

In partnership with

Cystic
Fibrosis why
we're here



British
Thoracic
Society



Peer review report
All Wales Adult Cystic Fibrosis Centre
University Hospital Llandough
25 September 2015

Contents

1.Executive summary		
	Overview of service	page 3
	Good practice examples	page 3
	Key recommendations	page 3
	Areas for further consideration	page 3
2. Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'		
	Models of care	page 4
	Multidisciplinary care	page 4
	Principles of care	page 4
	Delivery of care	page 4
	Commissioning	page 5
3. UK CF Registry data		page 6
4. Delivery against professional standards/guidelines not already assessed		
	Consultant	page 7
	Specialist nursing	page 8
	Physiotherapy	page 8
	Dietetics	page 10
	Pharmacy	page 11
	Psychology	page 12
	Social work	page 13
5. User feedback		page 14
6. Appendices		
	Performance against the Cystic Fibrosis Trust's 'Standards of Care (2011)'	page 15
	Staffing levels	page 22
	UK CF Registry data	page 23
	Patient survey	page 28
	Patient interviews	page 33
	Environmental walkthrough	page 41
	Panel members	page 45

1. Executive summary

Overview of the service

The Llandough Adult Cystic Fibrosis Centre is a very well established service providing excellent specialist care for approximately 260 patients, and this number is likely to increase to over 300 patients within a few years. They have developed a very well-trained and dedicated team of consultants and allied health professionals across all areas of multidisciplinary care, but further development of middle-grade doctor, pharmacist, social worker and psychologist input is recommended. There is an excellent outpatient clinic with appropriate facilities for segregation of patients. Although patients receive excellent dedicated care when admitted to hospital, the inpatient facilities are below the standards expected for a specialist CF Centre, with a lack of ensuite cubicles, and this needs to be urgently addressed to reduce the risk of cross-infection.

Good practice examples:

- There is an experienced and skilled medical and multi-disciplinary team (MDT) who demonstrate a high level of commitment to patient care.
- Outpatient services are excellent, with a dedicated clinic area, good segregation procedures, and good MDT input.
- There are strong links with associated specialist services, such as diabetes, hepatology, obstetrics, ENT and transplantation, delivering a comprehensive range of services.

Key recommendations:

- The inpatient facilities need urgent improvement in order to provide segregated care in ensuite cubicles, to reduce the risk of cross-infection and to meet the standards expected of a CF Centre.
- Further development of the multidisciplinary team is needed for pharmacy, psychology and social work input to bring the service into line with the 'Standards of Care, (2011)' Guidelines.
- The service currently has no middle-grade staff. With patient numbers at over 260 and as patient numbers and complexity increases a middle-grade (speciality doctor) should be appointed as a priority. This should be immediate and is absolutely pivotal for continued service development and growth.

Areas for further consideration:

- Development of a comprehensive home intravenous (IV) antibiotic service with delivery of pre-prepared antibiotics to patients in their homes would help in modernising the delivery of care.
- Consideration of the feasibility of expanding on the out-reach clinic, with more of the specialist MDT travelling to Carmarthen for clinics, so that some routine care can be provided closer to home, reducing the burden of travel for patients.
- Consider formalising the out-of-hours medical cover and developing the weekend physiotherapy service for patients with cystic fibrosis, to ensure sustainability of the service for the future.

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

Models of care

Summary

The Llandough Adult CF Centre has an experienced dedicated team, providing excellent care to approximately 260 patients from a wide area of South and West Wales. The number of patients is likely to increase to 300 soon, and may reach 350 in the future, and there is a need to plan for the increased numbers and complexity over the next five years. Improvement of inpatient facilities is urgently needed. Some outreach service is provided at Carmarthen, and development of a full outreach clinic there and further development of home IV antibiotic service would be welcomed by patients.

Multidisciplinary care

Summary

The CF team demonstrates a high level of enthusiasm and commitment to the care of patients, in accordance with the multidisciplinary principles of care. There is excellent communication between members of the team. All members of the team participate in educational events to maintain and develop their skills, and there are research and quality improvement activities, with good participation in UK and European specialist CF conferences. There are shortfalls in staffing in pharmacy, psychology and social work, and there will be a need to review staffing levels across the team as patient numbers increase.

Principles of care

Summary

The CF Centre shows full commitment to a multidisciplinary model of care for patients, following current guidelines and practices. Excellent segregation arrangements are in place for infection prevention and control in the outpatient area, but the lack of ensuite inpatient cubicles poses a risk. There are excellent links with associated specialist services (eg lung transplantation, liver, diabetes, ENT, obstetric services).

Delivery of care

Summary

User feedback surveys and patient interviews confirm a high level of satisfaction with the service. Some patients highlight the inherent travel distance from areas of West Wales. Although detailed microbiological monitoring of infections is reassuring, patients raise concerns about sharing inpatient areas and the lack of ensuite cubicles. There is a need to develop inpatient facilities. The shortage of staff restricts the availability of some disciplines in clinics (eg psychologist, pharmacist, social worker). There are well established links with paediatric CF services and good transition arrangements for young adults moving to the adult service.

Commissioning

Summary

The Adult CF Service based in University Hospital Llandough under Cardiff and Vale University Health Board provides tertiary services to the population of South, West and Mid Wales. Patient numbers have been steadily increasing over the last 10 years to approximately 260 at the time of the review.

Areas of good practice:

- The service has a well-developed team and fantastic outpatient and MDT facilities.
- The service has shown innovation with their use of virtual technology and skill mix of staff.
- The patient surveys undertaken for the last three years show that patients were very satisfied overall with the care that they received and were extremely complimentary about the patient-focussed and supportive staff.

Areas for improvement:

- The general absence of Health Board Management representatives at the Review was noted by the review team and it was felt that it would have been valuable for both the review team and the service, for management to have been present. The Lead Consultant was keen to stress that the CF centre received very good financial support from their accountant who was present at the review and that they did have a uniquely identifiable budget.
- Shortages in the key areas of pharmacy and middle-grade medical staff. Both these issues were raised as part of the 2015/16 Specialised Services Integrated Medium Term Plan (IMTP) and are due to be discussed in the agreed Joint Committee process within the next few months.
- The single biggest finding of the review was the lack of appropriate inpatient facilities, in particular the shared toilet and shower facilities on the ward. This has featured as a concern in previous peer reviews but the service believes that resolution of this issue is forthcoming as the Health Board is currently working on plans to be submitted to Welsh Government for a 15-20 all ensuite bedded ward, within the CF centre. This plan will address the capacity issues that the unit faces and also brings the inpatient ward within the newly established CF centre.

