189 patients) under a shared care arrangement. There is a skilled and dedicated multidisciplinary team (MDT) on both sites with a commitment to delivering high-quality care. Having taken into consideration local geography, predicted growth and economic factors, the two services have recently taken the decision to merge to become one centre, the Wessex Adult CF Centre, with care delivered by one team across the two hospital sites. There is clear engagement with the hospital management teams and commissioners to develop this innovative model of care, which will provide the opportunity to maximise resource and expertise across the merged service. While this peer review has assessed both sites independently, the recommendations from this review are based on the proposed 'one centre on two sites' model of care.

1.2 Good practice examples

1. Experienced and dedicated MDT committed to providing high-quality care on both sites. Regular joint clinics with specialists in diabetes, gastroenterology, rheumatology and liver at the Southampton site are a particular strength.
2. Commitment from senior clinicians and management to deliver a new, innovative model of care – one service delivered across two hospital sites.
3. A strong research infrastructure and a commitment to enrolment in clinical trials.

1.3 Key recommendations

- Develop a formal implementation plan, which will include a full risk assessment, to share with commissioners within six months from the date of peer review, detailing how the merged service will deliver the full service specification across both hospital sites.
- Formalise the governance and financial infrastructure for the merged service to address the complexities of joint working across two acute hospital trusts.
- Develop shared protocols and pathways for all aspects of service provision and clinical care to ensure equity of care and service delivery across both sites.
- Invest in IT infrastructure to support the merged service and ensure seamless access to patient records across both hospital sites.
- Review seniority and leadership in all multidisciplinary groups and consider the appointment of a service lead for each discipline. Review cross-cover arrangements and competency assessment for all disciplines in the MDT with sufficient frequency to ensure:
  - all members of the team on both sites are able to maintain the necessary skills to manage the complexities of adult CF care; and
  - adequate cover is available to meet the service specification on both sites at all times.

The panel recommends a follow-up review within two years following the implementation of the new 'one centre on two sites' model of care.

1.4 Areas for further consideration

- Provide information for all patients detailing the proposed changes to the service.
- Perform a review of external contracts, for example home IV antibiotics and enteral tube feeding, tailored to the needs of patients with cystic fibrosis to ensure equity of access across the merged service.
- Implement an infection control policy for the merged service, which will include:
  - a restructure of outpatient clinics at the Southampton site to ensure appropriate clinic segregation; and
  - regular monitoring for cross-infection and surveillance by molecular typing at the Poole site.
- Consider the appointment of a service manager to support the strategic, operational and financial management of the merged service across two sites.
- Continue to work with commissioners to develop and refine the long-term service strategy.
- Consider innovative ways of working across both sites to minimise the impact of geographical distance, for example, video linking for MDT meetings and joint specialty clinics.

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

2.1 Models of care

Summary

The teams at both hospital sites are currently able to meet the Cystic Fibrosis Trust's Standards of Care. There is a clear system in place for annual reviews with access to all members of the MDT at both sites, and consultant-led feedback to patients. Data is currently presented separately for each service on the UK CF Registry, but in future will be captured for the merged Wessex Adult CF Service.

2.2 Multidisciplinary care

Summary

There is an experienced and dedicated MDT at both hospital sites. However, lack of critical mass at the Poole site and a less complex case mix raises concerns about maintaining the necessary skills to recognise and manage the complications of cystic fibrosis. The introduction of cross-site working for all disciplines and shared pathways and protocols will ensure the team is able to provide a safe and equitable service across the two sites.

2.3 Principles of care

Summary

Both services have high standards of infection control for inpatient care. Outpatient clinics at Poole are segregated according to sputum microbiology. At the Southampton site, clinics are not currently segregated according to sputum microbiology – however, there is no communal waiting area and patients are isolated in individual rooms. A separate room is used for patients with Meticillin-resistant *staphylococcus aureus* (MRSA) or *Burkholderia cepacia complex* (Bcc). Molecular microbiological surveillance is ongoing.

Revision of the infection control policy for the merged service is in process and will need to demonstrate compliance with section 4.1 of the Cystic Fibrosis Trust's Standards of Care and include new guidance on non-tuberculous mycobacteria.

2.4 Delivery of care

Summary

The MDT delivers high-quality care to patients across both sites and the service is rated highly by its users.

The number of patients with chronic pseudomonas on regular nebulised anti-pseudomonal antibiotics appeared low in 2012 UK CF Registry data across both services. However, further review using 2013 data demonstrates that all eligible patients are assessed and prescribed nebulised antibiotics appropriately.

There are some inconsistencies in access to full MDT review across the two sites, eg only 64% of patients were reviewed in clinic by a physiotherapist in Southampton. A review of staffing across the merged service for each discipline will be necessary to ensure the merged team is able to deliver all aspects of the service specification at both sites at all times.

2.5 Commissioning

Summary

The Wessex Adult CF Service demonstrates a real commitment to the delivery of high-quality services for people with cystic fibrosis throughout the region. Significant thought has gone into models for the delivery of care and the team proved keen to develop the model of a single centre with two delivery hubs at Southampton and Poole. In order to advance and prove this model, the service will need to ensure:

1. Self-assessment against the full Cystic Fibrosis Service Specification across the whole of the service, including at the Poole hub, within three months of the peer review. This is to be shared with local commissioners and any required derogations agreed.

2. Development and formalisation of the proposed service model within six months of the peer review, to include:

- patient information and engagement, including concerns regarding parking and food provision;
- centre management, including access to beds;
- paediatric transition;
- data capture and sharing via proposed IT model;
- governance arrangements to cover employees of foundation trusts working in other organisations and joint working arrangements, including out-of-hours cover across the two locations;
- access to services without full geographic coverage, eg Healthcare at Home and equitable access to other specialties when clinically required;
- financial congruence between the two foundation trusts;
- monitoring of patient numbers and activity as the joint service evolves, recognising that the pace of growth at Poole is unlikely to be sustained;
- access to research and trials; and
- senior management support.

There are many strengths to the service, including a rigorous approach to complaints and incidents and excellent engagement of staff and managers across all disciplines.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	177

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and Median (range) FEV_1% pred by age range and sex	16–19 years	(11) 63.48% (27.11–99.55)	(7) 48.28% (23.93–125.34)
		20–23 years	(12) 73.27% (32.92–92.3)	(24) 69.94% (20.19–106.46)
		24–27 years	(20) 72.98% (14.71–100.32)	(22) 73.11% (29.52–117.7)
		28–31 years	(12) 54.63% (18.88–105.44)	(15) 68.72% (29.1–103.6)
		32–35 years	(7) 76.29% (27.53%–95.9)	(4) 88.48% (73.48–91.8)
		36–39 years	(5) 76.31% (41.9–103.45)	(5) 44.91% (24.41–103.04)
		40–44 years	(5) 53.64% (23.86–102.33)	(7) 92.82% (53.09–117.36)
		45–49 years	(3) 69.07% (25.63–97.65)	(3) 65.48% (50.87–90.5)
		50+ years	(9) 48.38% (25.53–103.92)	(6) 87% (35.31–111.42)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	31 (37%)	36 (39%)
	Number of patients and % with BMI <19 split by sex	16 (19%)	20 (22%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	24 (53%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	21 (88%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	79 (45%)
	Number and % of patients on chronic macrolide without chronic PA infection	34 (19%)

4. Delivery against professional standards/guidelines not already assessed

4.1 Consultants

There are three consultants based at Southampton (2.1 whole time equivalent – WTE) and one consultant based at Poole (0.5 WTE). All four consultants also have a commitment to general respiratory medicine, and the pressure of general respiratory work limits the amount of time all consultants have available for cystic fibrosis work, particularly at the Poole site. Two additional programmed activities (PA) of consultant time are currently provided in Southampton to support clinics. Funding for an additional consultant with an interest in cystic fibrosis at Southampton has been approved but, despite advertising, it has not been possible to recruit for this post to date.

All consultants have considerable experience with cystic fibrosis and are highly committed to the service. They attend national and international meetings with representation at the centre directors meeting annually. There is a clearly defined clinical lead role for the service and a cohesive and collegiate approach to both service delivery and service development. To maintain clinical expertise and support service development, the consultant from Poole attends Southampton for one day each fortnight, covering both inpatient and outpatient work. Since summer 2013, a reciprocal cross-cover arrangement by one of the Southampton consultants has been in place at Poole. In addition, a consultant from Southampton attends Poole for annual review report writing and feedback one day each month. There is sufficient capacity at Southampton to cover annual leave and study leave but, other than the two days per month of consultant input from Southampton, there is no prospective consultant cover for leave in Poole. The consultants and MDT at Southampton provide an outreach clinic at Salisbury District Hospital once a month.

There is adequate junior doctor support for the service at the Poole site. However, there is very limited support at Southampton. There are no junior doctors (F1 or SHO grade) allocated to the CF team and the rotational specialist registrar is only available around 60% of the time due to commitments to general medical services. A staff grade was appointed but is on long-term sick leave and locum cover has been intermittent. As a result, the consultants are spending significant amounts of time undertaking duties normally performed by more junior members of the medical team or by specialist nurses. This is an inappropriate use of their expertise and places an extremely heavy burden on the consultant team. In addition, the lack of a ward-based medical team raises potential concerns for patient safety. Consultant out-of-hours cover is provided by a respiratory on-call rota.