Recommendations:

- The associated revenue costs of staffing the additional beds will need to be funded through Welsh Health Specialised Services Committee and as such, need to be included in the Health Board's IMTP return for 2016/17. Based on the feedback of the peer review, the staffing requirements that have been modelled to date need to be revisited to ensure that they include other support staff such as physiotherapy, which would ensure that the team has the necessary complement of qualified staff and is able to provide adequate weekend provision on the ward.
- Although the clinical nurse specialists have been proactive in establishing an outreach clinic in West Wales it does seem to be on an informal basis in terms of use of facilities and equipment. These clinics should be formalised at Health Board level to ensure that they receive the appropriate clinic support and space to provide optimum care for patients and staff to work in. Once the middle-grade doctor is in post, it is hoped that outreach clinics would be expanded in the South West in particular, to include medical input.
- Revisit the proposal of providing IV home care. This has previously been looked at and disregarded on the basis that it was not cost effective. It is however working successfully in other services that the CF Peer Review team has reviewed and as it reduces the demand for inpatient beds it would be timely to look into this alongside the development of the inpatient facilities. How the service is currently being delivered will need to change to manage the growth in patient numbers and the service needs to start preparing for this and future-proofing developments such as the new inpatient ward. The proposal for IV home care is just one alternative that the service could look to for providing care.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	216
-------------------	--	-----

		Male	Female	
FEV₁	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	95.45% (56.23 – 111.8)	84.29% (40.29 – 110.58)
		20–23 years	77.76% (35.04-99.6)	70.18% (25.65 – 104.88)
		24–27 years	68.95% (15.95-101.02)	73.7% (10.19 – 110.56)
		28–31 years	51.71% (27.4-109.03)	71.96% (32.89 – 116.79)
		32–35 years	77.12% (13.05-105.61)	44.68% (37.47 – 86.01)
		36–39 years	69.48% (26.03-100.41)	60.09% (18.51 – 103.42)
		40–44 years	57.24% (39.57-103.09)	72.58% (35.92 – 96.71)
		45–49 years	69.94% (36.76-114.44)	41% (27.86 – 107.61)
50+ years	51.22% (20.94- 123.82)	60.83% (36.07 – 85.1)		

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n = 119); 51 (43%)	(n = 97); 41 (42%)
	Number of patients and % with BMI <19 split by sex	12 (10%)	22 (23%)

<i>Pseudomonas aeruginosa</i> (PA) chronic PA is 3+ isolates between two annual data sets	Number and % of patients with chronic PA infection	96 (44%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	85 (89%)

Macrolides	Number and % of patients on chronic macrolide with chronic <i>Pseudomonas aeruginosa</i> infection	71 (74%)
	Number and % of patients on chronic macrolide without chronic <i>Pseudomonas aeruginosa</i> infection	65 (54%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

The Llandough Adult Cystic Fibrosis Centre has three consultant physicians with 2.7 Whole Time Equivalents (WTE) dedicated to cystic fibrosis. This is an appropriate level of staffing and meets the Standards of Care guidance for staffing levels. They are fully trained and experienced in the care of cystic fibrosis, and are all actively involved in attending educational events and appropriate national and international cystic fibrosis conferences. They demonstrate a high level of commitment to cystic fibrosis, and undertake audits and quality-improvement projects. They also undertake research and some clinical trials work, presenting the results at national and international conferences. The patient survey confirms a high level of satisfaction with the care they provide. There is currently no middle-grade support from a Specialty Registrar or Clinical Fellow; as such, the service is consultant-delivered. The out-of-hours service provides a facility whereby patients contact the staff on the ward who then deal with enquiries as appropriate, contacting one of the consultants if necessary. The out-of-hours consultant input is voluntary. At present this is not an unduly heavy commitment, but this may need to be formalised for the future sustainability of the service as patient numbers and complexity increase.

Areas of excellence:

- Experienced consultants committed to the care of patient with cystic fibrosis.
- Good participation in educational activities and cystic fibrosis conferences.
- Commitment to research and clinical trials in cystic fibrosis.

Recommendations for improvement for this service:

- Development of middle-grade support for the service in the form of a specialty doctor or registrar.
- Establishing a more formal out-of-hours medical input for patients with cystic fibrosis to improve the sustainability of the service for increasing patient numbers and complexity.
- Improved home care services with delivery of pre-prepared antibiotics, which would reduce the need for patients to be admitted to hospital.

Specialist nursing

The Adult CF Specialist Nurse team are a very dedicated, motivated and experienced team, all of whom hold a first degree amongst other appropriate qualifications. There are currently six Cystic Fibrosis Clinical Nurse Specialists (CF CNS) WTE of five with no vacancies. They are able to provide their own cover for any absences. There are two Band 7 nurses, both of whom are Non-Medical Prescribers and the remaining four being Band 6. All members attend the Cystic Fibrosis Nurse Association meetings regularly as well as national and international conferences on the proviso they provide an abstract. They undertake regular research and audits as part of their continuing practice and development.

They attend the CF Centre weekly MDT meetings, which the CF ward staff also attend, maintaining strong links between both teams. This meeting is also an educational meeting, often including outside speakers to enhance knowledge and learning. They also attend joint MDT meetings with other disciplines such as the transplant team (using virtual technology across sites), the diabetic and microbiology teams. They are also embarking on joint working with the palliative care team with the development of a Supportive Care Clinic, beginning in October 2015. They provide a comprehensive home IV antibiotic therapy service, albeit in the absence of ready-made drugs.

Areas of excellence/good practice:

- A cohesive and extremely dedicated, well-established CF nursing team.
- Non-Medical Prescribers on the team.
- Attendance at network clinics in hard to reach regions.

Areas for improvement:

- Further development of the virtual clinics for greater patient access.
- Improved inpatient facilities.
- Utilisation of Non-Medical Prescribers at network clinic.

Recommendations:

- Ready-made IV drugs delivery service for improved patient care and safety.
- Utilise the CF Administration Team more fully for administration support.
- Increased frequency of network clinics.

Physiotherapy

The physiotherapy service is currently funded to staff 6.7 WTE posts. The team comprises 0.9 WTE Band 8a lead (split 0.5 clinical/0.4 research), 2.0 WTE Band 7, 1.0 WTE Band 6 (static), 1.0 WTE Band 5 (rotational), 1.0 WTE Band 4 exercise technician and 0.8 WTE Band 2 physiotherapy Assistant. The staffing establishment meets the National recommended 6.4 WTE for the current patient numbers (260). The team is well structured with inpatient and outpatient services having identified teams led by the CF specialist Band 7 staff and overseen by the 8a lead. The team does however comprise a high proportion (27%) of non-qualified physiotherapy staff who are qualified fitness instructors and primarily responsible for exercise delivery. When the team is at full establishment the current structure meets weekday service requirements, largely due to the extensive experience and commitment of the Band 4 and 2 working well beyond their roles. However recent long-term sickness and staff vacancy has put pressure on the qualified team to meet the recommended standards of care. Annual leave, sick leave and other absenteeism is covered by the CF team but this absence has put the service under significant pressure with staff working beyond their contracted hours with impact on non-clinical commitments. Occasional need to provide cross cover to other physiotherapy services can also impact on delivery of care.

The quality of physiotherapy care for both weekday inpatient and outpatient provision is excellent with patients receiving physiotherapy input as recommended by the CF Trust 'Standards of Care (2011)'. There is appropriate and timely support at all stages of disease management with open access to the service for outpatients. Facilities and access to exercise is excellent, in particular with the innovative development of B4 led virtual exercise clinics, exercise incentives and links to community based exercise programmes. Annual reviews are carried out or reviewed as recommended by specialist physiotherapists with all clinical needs addressed, including appropriate screening and referral pathways being in place for musculoskeletal, continence and sinus complications. There are appropriate cross-infection procedures in place for all clinical settings.

Weekend physiotherapy provision currently falls below recommendations. There is only one physiotherapist on call across the hospital site at weekends, limiting availability, but the key issue appears to be the departmental criteria for weekend provision. Patients are prioritised on acuity and their dependence for assistance with airway clearance and are therefore often expected to carry out their own treatment; this is highlighted as an area for improvement in patient-reported feedback.