There are consultant ward rounds three days a week at both sites and a daily MDT meeting each morning at Southampton. Joint clinics with specialists from other disciplines (gastroenterology, rheumatology, diabetes and liver) are run at the Southampton site and accessed by patients from Poole, as necessary. There are regular transition clinics and a close working relationship with the paediatric service.

There is a strong research infrastructure in Southampton, with a commitment to participation in clinical trials.

Areas of good practice

- Experienced and dedicated consultant team.
- Clear commitment to the proposed merger, with evidence of regular cross-site working at a frequency adequate for maintaining clinical expertise and supporting the service at both sites.

Areas for improvement/recommendations

- There is an urgent need to address the shortfall in junior medical support at the Southampton site.
- Additional consultant support is required at the Poole site. Consideration should be given to appointing a second consultant with an interest in cystic fibrosis at Poole, or to a cross-site appointment dedicated to cystic fibrosis.
- Review consultant staffing to ensure that there is prospective consultant cover for annual leave and study leave at both sites.

4.2 Specialist nursing

The clinical nurse specialist (CNS) teams at both sites are extremely hard-working, caring and dedicated to looking after patients with cystic fibrosis. There are 4.23 WTE CNS for 226 patients (3.5 at Southampton and 0.73 at Poole). Funding has been agreed for another 1.0 WTE CNS for cystic fibrosis at Poole.

A CNS is present on ward rounds and at the MDT meeting at both sites. All CNS are members of the Cystic Fibrosis Nursing Association. All CNS have attended educational meetings and national and international conferences over the last two years.

The CNS team members cover each other for annual leave and sickness at their own sites, however, this can be difficult at times at the Poole site due to the volume of CNS time allocated to cystic fibrosis.

The CNS teams at both sites have not been involved in any research due to time constraints, but have carried out several audits. These include a diabetic and liver audit at Southampton and, recently, those at Poole have carried out an audit looking at inhaler technique in cystic fibrosis.

The CNS teams at both sites are involved in all aspects of care, including inpatient, outpatient, annual reviews, transition and palliative care. However, involvement in key life stages, including end of life and transplantation, is limited at the Poole site due to the number of patients and severity of cystic fibrosis. Home visits in Southampton have been limited, but with recent increase in CNS time, the team is hoping to develop more homecare for patients with cystic fibrosis. There are currently no home visits in Poole.

Areas of good practice

- Poole: Both CNS are nurse prescribers. The annual review service has been updated in the last six months and is now more structured.
- Southampton and Poole: The CNS team members feel that they work well together and communication is excellent with other members of the MDT. The CNS team leads on educating the wider hospital staff about cystic fibrosis by organising regular teaching sessions.

Areas for improvement/recommendations

- Cross-site cover. This will help to expand skills and knowledge so that care is consistent across both sites. It will also help with staff absence, particularly at Poole.
- Southampton and Poole are currently using different policies, guidelines and documentation. They need to work towards shared documentation.
- 35% of patients are diabetic. Consider appointment of a CF diabetes CNS to work across both sites.
- All patients having home IV antibiotics have to learn how to draw up and administer the drugs themselves. Teams need to look at using a homecare service with reconstituted IV antibiotics to increase quality of life and safety for all patients.

4.3 Physiotherapy

In total there are 5.75 WTE physiotherapists providing care to 226 patients across two hospital sites: Southampton (n=189) and Poole (n=37). This equates to 4.45 WTE in Southampton and 1.3 WTE in Poole. Therefore the Southampton site is relatively understaffed according to standards. There are also 12 hours of physiotherapy assistant time at Poole. Overall, staffing is in line with the standard recommendation of six WTE physiotherapists per 250 patients, but does not take into account the additional non-cystic fibrosis clinical responsibilities that staff are expected to deliver. Nor does it take into account that the physiotherapy team and services currently run independently and the complexities involved in merging staffing across two sites of care.

The static CF specialist physiotherapists (1.3 WTE Band 7 at Poole and currently 0.45 Band 8a at Southampton) demonstrate excellent clinical cystic fibrosis experience and knowledge. It is recognised that staffing at the Southampton site is currently unstable due to a high number of staff on maternity leave. Taking this into account, there remains concern that the overall level of seniority of the physiotherapy team is inadequate to provide the specialist knowledge and skills required to allow for teaching and further service development.

The physiotherapy teams at both sites show a good commitment to further education and maintenance of their specialist skills, attending relevant specialist interest group meetings, conferences and educational courses. There is a good commitment to audit of the service, with a robust audit cycle against the Cystic Fibrosis Trust's Standards of Care, and the lead physiotherapist at Poole is involved in a research project into the management of cystic fibrosis sinus disease. The teams at both sites expressed an interest in participating in more research and service development. But, understandably, they are unable to prioritise this until the team is meeting all the Cystic Fibrosis Trust's Standards of Care and they have demonstrated that the merged service is fully operational.

There are inconsistencies across the two sites with regard to the physiotherapy input required to meet the standards of care. At the Southampton site, all inpatients are reviewed twice a day during the week and 94–97% of patients are offered exercise appropriately. On average, only 64% (range 16–89%) of patients were reviewed in clinic by a cystic fibrosis-specialist physiotherapist. In an audit of annual reviews, on average 54% of patients received a physiotherapy annual review within three months of their annual review date, and encouragingly this figure was showing improvement up to 81% at the end of the audit period (January–June 2012). At the Poole site, 79% of inpatients receive twice-daily airway clearance (although this lower percentage may be explained by patient choice) and all patients have access to appropriate exercise sessions as an inpatient. 100% of all clinic and annual review patients are reviewed by a CF specialist physiotherapist. Physiotherapy is fully integrated into the CF MDT at both sites and provides full representation at MDT meetings/ward rounds. The Cystic Fibrosis Trust's Standards of Care on providing physiotherapy at the weekend are not met at either site. Weekend physiotherapy is provided by the general respiratory weekend team at both sites and patients are prioritised against all other patients in the hospital requiring weekend physiotherapy. At Southampton, 28% of patients are put on the physiotherapy weekend list, of which 17% are seen twice daily. At Poole, 67% of patients receive assistance with physiotherapy at the weekends once a day and 8% twice a day.

Areas of good practice

- Highly skilled and committed physiotherapy teams at both sites, with a commitment to further education and representation at specialist meetings.
- Personalised and flexible approach to patient-centred care, particularly when reviewing outpatients at the Poole site.
- Robust audit process at the Southampton site.
- Commitment to a robust system of training physiotherapy staff – competency-based skills pro forma used at the Southampton site.

Areas for improvement/recommendations

- Review how staffing structure and cross-cover will work to ensure a consistent service is delivered across both sites. Consider the need for an overall physiotherapy clinical lead for both sites and a process for staffing cover in absence, particularly at the Poole site.
- Review the number of posts, level of seniority and protection of physiotherapy staff at the Southampton site.
- Urgently consider additional funding for weekend physiotherapy service at both sites.

4.4 Dietetics

In total there are 2.4 WTE dietitians providing nutritional care to 226 patients across the two hospital sites. Additionally, 0.9 WTE hours have been appointed, which will take the staffing to 3.3 WTE for the two sites. Currently, this equates to 1.9 WTE in Southampton and 0.5 WTE in Poole. Therefore both sites are well staffed, as recommendations would be 1.26 WTE for Southampton and 0.25 WTE for Poole. It is perhaps of concern that the WTE hours are made up of a number of dietitians (currently three dietitians form 1.9 WTE and two dietitians make up 0.5 WTE), all working part-time, with the 0.2 WTE the minimum contact (in Poole) and 0.8 WTE the maximum (in Southampton). At present the dietetic team and services run independently and there will be time considerations and complexities involved in merging the staffing across two sites, especially for the 0.2 and 0.3 WTE posts in Poole.

The dietetic team at the Southampton site vary in experience from three to 13 years, but all are currently part-time. The dietitians at Poole vary in experience from one to eight years, but both work part-time on cystic fibrosis. There is not currently a unified service at both sites and a Dietetic Clinical Lead should be identified to take this unified service forward. There are also concerns that 0.2 WTE Band 6 dietetic hours are insufficient to obtain adequate exposure to a critical mass of adult patients required to become a cystic fibrosis specialist.

The dietetic team shows commitment to continuing professional development. All the dietitians working in cystic fibrosis are members of the UK Dietitians Cystic Fibrosis Interest Group. The dietitians at Poole attend one meeting a year and the Southampton dietitians tend to alternate their attendance with their paediatric colleagues, and then feedback. The dietitians at Southampton have attended the European Cystic Fibrosis Conference and one of the dietitians at Poole has attended the conference, though funding is becoming more difficult each year. The dietitians at Southampton are active in audit and research, though less so recently due to time constraints. The dietitian at Poole reported that she participated in audit, but no evidence was submitted.