There is a homecare service available within a one hour radius of the hospital with exceptions being made appropriately for patients with end-stage complex disease. There is a drive to develop the service to ensure equity of care to patients living in the wider geographical area. This includes a monthly nurse/physiotherapy led satellite clinic at Carmarthen hospital and physiotherapy led virtual clinics. Whilst both these services have been well received by patients, there are current limitations with the virtual clinics due to the lack of equipment to carry out relevant physiological monitoring, namely spirometry. There is a dedicated budget for all other physiotherapy equipment with no shortfall.

The team is actively involved in MDT meetings and ward rounds, with input into all aspects of patient management. Physiotherapy team members are responsible for collection and monitoring of clinical data, ensuring availability for the MDT. Inefficiencies in the current databases impact on clinical time and ability to carry out audits.

The physiotherapy team are members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF). All staff attends weekly educational meetings and twice yearly regional meetings and there is opportunity and funding for staff to regularly attend national and international conferences.

There is team commitment to research with several team members regularly submitting abstracts to the European Cystic Fibrosis Conference and the North American Cystic Fibrosis Conference. The Band 8a is active in the development of national and international guidelines and is also currently involved with a Cystic Fibrosis Trust-led exercise project. She has also established and is active in an exercise research group linked with Cardiff and Swansea Universities.

Areas of good practice:

- A highly specialist, dedicated and innovative team delivering a high standard of weekday service across all clinical settings, with excellent access to physiotherapy support throughout all stages of disease management.
- A progressive exercise service with innovative use of Band 4/2 staff and technology, facilitating access to exercise, with a drive to continued development through active involvement in research, collaborating with local universities.
- Development of out-reach services to improve access for patients in geographically challenged areas with the use of virtual and satellite clinics.

Areas of improvement:

- Weekend physiotherapy provision currently fails to meet national recommendations, with patients frequently required to carry out their own treatment.
- The skill mix and the roles within the physiotherapy team requires careful monitoring to ensure that staff are able to continue to meet the demands of the service without having to work well beyond their remit and contracted hours.
- Inefficient databases adversely impacts clinical time and ability to perform clinical audit.

Recommendation:

- Urgent review of the weekend service to ensure appropriate out-of-hours services are available for all patients.
- With the proposed expansion of inpatient beds, there is a need to ensure that there are sufficient and appropriately graded staff to maintain the current high standards of care for inpatients for both weekday and weekend service provision.
- A review of the current databases to address inefficient use of physiotherapy time.
- Continued development of satellite and virtual clinics to address disparity of access to outreach services for distance patients. To review equipment requirements to ensure best utilisation of virtual clinics.

Dietetics

The dietetic service comprises two WTE Band 7 experienced (13 years and four years) CF Specialist Dietitians supported by 0.4 WTE Band 3 Dietetic Assistant (DA). There is also one session per month of a Band 5 dietitian as part of the Band 5 rotations. Both Band 7 dietitians also have additional roles within the general dietetic department.

Service – The dietitians provide cover to all of the outpatient clinics, although some of their tasks could be undertaken by less qualified team members. The dietitians review inpatients at least twice a week at the ward round and prior to the MDT. Additional reviews are carried out as clinically indicated and reviews are also undertaken by the DA. One of the dietitians attends the MDTs and ward rounds. Annual assessments are undertaken on both an inpatient and outpatient basis, although the outpatient annual assessment does sound to be quite labour intensive. If both CF Dietitians are unavailable then urgent cover is provided by a Band 7 dietitian from the Dietetic Department. The dietitians do not currently attend transitional clinic, but do attend the family “Welcome Evening”.

CPD – The dietetic team show commitment to continuing professional development. Both dietitians are active members of the UK Dietitians’ CF Interest Group and have the opportunity to attend national meetings and the European Cystic Fibrosis Conference. They are encouraged to participate in service development, research and audit though this could be further supported by additional DA hours.

Catering – There is a variety of food available including a seven-day menu, microwave meals, an ad-hoc menu to supplement the daily hospital menu, snacks and oral nutritional supplements. Meal vouchers are also available once a day to allow inpatients to go to staff/visitor canteen/ coffee shop. However when the canteen and coffee shop close there is limited access to hot food (other than a microwave meal) in the evening. There are also concerns about cross-infection as the voucher system may mean patients are in the same canteen at the same time.

Areas of Good Practice:

- Enthusiastic and motivated team with commitment to continuing professional development, attendance at meetings, research and audit.
- Excellent diet sheets and resources.
- Good and clearly defined pathways.

Areas for Improvement:

- Concerns highlighted about food provision (use of meal vouchers), which may have implications for cross-infection.

Recommendations:

- With increasing numbers, longer-term plans for additional post (Band 6) to allow for succession planning.
- Uplift of DA hours to 1 WTE to:
 - Contribute to skill mix allowing more appropriate use of expertise;
 - Support clinics, eg weigh patients which will help to reduce cross-infection risk;
 - Support data collection for research; and,
 - Support registration of home enteral feeding patients.

Pharmacy

- The CF team is supported by 0.3 WTE Band 8a pharmacist, which falls short of the standard of 1 WTE for >250 patients.
- The pharmacist attends the weekly CF MDT and most (but not all) annual review (AR) clinics. There is, therefore, inequity in access to the pharmacist at AR. There is no cover for the MDT or ARs when the pharmacist is on leave.
- There are homecare arrangements in place for the dry-powder inhaled antibiotics and the transition of aztreonam lysine to homecare is planned. Shared care arrangements are in place for other high-cost drugs. The CF pharmacist sits on the local pharmacy homecare group.
- There is no access to compounded IV homecare at present – patients can have home IV's but must reconstitute vials themselves. Patients are provided with infusion pumps where necessary and trained how to use these.
- Over the last five years, the pharmacist has provided input to a number of guidelines at a local and national level, including Welsh CF commissioning documents; local antimicrobial guidelines for CF and vitamin supplementation.
- The pharmacist is a member of the UK CF Pharmacists Group steering committee, and has attended and presented posters at international CF conferences.

Areas of Good Practice:

- The pharmacist is well integrated into the CF MDT.
- Homecare arrangements are in place for high-cost therapies, supported by shared care arrangements within primary care.
- The pharmacist undertakes a medicines review at AR which includes a review of GP medication records.

Areas for improvement:

- There is inequality in access to pharmacist at the annual review.
- There is insufficient cover for annual leave to maintain the service which has been established, particularly ARs and MDT.
- Home IV's supplied as vials for reconstitution – not compounded.

Recommendations:

- Staffing levels should be reviewed – with the current patient numbers and additional demands of homecare, there should be 1 WTE pharmacist dedicated to CF.
- All patients should see a pharmacist at their AR.
- Home IV compounding service should be explored.

Psychology

This service currently has a 0.6 WTE Band 8b Clinical Psychologist (CP) and is recruiting for a 0.5 8a CP (total provision = 1.1 WTE). This will provide two senior CPs, however, the service is and will remain understaffed as the Cystic Fibrosis Trust's "Standards of Care (2011)" recommends 2 WTE CPs for services with 250 patients or more. Absence cover is provided by on-site psychiatry liaison service for urgent mental health issues.

The CP is a member of UK CF Psychosocial Professionals Group and attends their study day annually. The CP currently attends 50% of inpatient MDT meetings and attends outpatient MDT meetings if a need is identified. The CP has attended and presented at the European CF conference and will attend the National CF conference in 2015.

The CP has been involved in audits and service development relating to substance use, experience of CF-related diabetes diagnosis, the use of virtual technology and parent evenings for transition. The CP attends transition clinics and supports team transition discussions. The CP has some availability to see patients being referred for transplant, at the end-of-life or planning a family if difficulties in coping/adjustment are identified.

Areas of good practice:

- Psychology is very well integrated and clearly valued in the team which allows for cases of milder distress to be managed by other members of the CF team who have ongoing training and consultation from the CP. The CP also effectively feeds into MDT discussions when available to bring a psychological perspective to patient care and provides reflective sessions for the team. Availability of CP to respond to referrals is good and in line with standards of care, with all referrals receiving a response within two weeks and an appointment within four.
- The CP shows a strong commitment to conference attendance, conference contributions and continued professional development courses. They are also key part of service development in areas such as transition and end-of-life.

Areas of improvement:

- The CP does not see most patients at AR, although a paper screen is offered, and does not routinely assess all patients referred for transplant or at the end-of-life. There are plans to significantly increase involvement in these areas with new CP post. More regular attendance of CP at MDT meetings would also be useful.

Recommendations:

- The provision will soon consist of two CPs at senior levels of banding, however, this will remain a limited resource. Increasing the staffing level in line with the Standards of Care would allow for more systematic involvement at key life stages and increased attendance at MDT meetings. It may also be helpful to consider the best models of care by which this high level of expertise can be used to deliver the most comprehensive service possible to a large number of patients.

Social work

Llandough social work support is provided by an experienced social worker with a current registration with Care Council for Wales. This is a full-time post and therefore the service appears understaffed against the recommended staffing levels of two WTE social workers for the number of patients attending the centre. Despite this, the service is able to meet the majority of the demands made on it.

Other than sickness, training and annual leave, there is a social worker available for patients. There is an open referral system with referrals being received directly from patients or via other professionals. Depending on the circumstances this may be followed up in clinic, via the telephone or via a home visit. This flexibility appears to suit the service and appears responsive to need. The accessibility appears to be valued and is reflected in the excellent patient satisfaction survey. While an increase in hours would allow for greater cover when on leave or sickness the service is flexible enough to respond to most of the current demands.

The post is hosted by Social Services who give access to support and supervision. The Social Worker is integrated within the CF team and attends relevant social work and CF training. The social worker is a member of the UK Psychosocial Professions in CF (UKPP-CF) and has been a committee member until recently. She has attended relevant CF-specific social work training days and has carried out research, which she has presented at conferences.

Any safeguarding concerns are case managed by a separate team with liaison/input from the social worker.

This is a flexible responsive service that appears to meet patient's needs. There is considerable experience and expertise with issues around benefits, transition and housing amongst other areas.

Areas for development:

- Consideration for increase in staffing – in particular to cover sickness and annual leave.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	2	12	5	2	1	1
Female	0	0	13	5	3	3	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	40	10	1	1
From the ward staff	33	3	7	1
From the hospital	29	14	5	2

Areas of excellence:

1. CF team's care: accessibility and communication with and from CF team.
2. Ward team's care.
3. Outpatient experience: availability of team members, cross-infection control/segregation, cleanliness of rooms.

Areas for improvement:

1. Outpatient clinic waiting times.
2. Admission waiting times.
3. Inpatient food.

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 Trust's 'Standards of Care (2011)'

Amber = Failing to meet all the Trust's 'Standards of Care (2011)' with improvements required

Red = Failing to meet the Trust's 'Standards of Care (2011)' with urgent action required

1 Models of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
1.1 Models of care	% of patients seen at least once a year by the specialist centre for an annual review.	90%	Green	Green	All patients are offered AR. Some fail to attend but have a report generated from notes
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	% of patients seen at least twice a year by the full specialist centre MDT (one consultation may include annual review).	95%	Green	Green	
	Do staffing levels allow for safe and effective delivery of service?	Y/N	Yes	Yes	
	% of MDT who receive an annual appraisal.	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months.	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group).	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Green	Green	

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant.	95%	Green	Green	
	% of patients with cystic fibrosis-related diabetes reviewed at a joint CF diabetes clinic.	100%	Amber	Amber	Patients with CFRD offered appointments but some fail to attend.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission.	100%	Red	Red	Lack of ensuite rooms; below standard expected of a CF centre.
	% of patients cohorted to outpatient clinics according to microbiological status.	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates <i>Pseudomonas aeruginosa</i> (PA) in the previous 12 months.	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat.	100%	Green	Green	
3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	

3.4 Cystic fibrosis-related diabetes	% of patients aged >12 years screened annually for cystic fibrosis-related diabetes	100%	Green	Green	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years.	100%	Green	Green	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services.	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years.	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consultations	% of patients seen by a CF consultant a minimum of twice a week while inpatient.	100%	Green	Green	
4.2 Inpatients/ outpatients	% of clinic letters completed and sent to GP/shared care consultant/ patient or carer, within 10 days of consultation.	100%	Green	Green	
	% of dictated discharge summaries completed within 10 days of discharge.	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist at each clinic visit.	100%	Green	Green	
	% of patients with access to a CF clinical nurse specialist during admission (excluding weekends).	100%	Green	Green	
	% of patients reviewed by a CF physiotherapist at each clinic visit.	100%	Green	Green	
	% of patients reviewed by a physiotherapist twice daily, including weekends.	100%	Green	Green	
	% availability of a CF specialist dietitian at clinic.	100%	Green	Green	
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic.	100%	Red	Red	Lack of psychology staff to provide full service.
	% availability of a clinical psychologist for inpatients.	100%	Red	Red	
	% availability of a social worker at clinic.	100%	Amber	Amber	Limited availability, eg for transition patients.
	% availability of a social worker for inpatients.	100%	Green	Green	
	% availability of pharmacist at clinic.	100%	Red: Available via phone	Red: Available via phone	Lack of pharmacy staff.
	% availability of a pharmacist for inpatients.	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment.	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life.	75%	Green	Green	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	<1%	<1%	
5.2	Number of clinical incidents reported within the past 12 months	<1%	8%	8%	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green	Green	

Appendix 2

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	University Hospital Llandough
Consultant 1	0.5	1	1	0.9 WTE
Consultant 2	0.3	0.5	1	0.9 WTE
Consultant 3			0.5	0.9 WTE
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.4	0.8	1	0
Specialist nurse	2	3	5	5.0 WTE
Physiotherapist	2	4	6	5.9 WTE
Dietitian	0.5	1	2	2.0 WTE
Clinical psychologist	0.5	1	2	1.1 WTE
Social worker	0.5	1	2	1.0 WTE
Pharmacist	0.5	1	1	0.3 WTE
Secretary	0.5	1	2	2.0 WTE
Database coordinator	0.4	0.8	1	0.6 WTE
CF centre manager				1.0 WTE
Dietetic assistant				0.4 WTE
Physiotherapy technician				1.0 WTE
Physiotherapy assistant				0.8 WTE
Outpatient Receptionist Clerk				0.95 WTE

Appendix 3

UK CF Registry data

(All references, data and figures are taken from the 'UK CF Registry Annual Data Report 2014, available at cysticfibrosis.org.uk/registry)

UK CF Registry data 2014	
Demographics of centre – University Hospital Llandough	
Number of active patients registered (active being patients within the last two years)	216
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	216
Median age in years of active patients	27
Number of deaths in reporting year	3
Median age at death in reporting year	21