The Southampton dietitians provide an excellent level of inpatient cover, with 96% of patients reviewed at least twice a week. They have prioritised the inpatient workload and, as a consequence, they were only available at 36% of cystic fibrosis outpatient clinics. This will be addressed by the new funding. However, they have prioritised input into their specialist cystic fibrosis-related diabetes (CFRD), bone and gastroenterology clinics. They attend the MDT but do not go on the ward round. They are also able to provide partial cover for each other (internally) when colleagues are on annual leave. The dietitians at Poole are available at 98% of outpatient clinics and attend three ward rounds each week. They reported that only 11% of inpatients were reviewed a minimum of twice weekly, though this was highlighted as a documentation issue. There are only 0.5 WTE dietetic hours, so they can only provide emergency cover (from the paediatric CF dietitian) at times of annual leave.

There are discrepancies between the services with regard to a number of management issues that will need addressing if an equitable and unified service is to be provided. The patients at Poole do not attend a CFRD clinic, which is essential. There are also issues with the bone mineral density (DEXA) scanning of paediatric patients in Poole, which means many patients who transition have

never had a DEXA scan.

Areas of good practice

- Dedicated team committed to continuing professional development, attending meetings and sharing knowledge.
- Innovative review process for patients with a low body mass index (BMI) in Southampton.
- Constantly evolving care to meet the needs of the changing population, with strong dietetic representation in specialist clinics, eg bone, gastroenterology and CFRD in Southampton.

Areas for improvement/recommendations

- Review dietetic staffing structure, identify an appropriately banded clinical lead and clearly define how cross-cover will work to ensure equity of service across both sites.
- Develop joint protocols and effective methods of communication due to the number of part-time staff providing the service. This may involve investment in a joint infrastructure.
- Promote a unified and equitable service, eg Poole patients should attend the Southampton CFRD clinic.

4.5 Pharmacy

There are 226 patients in total across the two sites. Pharmacy cover is 1.2 WTE, with 1 WTE at Southampton and 0.2 WTE at Poole. There is no cross-cover. This leaves a slight shortfall of about 0.3 WTE at the Poole site, based on numbers recommended in the Cystic Fibrosis Trust's Standards of Care. Ward cover is provided in their absence by non-CF specialist pharmacists. The pharmacist in Southampton is sometimes utilised to provide cover to non-CF wards. This is variable but can have a significant negative impact on the service to patients with cystic fibrosis. Both pharmacists are well supported by their managers and time above the 0.2 WTE at Poole is sometimes given when required.

There is no medicine management technician support for the service, however, a bid has been written and will be put forward in the near future. This will free up significant pharmacist time and result in a more effective service. The usual departmental services are provided, eg out-of-hours advice, medicines information, and Southampton hospital receives an excellent compounding service from pharmacy aseptics. There is no compounding service provided to outpatients. Patients are trained to reconstitute and self-administer IV antibiotics. A competency assessment is carried out on all patients who do this. Where this is not possible, home IV antibiotics are administered by non-CF specialist nurses who reconstitute and administer IVs. This is available to patients on twice-daily regimes who live in Hampshire. A homecare service for compounding and delivering antibiotics may make this available to more patients and lessen the impact of IV courses on patients.

The service is provided by two enthusiastic pharmacists who demonstrate a clear desire to develop the service to the CF centre. The pharmacist at Poole is currently a prescriber, and Southampton is applying for this. This should be utilised to develop their roles. They have attended regional educational meetings and the pharmacist in Southampton has attended the North American Cystic Fibrosis Conference, the Cystic Fibrosis Pharmacists Group (CFPG) study days and intends to attend the European Cystic Fibrosis Conference. The pharmacist in Poole will attend CFPG study days in future and other educational opportunities should be explored. Both are members of the CFPG and have access to the email forum.

Cross-site working has been limited, which has led to a variation in practice between the sites, eg in aminoglycoside policy. In future, the pharmacists intend to work more closely to develop standards across the service and more efficient working. The repatriation of high-cost drugs to secondary care is underway and is likely to have a significant impact on the service. A homecare pharmacist is due to be appointed at Poole and this role should be utilised to minimise the impact on the CF pharmacist's workload. Additional pharmacy support is likely to be required to facilitate

this and provide an efficient and timely service to patients.

The pharmacists are well integrated into the teams and participate in MDT meetings and consultant ward rounds where possible (this can sometimes be difficult at Poole due to the timing of the round). They provide access to a pharmacist for clinic, if requested. The pharmacists attend annual reviews. None of these activities are covered when pharmacists away.

An analysis of Ivacaftor use has been carried out and presented by the Southampton pharmacist.

The pharmacists have limited time to develop a more advanced role due to work pressures. This is likely to become worse, particularly as the repatriation of nebs is due soon. The pharmacists are eager to develop activities such as guideline development, financial reporting, audit, formulary applications and funding issues. Monitoring high-cost drug prescribing is essential to ensure prescribing is in line with national commissioning frameworks. As these roles develop, thought should be given to the current grading of the posts. The split sites also present challenges, with cover between sites not a realistic option. It is therefore important to provide similar services and expertise, which may be harder to maintain at the smaller site. Closer working is therefore essential.

Areas of good practice

- Service provided by enthusiastic pharmacists who show a commitment to the service, their educational development and a desire to develop a more advanced role.
- Pharmacists are well integrated into the team and participate in ward rounds, MDT meetings and annual reviews.
- Pharmacy aseptics provide an excellent compounding service to the Southampton ward, freeing up significant nursing time on the ward.

Areas for improvement/recommendations

- Work pressures limit the availability of pharmacists to develop a more advanced clinical role. A review of the staffing levels is required and support is needed to prevent the specialist pharmacists from being used in other clinical areas. The appointment of a Medicines Management Technician will help this. As the roles develop, a review of the posts' grading should be considered.
- Review and develop unified guidelines and policies for both sites. Close working between the sites is essential in order to develop an integrated service.
- A review of the homecare service is required to ensure IV antibiotics at home are available to all patients in the single service. The homecare service should be tailored to the needs of the CF patients.

4.6 Psychology

Staffing: There is a total of 0.9 WTE, significantly lower than the approximately 1.5 WTE recommended for a centre of this size. The psychology service is contracted under different agreements from separate trusts for the Southampton and Poole sites, so that 0.8 WTE (0.7 WTE Band 8c and 0.1 WTE Band 7) is provided for Southampton, and 0.1 WTE (Band 8d) for Poole. At Southampton, the service is provided by two psychologists, ensuring continuity of service. In both locations, the psychologists are part of clinical health psychology departments, so there is potential for cover during longer absences. All psychologists are registered with the Health and Care Professionals Council. Two are active members of the UK Psychosocial Professionals in Cystic Fibrosis Group (UKPP-CF), and the third is in the process of joining. One psychologist has attended a European Cystic Fibrosis Conference.

Areas of good practice

- The psychology service on both sites meets standards for seeing all referred patients and providing psychology input to annual reviews. This is commendable given the shortfall in staffing compared to recommended levels.
- Using creative approaches (eg student projects, well-qualified volunteers) to augment psychology research and audit activity.

Areas for improvement

- Current staffing levels mean that psychology provision has to focus on meeting referral targets. There is limited scope for other activity and training/consultation skills available within psychology are underutilised.
- Purchasing and staffing arrangements mean that travelling time, organisational issues and working patterns limit the scope for joint/cross-site working.

Recommendations

- Staffing should be increased in line with standards, to enable the psychologists to continue to meet future targets and make better use of the psychological expertise available.
- Plans for staffing should take account of the needs of the service as a whole and consider development of closer working practices, shared protocols, etc. It is of note that the psychologists are willing to engage in this process and welcome open discussion of all possibilities.

4.7 Social work

For the purposes of this report, the Southampton service includes the clinic based at Poole as the service is commissioned and funded as a single service.

The Southampton service has two CF social workers at 0.8 WTE each, resulting in 1.6 WTE for the 189 patients based at Southampton. Poole has 0.2 WTE CF social workers for 37 patients – a total of 1.8 WTE social workers for 226 patients across the whole service. This is largely in line with staffing recommendations.

Areas of good practice

- The three social workers have a range of experience, skills and interests, which enhances the service. They are generally able to provide cover for annual leave and short-term sickness.
- All three social workers are qualified and members of UKPP-CF and receive appropriate training and support in cystic fibrosis and social work issues. They are all employed by different agencies, so the support and supervision arrangements differ. They fulfil a unique role within their agencies and have established meetings with CF social workers based at nearby centres several times a year. This provides support and learning opportunities.
- The social workers are able to perform home visits, and the information obtained from these visits is valued by the team – particularly with regard to new patients who are transitioning to the service. Transition is an area that all three social workers have an interest in.