Age distribution (ref: 1.6 Annual Data Report 2014)		
Number and % in age categories	16–19 years	25 (12%)
	20–23 years	49 (23%)
	24–27 years	37 (17%)
	28–31 years	29 (14%)
	32–35 years	16 (7%)
	36–39 years	22 (10%)
	40–44 years	16 (7%)
	45–49 years	11 (5%)
	50+ years	11 (5%)

Genetics	
Number of patients and % of unknown genetics	16 (7%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2014)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=119); 51 (43%)	(n=97); 41 (42%)
Number of patients and % with BMI <19 split by sex	12 (10%)	22 (23%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	11 (92%)	17 (77.23%)

FEV₁ (ref: 1.14 Annual Data Report 2014)

		Male	Female
Medium FEV ₁ % predicted at age 16 year split by sex		0	0
Number and medium (range) FEV ₁ %n predicted by age range and sex	16–19 years	95.45% (56.23 – 111.8)	84.29% (40.29 – 110.58)
	20–23 years	77.76% (35.04–99.6)	70.18% (25.65 – 104.88)
	24–27 years	68.95% (15.95 – 101.02)	73.7% (10.19 – 110.56)
	28–31 years	51.71% (27.4 – 109.03)	71.96% (32.89 – 116.79)
	32–35 years	77.12% (13.05 – 105.61)	44.68% (37.47 – 86.01)
	36–39 years	69.48% (26.03 – 100.41)	60.09% (18.51 – 103.42)
	40–44 years	57.24% (39.57 – 103.09)	72.58% (35.92 – 96.71)
	45–49 years	69.94% (36.76 – 114.44)	41% (27.86 – 107.61)
	50+ years	51.22% (20.94 – 123.82)	60.83% (36.07 – 85.1)

Lung infection (ref: 1.15 Annual Data Report 2014)		
Chronic <i>Pseudomonas aeruginosa</i> (PA)		
Number of patients in each age group	16–19 years	25 (12%)
	20–23 years	49 (23%)
	24–27 years	37 (17%)
	28–31 years	29 (14%)
	32–35 years	16 (7%)
	36–39 years	22 (10%)
	40–44 years	16 (7%)
	45–49 years	11 (5%)
	50+ years	11 (5%)
Number of patients with chronic <i>P. aeruginosa</i> by age group	16–19 years	3
	20–23 years	15
	24–27 years	20
	28–31 years	15
	32–35 years	12
	36–39 years	13
	40–44 years	7
	45–49 years	6
	50+ years	5

<i>Burkholderia cepacia</i> (BC)	
Number and % of total cohort with chronic infection with BC complex	10 (5%)
Number and % of <i>B. Cenocepacia</i>	3 (1%)
Meticillin-resistant <i>Staphylococcus aureus</i> (MRSA)	
Number and % of total cohort with chronic infection with MRSA	2 (1%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	7 (3.2%)

Complication (ref: 1.16 Annual Data Report 2014)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	25 (12%)
Cystic fibrosis-related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	76 (35%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	32 (15%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (0.5%) without PH 1 (0.5%) with PH

Transplantation (ref: 1.18 Annual Data Report 2014)	
Number of patients referred for transplantation assessment in reporting year	26
Number of patients referred for transplantation assessment in previous three years	18
Number of patients receiving lung, liver, kidney transplants in previous three years	17

IV therapy (ref: 1.21 Annual Data Report 2014)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	229
	20–23 years	953
	24–27 years	981
	28–31 years	729
	32–35 years	330
	36–39 years	146
	40–44 years	173
	45–49 years	159
	50+ years	216
Number of days of home IV therapy in reporting year split by age group	16–19 years	16
	20–23 years	254
	24–27 years	286
	28–31 years	260
	32–35 years	328
	36–39 years	260
	40–44 years	390
	45–49 years	63
	50+ years	136
Total number of IV days split by age group	16–19 years	245
	20–23 years	1207
	24–27 years	1267
	28–31 years	989
	32–35 years	658
	36–39 years	406
	40–44 years	563
	45–49 years	222
	50+ years	352

Chronic DNase therapy (ref: 1.22 Annual Data Report 2014)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV ₁ , % predicted <85% (ie below normal) on DNase	(n=158) 130 (82%)
If not on DNase, % on hypertonic saline	32 (20%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2014)	
Number and % of patients with chronic PA infection	96 (44%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	85 (89%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	71 (74%) with chronic PA 65 (54%) without chronic PA

Appendix 4

Patient survey

University Hospital Llandough

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	2	2	12	5	2	1	1
Female	0	0	13	5	3	3	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	36	12	5	0
Communication	32	14	3	4
Out-of-hours access	14	17	10	2
Homecare/community	8	9	0	8

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	31	20	2	1
Waiting times	21	8	14	6
Cross-infection/segregation	38	10	4	0
Cleanliness	40	10	3	1
Annual review process	33	13	5	2
Transition	20	12	2	1

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	16	14	8	4
Cleanliness	22	11	3	5
Cross-infection/segregation	19	14	2	5
Food	9	13	11	8
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	27	10	4	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	14	15	5	5

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	22	7	1	1
Availability of equipment	31	13	2	1
Car parking	8	16	13	11

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	40	10	1	1
Of the ward staff	33	3	7	1
Of the hospital	29	14	5	2

Comments about CF team/hospital

“General wards often don’t have enough toilet and shower facilities. Sometimes dirty equipment is stored in wash rooms too. Food – poor for so many reasons. Physiotherapy at weekends poor for so many reasons. We all end up in pharmacy together.”

“I previously attended Papworth CF clinic for around 25 years before moving to Wales in April 2013. My first appointment at Llandough was four months later, despite needing monthly check-ups. I was taken in for two weeks on the ward and was shocked at the lack of segregation in place. Each room has a small notice on the door saying patients should not mix but there is a shared kitchen, a shared bathroom and a day room. Staff say I’m being fussy by refusing to go play pool or get something from the kitchen, but at Papworth I was kept in a purple area because of a certain bug I had that could be dangerous for other patients and they have things dangerous to me. Despite me telling them this, 18 months later nothing has changed and they still say I’m being silly. Every time I am on the ward, I lose weight. and the dietitian has admitted the food isn’t enough to keep me going. Also, they never have Dornase or Aztreonam on the ward, so when my supplies I brought in run out, my other half has to put in an order with our local pharmacy. So it takes almost three days, around £30 and a 100 mile round trip to get more. I have also had difficulty getting insulin and needles whilst on the ward. So other half does the same as with the other drugs, but since the insulin needs to be refrigerated, an hour and a half on a hot train it’s barely worth it. The general diabetes care at Llandough is better than at Papworth, where it was never looked after. My annual review has been four times in 18 months because the last one got lost each time. I occasionally receive appointment letters after the appointment date. Staff have started ringing the night before an appointment to check I know about it, but since the hospital transport people need at least 48 hours’ notice, my appointment is often rescheduled for two weeks later. I have five phone numbers for various members of the CF team, but it is very rare that any answer. There is usually at least a week’s wait for a bed on the ward. When given home IVs there is always way too much of some things and way too few of others. Have to do the 100 mile £30 journey for a blood test during home IVs to Llandough which takes five minutes. There is plenty more to say against Llandough, but I want to use my last few lines to praise the social worker. She has been a great help with various things, including PIP application, appeal, things related to my other half’s physical and mental health problems and countless other form-filling and phone calling.”

“I have been in a room and the cleaner did not come in for at least four days. Only when one of my visitors said to a nurse about it did she come the next day.”

“Cannot praise them highly enough. Very professional and approachable at all times.”

“Very helpful, dedicated team.”

“Physio only available on weekends if team feel you are in need. Otherwise self-percussion undertaken. CF unit only has seven beds available.”

“Not often hospitalised – excellent phone contact given. Distance 2.5 hours from home to Llandough, so sometimes feel ‘out on a limb.’”

“Due to the bugs I grow I’m not allowed on the CF ward. I’m placed on a ‘normal’ ward. These nurses sometimes don’t understand the needs of a CF patient.”

“In any organisation there are outstanding individuals who try to make things better only to be let down by certain people, funding and time constraints. Llandough is desperately needing extra staff to take the load. Calling to speak at time to a CF specialist is difficult and sometimes you need to leave messages that are not picked up until the next day.”

“Brilliant CF team. They are always there when I need them and they are very supporting and understanding.”

“Did not receive physio on the ward post haemoptysis. Only comment I could make is that it is a shame no CF clinical nurse specialist is working at weekends to replace IV line if it goes on a weekend, as you miss doses of home IV antibiotics until replaced on a week day.”

“Brilliant CF team but the lack of funding means that the CF centre is not reaching its full potential. Ward needs improvements to avoid cross-infection; currently quite lax.”

“In my view, the only thing that needs improving as soon as possible is the waiting times whilst at the clinic. Sometimes there is a fair amount of hanging around, waiting for each member of the CF team to visit.”

“The CF team complain that I need to gain weight, but how can I do that when the food is so bad. I wouldn’t even serve it to dogs.”

“Admission waiting times due to lack of beds, but can vary. Food has hasn’t always been poor. Many years ago the ward was served the same food as the canteen (very good then). I never understand the rules and regulations to physiotherapy on the weekends when in. Home care is being improved but is by no means continuous.”

“The CF team are amazing and very supportive.”

“Very good standard of care from all staff involved. Availability of the gym is very much appreciated. CF nurses very easy to contact and quick to handle issues raised.”

“One consultant is very certain in his views. He can be flippant and glib. By contrast, another consultant is warm, friendly and very approachable. He has a wonderful bedside manner and is very knowledgeable. I wish he were Director of the service.”

“Care from my CF team is excellent. However, more community and home care would be beneficial.”

“I feel outpatients waiting times are excessive as a normal appointment takes 2–3 hours which is a lot out of my working day, although the care is first class.”

“Home IVs – can’t get blocked line refitted on a weekend. My diabetes advice is disjointed with the CF clinic.”

“Very friendly and knowledgeable. Always available.”

“Never offered home care/community support or received any.” Patient’s rating of ward staffing care is based on a CF cubicle on a general ward.

“I find the annual review process rather poor as the questions etc are always just repeated on the second visit; a waste of time and impractical when you have to take time off work and travel distance is quite far. Would make for more sense to scrap the first visit and just have the annual review with the doctors present on the same day.”

“Cross-infection goes ignored in the CF ward. Patients seen openly communicating with each other, bragging about benefits. Food is meagre”

“Love them to bits. Only things I would change are the distance to hospital and having CF at all.”

“I have been to three different hospitals around the UK and Llandough hospital is one of the best.”

“Always welcoming and helpful. I appreciate long waiting times are often unavoidable.”

“They’re my angels, the Consultants, lovely and very kind. Bit chopsy but he’s great! CF nurse - she’s amazing – love her.”

“The CF team were excellent and the staff on the ward were really helpful.”

“I have attended the CF ward in Llandough for over 16 years. The team are fantastic, the ward staff are fantastic, but they are all over stretched! There are only seven beds available on the main ward with three more on other wards. I waited six weeks for a bed and then ended up doing home IVs. I live outside of the hospital’s district cover, so I was unable to receive home care or home physiotherapy. I felt as though I was just left to carry on with home IVs on my own. The team is over-stretched for the amount of CF patients in our area!”

Appendix 5

Llandough Adult CF Centre – Peer Review 2015 – patient telephone interviews

Patient A

Outpatients

Patient A was happy with the segregation measures at outpatients. He is ushered straight to a consultancy room on arrival at clinic where he said hand gels are used from the moment he arrives. Outpatient clinic is on the second floor, with 15 consultancy rooms, between which the CF MDT rotate.

Patient A believed he got to see a doctor at outpatient clinic same day on 99% of occasions. He explained that he normally saw the full MDT at clinic, where he felt the CF team listen to his experience and point of view when making decisions about changes to treatments. He felt the CF team very much involve him in this decision making process.

At hospital pharmacy Patient A sometimes has a wait of 90 minutes, but it varies between 15 minutes to two hours wait in what he described as 'a very small waiting area'. However, the CF clinic nurses try to fax his prescriptions to pharmacy to achieve a quick collection of medication.

Inpatient care

Patient A is seen on the seven-bed unit but he added that he felt the treatment when not on the CF unit is so much different. However, nurses on other wards treating CF are on three month rotation on the CF unit to get up on CF. Patient A described a communal toilet/bathroom for male and female patients respectively on the CF ward which concerned him. He felt food on the ward had improved as compared with the 'like it or lump it' culture in the past. He added that the dietitians have been partly responsible for improvements to catering – there is now a list of four set menus and some flexibility in what can be served.

Patient A described a privately funded gym in the new outpatient department and he uses the gym, accompanied by the dedicated gym physiotherapist on a Monday and Weds, for one hour, describing it as 'excellent'.

Annual review

Patient A receives an annual review appointment each year and has had this year's appointment. He described how his questions and team's questions are handled with full and up-to-date information. The outcome of his annual review is fed back to Patient A at clinic and in a letter/report four weeks after the annual review appointment. Some of the annual review assessments take place in advance of the annual review appointment, others on the day.

Home care

Patient A collects his prescriptions for DNase, prescribed by his GP, from his local pharmacy. His nebulised/inhaled antibiotics are prescribed and collected locally too, but he expects these to become a home delivery package in the near future, although this has not materialised as yet.

Patient A visits his CF centre every four to six weeks to get his port flushed, tying this in with a visit to the ward gym. He has an understanding employer too which helps in this respect.

Good practice:

- "The lead consultants and CF team are very approachable."
- "I have a good relationship with the Clinical Nurse Specialists"

Area for improvement:

- “We have to do our own physio at weekends on the ward, or I use a Hill Rom physio vest. I don’t see a physio at weekends.” – ie need for improved physiotherapy provision on the ward at weekends.

Patient B

Outpatients

Patient B has to attend general outpatient clinic due to microbacterial status. She has to wait a while at outpatient clinic. She described the CF team as a ‘fabulous team’ with whom she can really connect. However, she felt that some show greater natural enthusiasm and interest in her and want to listen to her more than others, adding that she felt things were better before one of the clinical nurse specialists left.

Inpatient care

Patient B described the non-CF wards, adding that it is difficult to get an admission sometimes and has to sometimes start an antibiotic IV course at home. She described a lack of physiotherapy provision at the weekends, although added that she prefers to do her own physio at the weekend anyway, twice daily. During the week physio is offered to her twice daily.

Patient B was very enthusiastic about the ward nursing, adding that she ‘adores’ them, describing them as ‘like a second family’. She added that her IVs were given on time on the ward and they will administer the IVs if patient B felt too tired.