Areas for improvement/recommendations

- All three social workers have different employers and therefore different agency requirements, especially around recording information. In order to move to a more integrated service between the two sites, consideration will need to be given to access to notes and the recording of social work information. Currently, only one of the three social workers routinely makes records in the medical notes, and this would appear to be the most logical place to record a summary of involvement. Consideration should also be given to recording and accessing confidential information.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	2	5	6	7	5	2
Female	3	2	19	5	3	4	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	48	15	1	1
From the ward staff	30	14	3	1
From the hospital	25	26	6	2

Areas of excellence

1 Accessibility of CF team

2 Outpatient and inpatient infection control

3 Outpatient cleanliness

Areas for improvement

1 Inpatient waiting times

2 Ward – food

3 Outpatient waiting times

6. Appendices

Appendix 1

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

Report and actual compliance below follows a Red, Amber, 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

University Hospital Southampton

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% patients seen at least once a year by the specialist centre for an annual review	90%	Green	Green	
1.2 Specialist centre care	% of patients with completed data on the UK CF Registry	90%	Green	Green	
1.3 Network clinics	% of patients who have had a discussion with the consultant and an action plan following annual review	90%	Green	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)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	No, we do not meet the full service	The team provides a safe service, but due to staffing levels in some disciplines, it is not currently able to fulfil all aspects of the service specification.	
	% of MDT who receive an annual appraisal	100%	Amber	Amber	
	% of MDT who achieved their Professional Development Profile (PDP) in the previous 12 months	100%	Amber	Amber	
	% of MDT who have attended a CF educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Amber	Amber	

2.1 Multi-disciplinary care	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red. No pathways. However, joint clinics are run.	Green	The service has joint clinics, eg for diabetes, gastroenterology, and has clear links with all necessary disciplines.
	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	
	% patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red	Red	58% of patients with CFRD seen in the joint diabetes clinic. Review of process required to ensure all patients with CFRD are reviewed.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% patients cohorted to outpatient clinics according to microbiological status	100%	Red	Red	The service has an action plan to address this.

3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* in the previous 12 months	100%	Amber	Amber	An action plan and new process for results review has been introduced, which will address this.
	% 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%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

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

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
	% availability of clinical psychology at clinic	100%	Amber	Green	Patients are referred as needed. There is no significant delay for review and the psychologist is able to offer a responsive service to meet clinical needs.
	% availability of clinical psychology for inpatients	100%	Green	Green	
	% availability of social worker for at clinic	100%	Green	Green	
	% availability of social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Green	Green	Available on request.
	% availability of pharmacist for inpatients	100%	Green	Green	
4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	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%	2 (1.1%)	Green	The service has a rigorous approach to complaints.
5.2	Number of clinical incidents reported within the past 12 months	<1%	21	21 incidents reported	The service has a rigorous approach to incident reporting.
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service Level Agreements in place for all	100%	Red. In progress for care in Poole	Red	In progress as the service merges with Poole.

Appendix 2

Staffing levels (Adult)

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

	75 patients	150 patients	250 patients	University Hospital Southampton
Consultant 1	0.5	1	1	6 sessions
Consultant 2	0.3	0.5	1	5 sessions
Consultant 3			0.5	3.75 sessions
Staff grade/fellow	0.5	1	1	0.9 WTE
Specialist registrar	0.4	0.8	1	1.0 WTE
Specialist nurse	2	3	5	0.9 WTE
Specialist nurse				1 WTE
Specialist nurse				1 WTE
Specialist nurse				0.6 WTE
Physiotherapist	2	4	6	4.45 WTE
Dietitian	0.5	1	2	1.9 WTE
Clinical psychologist	0.5	1	2	0.8 WTE
Social worker	0.5	1	2	2 x 0.8 WTE
Pharmacist	0.5	1	1	1 WTE
Administrator				0.8 WTE
Secretary	0.5	1	2	1 WTE
Database coordinator	0.4	0.8	1	0.4 WTE

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

CF Registry data 2012	
Demographics of University Hospital Southampton	
Number of active patients (active being patients within the last two years) registered	181
Number of complete annual data sets taken from verified data set (used for production of the Annual Data Report 2012)	177
Median age in years of active patients	27
Number of deaths in reporting year	7
Median age at death in reporting year	40

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number in age categories	16–19 years	18
	20–23 years	36
	24–27 years	42
	28–31 years	27
	32–35 years	11
	36–39 years	10
	40–44 years	12
	45–49 years	6
	50+ years	15

Genetics	
Number of patients and % of unknown genetics	52 (29%)

Body Mass Index (BMI) (ref: 1.13 Annual Data Report 2012)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	31 (37%)	36 (39%)
Number of patients and % with BMI <19 split by sex	16 (19%)	20 (22%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	12 (75%)	11 (55%)

FEV_1 (ref:1.14 Annual Data Report 2012)			
		Male	Female
Median FEV_1% pred at age 16 years split by sex		0	0
Number and median (range) FEV_1 % pred by age range and sex	16–19 years	(11) 63.48% (27.11–99.55)	(7) 48.28% (23.93–125.34)
	20–23 years	(12) 73.27% (32.92–92.3)	(24) 69.94% (20.19–106.46)
	24–27 years	(20) 72.98% (14.71–100.32)	(22) 73.11% (29.52–117.7)
	28–31 years	(12) 54.63% (18.88–105.44)	(15) 68.72% (29.1–103.6)
	32–35 years	(7) 76.29% (27.53%–95.9)	(4) 88.48% (73.48–91.8)
	36–39 years	(5) 76.31% (41.9–103.45)	(5) 44.91% (24.41–103.04)
	40–44 years	(5) 53.64% (23.86–102.33)	(7) 92.82% (53.09–117.36)
	45–49 years	(3) 69.07% (25.63–97.65)	(3) 65.48% (50.87–90.5)
	50+ years	(9) 48.38% (25.53–103.92)	(6) 87% (35.31–111.42)

Lung Infection (ref 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	18
	20–23 years	36
	24–27 years	42
	28–31 years	27
	32–35 years	11
	36–39 years	10
	40–44 years	12
	45–49 years	6
	50+ years	15
Number of patients with chronic PA by age group	16–19 years	7
	20–23 years	19
	24–27 years	30
	28–31 years	16
	32–35 years	6
	36–39 years	6
	40–44 years	5
	45–49 years	3
	50+ years	9
***Burkholderia cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	4 (2%)	
Number and % of *cenocepacia*	2 (50%)	
Meticillin-resistant *staphylococcus aureus* (MRSA)		
Number and % of total cohort with chronic infection with MRSA	9 (5%)	
***Non–tuberculosis mycobacterium* (NTM)**		
Number and % of total cohort with chronic infection with NTM	13 (7%)	

Complication (ref 1.16 Annual Data Report 2012)	
ABPA (Allergic Bronchopulmonary Aspergillosis)	
Number and % total cohort identified in reporting year with ABPA	18 (10%
Cystic fibrosis-related diabetes (CFRD)	
Number and % total cohort requiring chronic insulin therapy	46 (26%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	24 (14%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	6 (3%) with PH 9 (5%) without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	15
Number of patients referred for transplantion assessment in previous three years	28
Number of patients receiving lung, liver, kidney transplants in last three years	6

IV therapy (ref:1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	224
	20–23 years	541
	24–27 years	564
	28–31 years	191
	32–35 years	165
	36–39 years	69
	40–44 years	234
	45–49 years	113
	50+ years	158
Number of days of home IV therapy in reporting year split by age group	16–19 years	188
	20–23 years	563
	24–27 years	453
	28–31 years	258
	32–35 years	45
	36–39 years	96
	40–44 years	160
	45–49 years	61
	50+ years	116
Total number of IV days split by age group	16–19 years	412
	20–23 years	1104
	24–27 years	1017
	28–31 years	449
	32–35 years	210
	36–39 years	165
	40–44 years	394
	45–49 years	174
	50+ years	274

Chronic DNase therapy (ref 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged >16 years FEV1, % predicted <85% (ie below normal) on DNase	(n=116) 74 (64%)
If not on DNase % on hypertonic saline	17 (15%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	101 (57%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	67 (66%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	79 (45%) with chronic PA 34 (19%) without chronic PA

Appendix 4

Patient survey

University Hospital Southampton

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	2	2	5	6	7	5	2
Female	3	2	19	5	3	4	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	42	20	1	2
Communication	34	25	5	1
Out-of-hours access	17	22	6	2
Homecare/community support	11	11	2	4

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	35	23	6	1
Waiting times	20	22	16	4
Cross-infection/segregation	43	14	2	0
Cleanliness	44	16	3	1
Annual review process	31	24	5	2
Transition	15	11	1	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	14	17	12	4
Cleanliness	29	16	1	1
Cross-infection/segregation	34	10	2	1
Food	4	9	20	12
Exercise	10	20	11	4

How would you rate:

	Excellent	Good	Fair	Poor
Home intravenous (IVs) antibiotic service	19	9	4	3
Availability of equipment	24	22	4	2
Car parking	1	16	25	14

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	48	15	1	1
Of the ward staff	30	14	3	1
Of the hospital	25	26	6	2

Comments about CF team/hospital

"Really good and always help me out and they are always at the end of the phone if need be."

"I cannot praise Southampton CF centre highly enough – very slick, good communicators, friendly. Can't thank them enough for the care they give!"

"CF outpatients is ok but as an inpatient it's awful. The wards are like cells. I found I got worse as an inpatient as I felt like I was in prison. Something needs to be done about the ward!"

"The CF team do an excellent job with what they have available to them. They have made many improvements over the past 15 years. I hope they continue to do so."

"Very happy with the care I receive compared with other hospitals."

"Salisbury team were very friendly and helpful."

"Later in the day appointments if coming from the Isle of Wight."

"Our CF team are very good and helpful. If I have a problem I just phone and they tell me to come on that day."

"Excellent and accessible team, get on well with all the Drs and CF nurses. Improvements in my opinion would be waiting times in clinic and waiting times for admission and the hospital food!"

"Appalling experience at Southampton from route to diagnosis, advising of diagnosis, care, communication and response to concerns. I now experience severe anxiety."

"Fantastic CF team: easy to get hold of, always help you fix any problems you have."

"My CF team have always been there for me whatever my issue/problem. The inpatient team were great and the outpatient team were always amazing. You could not ask for a better, more dedicated team and although I don't need to see them as much at the moment, I can hand on heart say I couldn't have got through everything without them."

"Hospital food needs to improve, especially for a CF with diabetes. Better than other hospitals but needs more choice. Great that there's a little kitchen, I can request toast, cereals and microwaveable items. Hospital needs to review its decisions about letting patients keep our own meds in room with us without us hiding them or fear of ward staff losing their jobs if they are caught letting us keep drugs in room."

"When I arrive for my outpatient appointments, I am quite often waiting around for an hour or more."

"They mostly do an excellent job, though I have encountered delays with information being cascaded down to me. On a few occasions waiting times have been prolonged. Car park charges excessive."

"Great people. Got me through when I was near death. Had double lung transplant, thanks to my CF team."

"I find they always have my best interests at heart and have helped me through some major life challenges. Thank you."

"Something needs to be done to the shower in the bathroom in hospital rooms as whenever use, shower curtain not long enough and bathroom and bedroom are flooded."

"Considering that there are nine individuals who make up the team for a CF patient, they do a pretty good job!"

"They are all wonderful."

"An excellent team – they do a fantastic job!"

"I am very happy with the team and feel that they are happy to review processes."

"The CF team at Southampton are wonderful caring people who put 110% into their job."

"The CF team are excellent, unfortunately let down by the very poor ward staff."

"Exceptionally well-run clinic with competent and friendly staff."

"The CF team are fabulous! They have been great right from the start."

"Could not wish for a better team of people to look after me."

"I am currently under shared care with Heartlands Hospital, Birmingham and so I do not use all Southampton services."

"Good team, very friendly and easy to talk to when I have needed to."

"Fantastic team and I am very lucky to have them look after me! Always organised, efficient and I enjoy my visits."

"Excellent communication throughout the whole team. They are very professional yet compassionate, I am very lucky to be under this team."

"We have at Southampton a very professional, caring and knowledgeable multidisciplinary team, who work very well together, but within the constraints and restrictions of a general ward. They desperately need their own unit and dedicated ward and facilities to improve patient care and build on the progress already made over the last few years."

"My team are very good and we all work together to make sure everyone is happy with the future plans. My ward is good but is old, needs modernising and to be CF only ward, as we share and not all our rooms can have a big TV, fridge and things to make hospital admissions better."

"Having gone through a difficult three years with my personal life, the CF team were always there for me."

"Too long waiting times for inpatient admissions. Car parking is ridiculous - cheaper to park in the city centre."

Appendix 5

Patient interviews

Patient C

Outpatient clinic

Patient goes straight into individual consultation rooms where weight, height and spirometry are carried out too.

MDT (using plastic gowns) rotate, so that patient remains in same consultancy room.

Decisions on treatments are discussed with patient, rather than dictated to patient. Patient knows when he needs IVs.

Prescriptions taken to pharmacy by nurse, so only a 20-minute wait at pharmacy, in large waiting area.

Annual review

Patient invited to annual review (AR) each year; this year's is next month. He sees/has access to each member of the MDT. All AR tests take place at Southampton Hospital, including 'in-depth' respiratory tests, exercise test (in gym), but separate diabetes clinic.

AR outcome is reported back to patient in AR report/letter (copy to GP).

Inpatient care

Can expect to be admitted within one to two days, always to own en suite side room with TV.

Ward staff are "pretty good". IVs and medications are "just about" given on time, with a bit of variance. The timings have not been a concern to the patient.

Patient feels there is a good gym on ward and can be given a bike for patient side room if needed. He feels the ward lacks some gym equipment though.

Patient feels catering is "pretty good", that "extras for CF patients are never a problem" and he rates the cooked breakfast "quite nice" and hospital menu "adequate".

Homecare

Patient used to mix home IVs himself, but more recently has had BUPA pre-mixed package delivered next day or following day with additional IV supply every six days. Administers his IVs via longline, with phone support from CF team. Patient has Tobramycin levels checked at CF centre, 20 minutes from his home.

Give three areas of good practice in your CF service, if you can:

- Availability of team (quick to ring back/can see at short notice).
- Knowledgeable team.

Give three areas for improvement in your CF service, if you can:

- To improve cleanliness of ward side room – cleaners are inconsistent/hygiene varies.
- To improve system for bed availability on day of admission – "seems that they can't get room cleaned quickly".

Patient G

Outpatient clinic

Patient directed straight to consultancy room on arrival at clinic. Height, weight and spirometry performed in this side room. MDT rotate to ensure patient stays in same consultancy room. All decisions on treatments discussed with patient.

Nurse delivers prescription to hospital pharmacy. Patient picks up medication at pharmacy with reduced delay.

Annual review

Patient's last AR was October 2013. Offered an AR each year and sees all of the MDT at the review. All AR tests take place at Southampton, while the liver scan is conducted on a separate occasion. Patient receives written report of AR outcome (with copy to GP) and outcome is discussed at next routine clinic.

Inpatient care

Patient has only needed one hospital admission; admitted same day at outpatient clinic review, "but waited all day for admission".

Patient was treated in an en suite side room and felt ward staff were "reasonably knowledgeable".

Patient received IVs and other medications on time. She wasn't sure about the availability of equipment on the ward (ie IV pumps, gym equipment, etc.), but was impressed by the "nice food", "big variety" on menu (20–30 choices) and "high cal. stuff".

Patient felt the staff on the ward were helpful.

Homecare

N/A – milder CF case.

Give three areas of good practice in your CF service, if you can:

- "The CF team know me – I'm not just a number."
- Cleanliness and hygiene standards at the CF centre (and isolation/cross-infection measures on the ward).
- Open-minded care (eg CF consultant's trial treatments) and patient treated as "the expert".

Give three areas for improvement in your CF service, if you can:

- To improve speed of admission/admission process.

Patient K

Outpatient clinic

Patient directed straight to consultancy side room on arrival at clinic. Her height, weight and spirometry are measured here. Patient remains in side room throughout clinic, while MDT rotates.

Decisions on treatments are discussed/negotiated more with this patient now. She'd had a previous clash with a doctor regarding patient involvement in decision-making.

Annual review

Patient last had AR at end of 2013. She is always offered an AR appointment. At AR, patient sees each of the MDT ("all of them want to see me, if only to touch base"), but might not see the psychologist. The psychologist always hands out a questionnaire at the AR.

All AR tests take place at Southampton. Patient's DEXA scan carried out during recent hospital admission.

Inpatient care

Patient doesn't find admission process quick – "It takes three to four days, even a week to get admitted".

She's always admitted to an on-site side room on C5 ward (shared with Infectious Diseases). Once she had to be admitted to another ward, but patient was concerned about infection risk and lack of nurses' knowledge away from C5. Patient hopes TB/MRSA cases will be transferred to new isolation unit.

Patient feels IVs and medications are given on time and that ward staff will notify her if there's any delay over 10 minutes. She feels nurses are good at catching up for lost time in IV schedule and accommodating weekend temporary discharges by adjusting IV timings.

Patient is offered exercise equipment on the ward. She isn't aware of a lack of any medical equipment.

She feels ward food is "awful, boring and hates it". She suggests ward reverts to daily menu on three-week rolling schedule. She doesn't like the Steamplicity 'ready meals', but orders from the CF menu "which is better" and gets a burger from the hospital-based Burger King outlet.

Homecare

Patient used to mix own home IVs, but now has all IVs as inpatient. She administers these via portacath. She used to return to CF centre specifically for port flushes, but now they coincide with outpatient clinic appointments. When on home IVs, Tobramycin levels were checked at the CF centre.

Give three areas of good practice in your CF service, if you can:

- Very good aseptic techniques.
- Good, reliable communication from the CF team; phone messages answered/acted upon promptly. CF team are nice to me and DO listen."

Give three areas for improvement in your CF service, if you can:

- More community support – ie blood tests, minor assessments locally – as patient worries about taking time off work when well.

Patient L

Outpatient clinic

Patient directed to consultancy side room on arrival at clinic. Height, weight, spirometry conducted in this side room. Patient sees equipment wiped down. MDT rotate to ensure patient stays in same room.