Patient B was not so complimentary about the food on the ward. She explained that she could order what she wanted but that she prefers ‘home food’, that’s to say pasta bake, roasts, meat and two veg. She explained that the ward fridge was for snacks only, with no food outlets in the hospital open at the weekends, as far as she knew. She has complained to the dietitian on several occasions and they have offered to pass her concerns onto the catering staff. Patient B mentioned there being snacks in the cupboard on the CF ward, but she cannot access the CF ward herself and that she was restricted from having sugary snacks due to less well controlled diabetes. She felt that those like her with her microbacterial status were ‘not heard’.

Home care

Patient B attends Llandough for port flushes, adding that this is her choice as she likes to keep home and hospital separate. All medications are prescribed through her GP.

Patient B explained that the CF team has discussed gastrostomy PEG feed with her. She has not yet opted for this.

Good practice:

- “Some of the CF team are great, especially the doctors.”
- “Staff on the non-CF wards make a massive contribution to my care.”

Area for improvement:

- “The ward food definitely needs improving.”
- “Improve inclusion of CF patients who cannot go on the CF ward – treat us as equals.” (patient feels excluded and left out).

Patient C

Outpatients

Patient C was happy with the segregation measures and hand hygiene practised in clinic. She felt fully involved in decisions made around changes to any treatments and she saw the full MDT at each clinic appointment. Patient C was also aware that she could access psychosocial support, if necessary.

Inpatient care

Patient C felt that it was not easy to get admitted to the ward, given the number of beds available in proportion to patients accessing the service. She felt the nursing was fine on the ward and described the food as 'amazing' – soups, snacks, sandwiches – as compared with the hospital canteen food which she felt was not good.

Patient C was offered physiotherapy twice daily, including at weekends if poorly enough.

Home care

Patient C felt that the home care provided for her was 'amazing', adding that she had home visits from the Clinical Nurse Specialist, to help her with IV medication, conduct port flushes and to deal with a stomach-related concern. Patient C has occasional home deliveries of gastrostomy feed from Nutricia, a service that she rated positively.

Good practice:

- "The doctors and the nursing care – both very good."
- "Food on the ward is very good."

Area for improvement:

- "Shortage of beds – seven beds for the whole of Wales' adult CF population attending Llandough"

Patient D

Outpatients

Patient D has to attend a non-CF outpatient clinic due to her microbacterial status. She described 'constant use' of hand gels by staff during her attendance at clinic. She felt that the CF team try to take everything into account when making judgements on her treatments, adding that "They make it work for me."

Patient D described pharmacy prescription collection process as okay, apart from the waiting time.

Inpatient care

Patient D referred to inpatient care as really good, although not accommodated on the CF ward. She felt that nursing staff did their best and that the physiotherapist came to see her for her twice daily session.

Patient D described the ward food as 'okay', explaining that they allowed her extra portions which she really appreciated, but no snacks were provided between meals. She described ward staff as great, adding that they were 'always there' and made her feel more comfortable. She also mentioned that IVs were always given on time, and that the home IV competence training was 'brilliant'.

Home care

Patient D hadn't had home IVs for a number of years but was given good training to self-administer and she was given all the necessary ancillaries to go home with. All her other CF medications are prescribed through her local GP and collected from local pharmacy.

Annual review

Patient D described annual review as 'detailed' and added that the outcome is reported back to her via a very detailed letter. At the review appointment she explained that the CF team 'talk constantly about everything'. Some of her annual review assessments take place prior to annual review day; the DEXA scan takes place at Singleton Hospital.

Good practice:

- "Attention to hygiene is phenomenal."
- "Really thoughtful staff."

Area for improvement:

- "To provide easier access to snacks on the non-CF wards for CF adults unable to have their care on the CF ward due to microbacterial status. Some patients are not well enough to collect own snacks."

Patient E

Outpatients

Patient E said that he never seemed to see another CF adult at outpatient clinic, although he later explained that he considers himself a 'mild case' of CF, requiring just annual review attendance, and so has spent little or no other time at outpatient clinic. He thought segregation measures seemed good.

Patient E felt that the CF team always made him well aware of treatment changes, adding that he was most definitely able to ask questions and adding that he felt that the team's explanations to him were good.

Inpatient care – not applicable to this patient.

Home care – not applicable to this patient who requires no respiratory-related treatments.

Annual review

Patient E is offered an annual review appointment each year and has had this year's appointment. Feedback on the outcome of his annual review is provided by the Consultant at clinic and also within a month of annual review, in a letter. All patient E's annual review assessments take place at Llandough.

Good practice:

- "The CF team is a switched-on, friendly team. It's a nice experience to attend annual review with them."
- "The CF team have made it clear which facilities (eg use of gym, supervised) are available as part of the service to me."

Area for improvement:

None recommended

Patient F

Patient F's father commented, in patient F's absence whilst in hospital.

He described his dissatisfaction at the lack of beds for cystic fibrosis patients at Llandough, including for those with the more challenging microbacterial status that affects his daughter. He explained what he described as unacceptable, recent treatment of his daughter, left at A&E, then moved to a side ward on the ANU unit, with what he felt were nurses unqualified to manage CF – example: asking his daughter how to put her IV antibiotic through when she questioned their approach.

Father described the level of hygiene on his daughter's ward as 'disgusting'. He explained that his daughter has become afraid to comment to the nurses in case any of the doctors or clinical nurse specialists hear of her complaints.

Father of patient F felt that timings of physio treatment were unreliable – the physiotherapist arriving to provide physiotherapy later than expected, then returning at an inconvenient time.

Both father and daughter, he felt, had lost faith in their CF service.

Patient G

Outpatient clinic

Patient G felt that segregation measures were quite strict and quite good at outpatient clinic. He is ushered straight to a side room on arrival at clinic, where he sees staff making good use of hand gel and wiping down lung function/spirometry equipment before and after use.

Patient G sees all whom he needs to see in the CF team at clinic, as they rotate between patient consultation rooms. He only leaves that room at the end of clinic. He felt that in discussions about his treatments and care, first priority of the team is the effect on him, their patient. He added that both he and the CF team listen to one another and come to agreements on treatments. He felt that the outpatient clinic experience was excellent.

Inpatient care

Patient G's inpatient experience is very good, apart from the food, which he felt could be improved. He usually sees a physiotherapist twice daily seven days a week, adding that the team can telephone the on-call physiotherapist to arrange an extra session if needed too. He explained, "You have to proactively request for a physiotherapist at the weekend, but if you did it's no problem for me."

Patient G felt that the food on the ward could taste nicer, although he described it as 'perfectly edible' – he is not on the CF ward due to microbacterial status. He explained that they receive snacks, but felt that meal portion sizes could be bigger and served later in the evening, rather than nearer 5pm-5.30pm, causing him to get hungry mid-evening. There is no official snack trolley service or housekeeper to provide food/snacks to top him up mid-evening, but the nurses will get him some cereal and milk and, he acknowledged, do try to accommodate him.

Home care

Patient G collects his IVs from hospital, and Dnase. He is expecting Tobi and TIP to soon be delivered via BUPA. Patient G lives very close to the hospital and so attends the hospital for port flushes rather than having home visits.

Annual review

Patient G receives an annual review appointment each year, including this year. The outcome of his annual review is reported to him through a letter and discussed at next clinic appointment.

Patient G felt communication from the CF team was usually quick in response to his queries/ messages. The CF team respond to messages left on the answer machine same day, but he thought that they do not use email for communication as it is felt less secure.

Good practice:

- “Attitude and dedication by a passionate team. They go the extra mile to make it easier for me.”

Area for improvement:

- “All rooms should be ensuite for CF patients. Only one room on the non-CF wards has an ensuite.”