Treatment decisions: This depends on the doctor. A couple of doctors listen/discussed well; she felt other doctors dictate more to her, which she didn't like.

Patient felt outpatient pharmacy/prescription system had been great (nurse delivering script to pharmacy), but this stopped in November 2013.

Annual review

Patient just had AR and is offered one each year. She has access to all of the MDT at AR, though some were on annual leave last December. She attends a tertiary liver service in another hospital for her liver assessment.

Patient receives AR report six weeks after AR. Patient expects a three-month wait for AR report this time. She'd prefer a six-week routine appointment after AR to hear/discuss outcome. Receives update letter after each routine outpatient clinic, but not specifically covering AR.

Inpatient care

Patient feels admission process is very slow – has waited two weeks and feels this is becoming the norm due to increase in patient numbers. She's always had to wait (over last four years), except for last February when she was admitted immediately for planned IVs. Patient always accommodated on ward in en suite side room.

Patient rates ward staff as "fantastic", receives "great treatment" and appreciates ward staff acknowledging that "patient knows best" in her case. She feels IVs/meds are given on time, but if delayed, patient is always notified of delay.

Patient thinks there is sufficient equipment on ward (as far as she's aware), is offered exercise equipment, always provided with laptop but no TV.

She finds food on ward ok ("have had worse", typical hospital food", "CF menu better"). She's offered a fry-up breakfast and notes a fridge always in the room.

Homecare

Patient starts IVs in hospital and mixes own IVs, administering them through mid-line.

Give three areas of good practice in your CF service, if you can:

- Friendly, helpful ward staff.
- Cleanliness/hygiene and infection control – both CF team and ward team rated "good" at this.

Give three areas for improvement in your CF service, if you can:

- To improve speed of reporting back on ARs.
- To improve consistency/continuity of consultants' care/manner.
- To reduce delays in ward admission process.

Patient interviews on peer review day

Patient one

A 25-year-old female diagnosed with cystic fibrosis at birth. Attended Southampton paediatrics and transitioned to adult service aged 17. Works as an interpreter for the deaf.

Areas of good practice

- Staff are friendly and knowledgeable with good communication skills, and deliver a personal service. They are considerate of working arrangements.
- Inpatients: Clean, considerate regarding visiting hours with an excellent service. A laptop is offered for use. No problems to date with admission times.
- Outpatients: good communication, little waiting time.

Areas for improvement

- Food
- Car parking charges
- Décor of ward

Patient two

A 22-year-old female diagnosed at 18 months with cystic fibrosis. Works part time two days per week and volunteers two days per week.

Areas of good practice

- New ward side rooms, all with negative pressure ventilation. Can exercise in room as plenty of space in three new rooms.
- Staff are helpful, friendly and knowledgeable, leading to confidence in the team.
- Nurse and physios are excellent.

Areas for improvement

- Weekend and bank holiday access to specialist staff for on-call staff of all disciplines to provide advice and treatment discussions. At present, some decisions have to wait until after the weekend or holiday.
- Ward food not nice. CF menu much better but limited if a long admission. The previous ward food system was better.
- Good cross-infection guidelines, however, these are not always adhered to by all patients.
- More home support required from physio and nursing staff, especially with IVs.
- Would be good to have blood levels done locally rather than having to travel to Southampton.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	University Hospital Southampton
	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)	N/A	There is no waiting room. Patients are met by the nurse in a corridor and go straight to the clinic rooms. There are six appointments each clinic, with appointment times 2pm and 3:30pm.
Do patients spend any time in waiting room?	N/A	No waiting room.
Is there easy access to toilets?	Yes	All microbiology patients may use same toilet facilities. Only one toilet.
Where do height and weight measurements take place? Is this appropriate?	Yes	Performed in clinic rooms.
Where are the lung function tests done for each visit?		Performed in clinic rooms.
Are clinic rooms appropriately sized?	Yes	Four clinic rooms.
For annual review patients, are any distractions provided?	N/A	AR held in clinic room 9am–1pm. Staff work to make sure there is minimal waiting.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		CF diabetic clinic held twice per month.
Transition patients – can they get tour of outpatient facilities?		Tour offered.
Transition/new patients – do they get information pack?		Welcome pack – Ready, Steady, Go – available from paediatrics.

Additional comments

- Clinic rooms have no computers (they did previously, but they were removed as they were not used). Computers are available in a separate room which is utilised by clinic staff during clinics.
- Patient notes housed centrally in clinic. CF clinic corridor has bright artwork on walls.

Environmental walkthrough: ward

		Hospital name	University Hospital Southampton
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Isolation ward.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		14	All negative pressure. Three newly refurbished rooms.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Locker.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	If required, put-up beds available and three reclining chairs.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Normal visiting hours are 3–8pm. These can be negotiated case by case.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?			No microwaves. Microwave in ward kitchen. Six portable fridges in the process of being replaced. Plans to equip all rooms with a fridge.
What facilities are provided for teenagers?			Wii/DVD player/laptops/Playstation/iPad and Samsung Galaxy tablets available

Ward name: C5 isolation

Microbiology status: all microbiology

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Access to physiotherapy gym and range of equipment for use in rooms – cross-trainer, bike, ball, trampette, weights. No CF-specific gym.
What facilities are there to help with school and further studies?		Bring in own laptops, no desks. Can get Wi-Fi by requesting the code.
Is there a relatives' room?	No	There is a room called the 'Blue' room which is used by the psychologist and social workers. This room can be used by relatives when not in use, day or night.
What internet access is there?		Wi-Fi.
What facilities are there to enable students to continue work and study?		Laptops and Wi-Fi.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Use of basin in anti-room or own bathroom sink.
What facilities are provided for those with MRSA?		Negative pressure rooms and staff gown and glove.
What facilities are provided for those with *B. cepacia*?		Negative pressure rooms and staff gown and glove.
What facilities are provided for those with other complex microbiology?		Negative pressure rooms and staff gown and glove.
Are patient information leaflets readily available on ward?	No	Available on website/Twitter/ newsletter.
Transition patients – can they get tour of ward facilities?	Yes	Transition clinic meets them at 14–15 years of age and offers visit to ward prior to transition.

Additional comments

- Ward, patient rooms and 'Blue' room all bland and would benefit from improved décor and artwork. Ward is clean and paintwork recent, however, a warmer atmosphere could be provided.

Environmental walkthrough: other

	Hospital name	University Hospital Southampton
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	All inpatients and outpatients can ask for a letter discounting parking fees (a reduction of £16). However, some other patient groups receive free parking.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To outpatients and ward.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control eg radiology, pharmacy, bone mineral density (DEXA) scan?		Radiology – large waiting area. Pharmacy – nurses/ administrative staff take prescriptions to pharmacy.
Do patients have to wait at pharmacy for prescriptions?	No	They only have to collect them.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	'Friends and Family' programme to be introduced to clinic
Are there patient comment/ feedback boxes?	No	Awaiting box from 'Friends and Family' for clinic area.

Additional comments

- The nurses clean the clinic rooms during the day between patients, as required, and the cleaners clean them every night after clinic.
- Rooms utilised by people with NTM are deep cleaned by the hospitals' cleaning company.
- The MDT office room can accommodate up to 18 people and can get very warm. There are insufficient computers and also inadequate seating. Many chairs do not conform with Health and Safety regulations.

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

Report and actual compliance below follows a Red, Amber, 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

Poole 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%	Green	Green	

2 Multidisciplinary care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
2.1 Multi-disciplinary care	% patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review)	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Depending on the acuity and dependency of patient.	Yes	Patients with complex CF care needs transferred to Southampton.
	% 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%	Red. These exist, but are not documented	Green	Referral to Southampton for specialist review in joint clinics or by specialist.
	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	Not currently undergoing regular surveillance for Pseudomonas, including molecular typing.
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red. Seen in diabetes clinic.	Red	Patients seen in diabetes clinic or as inpatients by a diabetologist.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* in the previous 12 months	100%	Green	Green	
	% patients admitted within seven days of the decision to admit and treat	100%	Green	Green	
3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red. UHS – 48 hours.	Green	This service is now available at Poole.

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%	Green	Green	
3.6 Male infertility	% male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Red. Only discussed with 2 out of 7 patients.	N/A	Adult service.
3.7 Reduced bone mineral density (BMD)	% patients >10 years of age with a recorded bone mineral density (DEXA) scan in the last three years	100%	Amber	Amber	See dietetic report.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Green	Green	
4.2 Inpatients/ outpatients	% clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation	100%	Green	Green	
	% dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% patients reviewed by a CF clinical nurse specialist at each clinic visit	100%	Green	Green	

	% patients with access to a CF CNS during admission (excluding weekends)	100%	Green	Green	
	% patients reviewed by a CF physiotherapist at each clinic visit	100%	Green	Green	
	% patients reviewed by a physiotherapist twice daily, including weekends	100%	Amber	Amber	Not all patients receive twice daily review at weekends.
	% 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%	Red. Dietitian is available.	Green	This standard is met. The reported red rating was a documentation issue which has been addressed.
	% availability of clinical psychology at clinic	100%	Red. Outpatient review can be arranged.	Red	Patients are referred as needed. There is no significant delay for review and the psychologist is able to provide a responsive service.
	% availability of clinical psychology for inpatients	100%	Green	Green	
	% availability of social worker for clinic	100%	Green	Green	
	% availability of social worker for inpatients	100%	Green	Green	
	% availability of pharmacist at clinic	100%	Green	Green	Available to see patients on request.
	% availability of pharmacist for inpatients	100%	Green	Green	

4.3 Home care	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end of life	75%	Green	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%	1	1	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service Level Agreements in place for all	100%	Red. Ongoing with UHS.	Red	In development as part of planned merger.

Appendix 7

Staffing levels (adult)

Whole time equivalent (WTE)

	75 patients	150 patients	250 patients	Poole Hospital 37 patients
Consultant 1	0.5	1	1	0.5 WTE
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.4	0.8	1	0.2 WTE
Specialist nurse	2	3	5	0.73 WTE
Physiotherapist	2	4	6	1.3 WTE
Dietitian	0.5	1	2	0.5 WTE
Clinical psychologist	0.5	1	2	0.1 WTE
Social worker	0.5	1	2	0.2 WTE
Pharmacist	0.5	1	1	0.2 WTE
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	
Physiotherapy technician				0.3 WTE

Appendix 8

UK CF Registry data

(All references, data and figures are taken from the UK CF Registry Annual Data Report 2012, available at cysticfibrosis.org.uk/registry)

CF Registry data 2012	
Demographics of Poole Hospital	
Number of active patients (active being patients within the last two years) registered	36
Number of complete annual data sets taken from verified data set (used for production of the Annual Data Report 2012)	31
Median age in years of active patients	25
Number of deaths in reporting year	1
Median age at death in reporting year	30

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number in age categories	16–19 years	8
	20–23 years	6
	24–27 years	5
	28–31 years	5
	32–35 years	6
	36–39 years	0
	40–44 years	0
	45–49 years	1
	50+ years	0

Genetics	
Number of patients and % of unknown genetics	12 (39%)

Body Mass Index (BMI) (ref: 1.13 Annual Data Report 2012)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	5 (22%)	5 (56%)
Number of patients and % with BMI <19 split by sex	6 (27%)	0
Number of patients and % with BMI <19 split by sex on supplementary feeding	5 (83%)	0

FEV_1 (ref:1.14 Annual Data Report 2012)			
		Male	Female
Median FEV_1% pred at age 16 years split by sex		0	0
Number and median (range) FEV_1 % pred by age range and sex	16–19 years	(5) 58.07% (34.65–77.9)	(3) 79.47% (35.75–87.38)
	20–23 years	(5) 70.09% (54.35–108.23)	(1) 59.12%
	24–27 years	(3) 41.74% (31.82–47.59)	(2) 86.18% (79.42–92.93)
	28–31 years	(4) 64.85% (43.6–101.52)	0
	32–35 years	(5) 59.09% (26.71–80.76)	(2) 73.36% (50.91–95.81)
	36–39 years	0	0
	40–44 years	0	0
	45–49 years	0	(1) 48.94%
	50+ years	0	0

Lung Infection (ref 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	8
	20–23 years	6
	24–27 years	5
	28–31 years	5
	32–35 years	6
	36–39 years	0
	40–44 years	0
	45–49 years	1
	50+ years	0

Number of patients with chronic PA by age group	16–19 years	3
	20–23 years	5
	24–27 years	4
	28–31 years	5
	32–35 years	5
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
***Burkholderia cepacia* (BC)**		
Number and % of total cohort with chronic infection with BC complex	0	
Number and % of *cenocepacia*	0	
Meticillin-resistant *staphylococcus aureus* (MRSA)		
Number and % of total cohort with chronic infection with MRSA	4 (13%)	
***Non–tuberculosis mycobacterium* (NTM)**		
Number and % of total cohort with chronic infection with NTM	2 (7%)	

Complication (ref 1.16 Annual Data Report 2012)	
ABPA (Allergic Bronchopulmonary Aspergillosis)	
Number and % total cohort identified in reporting year with ABPA	3 (10%)
Cystic fibrosis-related diabetes (CFRD)	
Number and % total cohort requiring chronic insulin therapy	11 (36%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	2 (7%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (3%) with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	1
Number of patients referred for transplantion assessment in previous three years	1
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (ref:1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	70
	20–23 years	83
	24–27 years	104
	28–31 years	212
	32–35 years	75
	36–39 years	0
	40–44 years	0
	45–49 years	30
	50+ years	0
Number of days of home IV therapy in reporting year split by age group	16–19 years	0
	20–23 years	9
	24–27 years	101
	28–31 years	55
	32–35 years	33
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
Total number of IV days split by age group	16–19 years	70
	20–23 years	92
	24–27 years	205
	28–31 years	267
	32–35 years	108
	36–39 years	0
	40–44 years	0
	45–49 years	30
	50+ years	0

Chronic DNase therapy (ref 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged >16 years FEV1, % predicted <85% (ie below normal) on DNase	(n=23) 12 (52%)
If not on DNase % on hypertonic saline	2 (9%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	22 (71%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	13 (59%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	11 (36%) with chronic PA 3 (10%) without chronic PA

Appendix 9

Patient survey

Poole Hospital

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	8	2	1	0
Communication	7	3	0	1
Out-of-hours access	4	0	4	0
Homecare/community support	2	0	0	2

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	3	4	2	0
Cleanliness	4	3	2	0
Cross-infection/segregation	5	3	0	0
Food	1	3	3	2
Exercise	3	4	1	1

How would you rate:

	Excellent	Good	Fair	Poor
Home intravenous (IVs) antibiotic service	4	1	0	0
Availability of equipment	5	5	0	1
Car parking	2	4	4	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	8	2	0	1
Of the ward staff	4	4	1	0
Of the hospital	5	4	2	0

Comments about CF team/hospital

"I don't think they have very good communication with my CF team down in Truro."

"The CF team at Poole hospital has improved dramatically over the last few years with more staff and new equipment. I am very happy with my team and feel my quality of life would be dramatically decreased without them."

"Poole Hospital CF team have restored my confidence in CF care. They have proactively and systematically dealt with care issues and communication and bedside manner is excellent. They have helped me to self-manage my care and are readily available for advice. Exceptional team. Well done!"

"Annual review – whole day and still have to pay for car park. Cleanliness – not the best. Inpatient food is rubbish. The food poor because no junk food. Years ago it was better we got coke cans, chocolate and crisps, also better things. I just wish that staff would understand that we find it hard to keep a job, but they want you to drop everything for appointments – it is sad. I don't want to lose my job. Some of the team members are rude about me getting a Motability car. I am sorry I have been given CF, I did not ask for it. My car helps me get to them, please don't take it away.

"Need to update look of the hospital."

"Excellent care!"

"Very helpful and willing to help."

Appendix 10

Patient/parent interviews

Outpatient clinic

Patient arrives at outpatient clinic, waits in open clinic area and is directed to a consultancy room. Patient "prefers to talk to other patients and feels completely separated when put into consultancy room". He has height and weight measured in another room, but spirometry is conducted in consultancy room. He notices equipment is wiped down between patients. MDT rotates, so he stays in the same consultancy room.

Patient feels decisions on treatment are made for him rather than with him.

Patient has difficulty getting some medications from his GP, eg vitamins and DNase. GP will not prescribe these. He has been recommended to buy his own vitamins. He receives one month's supply of DNase from the CF centre, but has to return to the CF centre if he requires more – he doesn't return for extra DNase.

Annual review

Patient last had Annual Review (AR) in December 2013. He's offered AR each year. All his AR tests take place same day at the CF centre, with access to each member of the MDT. His DEXA scan and liver scan are conducted on separate occasions. He receives a written report of his AR outcome (copy to GP).

Inpatient care

Patient can usually be admitted to the ward within a week for planned IVs; if very ill team tries to admit him within two days. He is always accommodated in an en suite side room. He feels the ward staff are knowledgeable about his CF needs, but that IVs/meds are not always given on time ("we're always left 'til last as they think we all like staying up late anyway" – I don't). The ward is not a dedicated CF ward.

Patient feels there is sufficient equipment on the ward – push pumps/drips provided.

Patient feels the ward catering is "rubbish" – his comments: "CF menu is never updated, we used to have snacks between meals (no longer), they forget what you've ordered sometimes. Hospital menu is poor quality, so I don't like to stay in for whole two weeks of IVs."

Homecare

No homecare company for home IVs; patient must mix his own home IVs. Patient complained that he's not always sent home with enough IVs/ancillaries, so has to return to hospital for further prescription, which results in a wait. IVs are administered via portacath, but patient is concerned that he's only given Hepsal every three days, with saline for all other flushes. Patient does his own port flushing and has Tobramycin level checked after first dose in week one only; apparently no level taken in second week when on home IVs (according to patient).

Give three areas of good practice in your CF service, if you can:

None given

Give three areas for improvement in your CF service, if you can:

- Catering – patient would like more snacks/'luxuries' (eg choc, crisps, nuts), as he states "We get forgotten on tea round, because tea lady is put off by 'must wear gowns/hats' notice on CF patient door".
- More local support – patient would like spiro and other routine tests offered locally, to reduce trips to CF centre and time needed off work – employer does not understand.

Patient interviews

Poole Hospital

Patient one

Male patient of 23 years of age, admitted to hospital 11 days ago. Lives in Portland, which is approximately 35 miles away and around a one-hour drive. He used the hospital transport to come into hospital for the stay. He usually drives to the hospital for his clinic appointments. He has no problem with the parking fees.

When in hospital, he likes the fact that he has his own room and privacy. He enjoys working out and practices martial arts. He has only been admitted for one week since September 2013 and puts this down to the fact that he exercises regularly and practises his martial arts.

His opinion is that the food is okay. He orders breakfast from the menu and requests double portions, but does not always get this as requested. Usually he requests a snack box for the evening, but does not always get this delivered, so the dietitian will go to catering to fetch him more food.

He thinks the staff are helpful, happy and accessible. He has a contact number for the team if required at any time of day.

Patient two

Male patient of 23 years of age, admitted to hospital three days ago. He lives a half-hour drive away (approximately 30 miles).

He was last admitted two months ago.

During his stay he has exclusive use of an exercise bike. He also receives physiotherapy twice daily and once a day at weekends.

He thinks the high energy menu is good, although a little limited, as he prefers certain foods so tends to eat the same thing. He buys his own snacks as the hospital ones are not to his liking.

He likes the fact that he has his own room, which is good at night for peace and quiet. However, this can be isolating at times during the day.

He thinks the staff are generally good – a mixture of friendly, understanding staff and others not so much.

He finds the multi-storey parking too far away, it takes him 10 minutes to walk to the hospital from his car and he feels that the minimum parking charge of £1.80 is too high for a half-hour appointment.

He feels the staff are very accessible. If he cannot speak to a member of staff, he will leave a message and they will always get back to him very quickly.

He does feel that, as the team is growing, he is receiving conflicting messages, eg one physiotherapist will say one thing and another will say something else.

He also feels that he would like clarification and reassurance. If he asks a member of staff why they are doing something, they do not always make it clear why.

Appendix 11

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	Poole Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room etc)	Yes	After checking in at reception, patients go immediately to the clinic room.
Do patients spend any time in waiting room?	No	Staff would ensure patients are not waiting together in one area, although the area is of a good size.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Height and weight room equipped for this.
Where are the lung function tests done for each visit?		In the clinic room with handheld equipment.
Are clinic rooms appropriately sized?	Yes	Rooms are very basic and plain, although fit for purpose.
For annual review patients, are any distractions provided?	N/A	
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Patients are seen within clinic by the diabetes consultant and also attend the diabetes clinic.
Transition patients – can they get tour of outpatient facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	

Additional comments

- Outpatients is in the refurbished part of the hospital. Clinics are microbiology-specific.
- Clinics are held on Wednesday afternoon. Two rooms are available for clinic either side of the MDT meeting room. Two patients would be seen at 2:30 and two at 3:30. Patients with other bugs would be seen at the later appointment time.
- Annual reviews are held in the medical investigation unit, which is situated on the same floor as Arne Ward.
- The room is a bright and airy single room with a bed, an armchair and sink, for the duration of their visit. The patients are given refreshments and sandwiches during their visit. The toilet is close by, off the corridor.

Environmental walkthrough: ward

Ward name: Arne Ward (A4)

Microbiology status: Medical ward specialising in respiratory

		Hospital name	Poole Hospital
		Yes/no/ number/ N/A	Notes/comments
Is ward a dedicated CF ward or ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		11 total, five used for CF	Five negative pressure rooms allocated for CF patients, each has an anti-room.
Do the en suites have:	**Toilets?**	Yes	All bathrooms clean and fit for purpose.
	Wash basins?	Yes	Shower cubicle.
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	All have lockable, metal wall cabinet in anti-room.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	This has been free for the last two to three years. Patients call the patient line to obtain free access.
If no, are there any concessions for CF patients?			
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Most rooms have a window seat, which acts as a single bed. There are also Z beds available.
Visiting hours – are there allowances for CF patients/ families out of normal hours?		Yes	Negotiable – case by case.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	All rooms have their own fridge. There is access to a microwave on the ward.

	Hospital name	Poole Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Rates are £1.80 for up to one hour. Arrangements have been made for CF patients to pay £16 per week when admitted, instead of the £9 per day. In discussion at the moment for a fixed rate for AR visits – £3.60 for 4 hours plus. End of life – for close family, a laminated card is issued for free parking.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To general ward A4.
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control eg radiology, pharmacy, bone mineral density (DEXA) scan?		DEXA scans are carried out at Bournemouth. There are 20+ seats in the pharmacy area. Generally the staff take the prescription to pharmacy and it is collected by the patient. There shouldn't be any need to wait.
Do patients have to wait at pharmacy for prescriptions?	No	
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Also leaflets available on demand.
Are there patient comment/ feedback boxes?	No	A box in every ward.

Appendix 12

UK CF Registry data – Salisbury DH data is now collected by SGH as of August 2013

(All references, data and figures are taken from the 'UK CF Registry Annual Data Report 2012', available at cysticfibrosis.org.uk/registry)

CF Registry data 2012	
Demographics of Salisbury District Hospital	
Number of active patients (active being patients within the last two years) registered	8
Number of complete annual data sets taken from verified data set (used for production of the Annual Data Report 2012)	7
Median age in years of active patients	33
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2012)		
Number in age categories	16–19 years	1
	20–23 years	2
	24–27 years	0
	28–31 years	0
	32–35 years	1
	36–39 years	0
	40–44 years	1
	45–49 years	1
	50+ years	1

Genetics	
Number of patients and % of unknown genetics	0

Body Mass Index (BMI) (ref: 1.13 Annual Data Report 2012)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	1 (17%)	1 (100%)
Number of patients and % with BMI <19 split by sex	1 (17%)	0
Number of patients and % with BMI <19 split by sex on supplementary feeding	0	0

FEV_1 (ref:1.14 Annual Data Report 2012)			
		Male	Female
Median FEV_1% pred at age 16 years split by sex		0	0
Number and median (range) FEV_1 % pred by age range and sex	16–19 years	1, 76.63%	0
	20–23 years	2, 90.10% (79.86–100.33)	0
	24–27 years	0	0
	28–31 years	0	0
	32–35 years	0	1, 113.73%
	36–39 years	0	0
	40–44 years	1, 62 51%	0
	45–49 years	1, 71.09%	0
	50+ years	1, 87.4%	0

Lung Infection (ref 1.15 Annual Data Report 2012)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	1
	20–23 years	2
	24–27 years	0
	28–31 years	0
	32–35 years	1
	36–39 years	0
	40–44 years	1
	45–49 years	1
	50+ years	1
Number of patients with chronic PA by age group	16–19 years	0
	20–23 years	0
	24–27 years	0
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	1 (100%)
	45–49 years	0
	50+ years	1 (100%)

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	**0**
Number and % of total cohort with cenocapacia	**0**
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	**0**
***Non–tuberculous mycobacterium* (NTM)**	
Number and % of total cohort with chronic infection with NTM	**2 (29%)**

Complication (ref 1.16 Annual Data Report 2012)	
ABPA (Allergic Bronchopulmonary Aspergillosis)	
Number and % total cohort identified in reporting year with ABPA	1 (14%)
Cystic fibrosis-related diabetes (CFRD)	
Number and % total cohort requiring chronic insulin therapy	2 (29%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (14%) with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2012)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in last three years	0

IV therapy (ref:1.21 Annual Data Report 2012)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	0
	20–23 years	0
	24–27 years	0
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
Number of days of home IV therapy in reporting year split by age group	16–19 years	0
	20–23 years	0
	24–27 years	0
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	42
	45–49 years	0
	50+ years	0

Total number of IV days split by age group	16–19 years	0
	20–23 years	0
	24–27 years	0
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	42
	45–49 years	0
	50+ years	0

Chronic DNase therapy (ref 1.22 Annual Data Report 2012)	
DNase (Pulmozyme)	
% of patients aged >16 years FEV1, % predicted <85% (ie below normal) on DNase	(n=4) 1 (25%)
If not on DNase % on hypertonic saline	1 (25%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2012)	
Number and % of patients with chronic PA infection	2 (29%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (14%) with chronic PA 3 (43%) without chronic PA

Appendix 13

Panel members

Caroline Elston*	Consultant	King's College Hospital
Alison Morton	Dietitian	St James's University Hospital
Lily Lamb	Psychologist	Liverpool Heart and Chest Hospital
Tim Gleeson	Pharmacist	Sheffield Hospital
Hannah Parkinson	Physiotherapy	King's College Hospital
Josie Hussey	Clinical Nurse	Birmingham Heartlands Hospital
Penny Martin	Social Worker	Papworth Hospital
Sarah Freeman	Commissioner	NHS England West Midlands
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for peer review panel

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