Patient H

Outpatients

Patient H rarely sees other CF adults at outpatient clinic and felt that segregation was very good. However, she expressed the negative impact of segregation, describing it as ‘isolating’ both at clinic and on the ward. At outpatient clinic she can wait a while between seeing members of the CF MDT . She sometimes takes a magazine along to read at clinic. Patient H lives 65 miles from the CF centre and so has very infrequent visits from family and friends as an inpatient.

At outpatient clinic she felt that she has some involvement in decision making on changes to medications, but that sometimes some doctors listen to her more than others – the change from nebulised Colomycin being an example. Patient H also felt that she has to repeat the same information to different members of the MDT. She felt that CF MDT staff could communicate patient comments better between one another. Patient H sees all of the MDT whom she’d like to see at each outpatient clinic, including a social worker. She knows she can assess a clinical psychologist too, but hasn’t needed to recently.

Inpatient care

Patient H felt that the ward nursing staff were ‘brilliant’, adding that they will come into her room and chat to her when there is time, although she recognised that they are very busy. She felt that IVs and other medications are usually given on time and nursing staff are flexible in allowing her to request some treatments earlier in the morning than drug round allows.

Patient H felt that there was good physiotherapy support on the ward, but did mention that she on the last few admissions she’s done her own physiotherapy. However, she was aware she only had to ask for physiotherapist support to receive it if required.

Home care

Patient H has just signed up for home deliveries of Tobramycin Inhaled Powder (TIP). She currently collects her nebulised antibiotics (Azli) from the CF centre at Llandough. She also returns to Llandough for port flushes, or she can have her portacath flushed at a clinic local to her.

Annual Review

Patient H is offered annual review each year, her last being in autumn 2014. She felt that annual review had slipped over the years, so that she has to remind the team of her need for an annual review appointment. The outcome of annual review is reported back to her at the follow-up clinic, a month after annual review. She then receives a written annual review report one to two months after the follow-up clinic. Patient H liked having the annual review written reports to reflect on what has been said at clinic in her own time and so that she can make comparisons with previous annual review information on health status.

Good practice:

- “I have a brilliant CF team and ward team – unfortunately some have retired.”

Area for improvement:

- “Outpatient clinic could do with speeding up. My appointment starts at 2–2.30pm, but doesn’t finish until 4.30–5pm. I wait, sat alone twiddling my thumbs for a while between seeing staff.”

Patient Interviews Llandough Adult CF Service – face to face

Patient A

A 23-year-old female diagnosed at two months with CF in Manchester. Moved to West Wales and was treated locally. Transitioned to adult care at Cardiff aged 18 years. She is employed as a Youth and Community worker.

She felt that her views were taken into consideration and usually saw the same consultant, which was helpful. She sees all of the MDT that she feels she needs to. She was reassured by the team at the time of diagnosis.

Inpatient care (ward): Patient A explained that the ward was clean, her room was ‘OK’ however, she was having to share a toilet and shower with other CF patients, which was of some concern. The food is ‘alright’.

She described the physiotherapists as being very helpful, especially with exercise.

She was very happy with the communication from her CF team who all listened to her and took her feelings into consideration.

Outpatient Care: Clinic facilities are excellent at Llandough however, increased outreach clinic would be very helpful as too much time is spent travelling.

Areas of good practice:

- Good, friendly ward staff and MDT who know you as an individual. Work well together to provide tailor-made treatments.
- Supportive and responsive staff who communicate well making her feel valued.
- Excellent outpatient facilities.

Areas for improvement:

- Improvement in waiting times for a bed for admission, increased ensuite beds available to CF patients to prevent cross-infection.
- Increased local access in Carmarthen Clinic for IVs, aminoglycoside levels etc to cut down on travel time.
- Lower the risk of cross-infection in ward kitchen by possibly having a housekeeper or other staff to prepare food rather than patients being allowed in to do so.

Patient B

A 30-year-old male diagnosed at 14 years old in East Glamorgan. Moved to Llandough at 18 years old.

Inpatient care (ward): Patient B felt increased beds with ensembles are required as sharing toilet and bathroom with other CF patients is not ideal. He explained that he thought the physiotherapists were very good and particularly enjoyed the exercise sessions when well enough to take part and had twice daily physio as required at weekend.

He described the ward food as 'not very good'. The ward is clean and the ward staff are great. Prefers this ward as admission to other wards not good as the staff aren't familiar with him. His quickest admission is one day and longest one week. He was offered bed on another ward but wanted to hold out for the ward where he is known and well cared for.

Outpatient Care: Clinic facilities are great at Llandough with good segregation and very clean. Appointments can be too long waiting alone in a room for the staff. Increased outreach clinic would be very helpful particularly when on IV's at home.

Areas of good practice:

- "Very friendly brilliant team and lovely friendly ward staff."
- "Good relationships and communication, always discuss options."
- Gym

Area for improvement:

- More rooms with ensuite facilities to be made available as soon as possible to prevent risk of cross-infection
- Outreach for home IV's
- Better food choices
- Repaint and revitalise ward or better still a new ward

One other patient expressed her views during the walkthrough. She felt the ward she was on needed repainting or livening up with artwork, for example. She felt the ensuite she was in had a too small toilet and shower cubicle. She also expressed the fact she would like the facility to be able to prepare her own food in her room as she did not like the hospital food.

Appendix 6

Environmental walkthrough: outpatients department

Outpatients/CF clinic

	Hospital Name	University Hospital Llandough
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
Do patients spend any time in waiting room?	No	
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	
Where are the lung function tests done for each visit?	N/A	Spirometry is performed in patient clinic rooms with infection appropriate spirometer.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	
Transition patients – can they get tour of outpatients’ facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	

Environmental walkthrough: ward

Ward name: CF Unit

Microbiology status: Pseudomonas only (where possible Staphylococcus and normal flora are cared for on W1 to avoid any potential cross-infection from sharing)

		Hospital name	University Hospital Llandough
		Yes/no/number/N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Seven dedicated ring fenced beds for CF inpatients.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		7	
Do the en suites have:	Toilets?	1	
	Wash basins?	7	
	Bath or shower?	1	
Do CF patients have to share any bathroom facilities?		Yes	Only one ensuite room on current CF ward.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	
Visiting hours – are there allowances for CF patients’ families out of normal hours?		9.30am to 9.30pm	Flexibility around these hours depending on circumstances.
Is there access to a fridge/ microwave either in the side rooms or in the parents’ kitchen?		Yes	All rooms have fridges as well as there being a fridge, freezer and microwave for patient use.
What facilities are provided for teenagers?			Adult service, however there is a day room with games, snooker table etc. Snooker table, free internet access for all patients, ping pong table (off-ward).

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Patient gym is off-ward, but patients can have a piece of exercise equipment in their room if requested.
What facilities are there to help with school and further studies?		For patients in higher education, free internet access to enable course work completion and uploading to college/university etc, so that inpatients studying do not fall behind their counterparts where possible.
Is there a relatives' room?	No	
What internet access is there?	Yes	Free internet access for all patients.
What facilities are there to enable students to continue to work and study?		For patients in higher education free internet access to enable course work completion and uploading to college/university etc so that inpatients studying do not fall behind their counterparts where possible. The same applies for those working to enable close contact to be kept with work colleagues etc if desired by patients, this also allows those running their own businesses to keep abreast of work-related matters.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Each patient room is about to be equipped with steam sterilisers (currently on order).
What facilities are provided for those with MRSA?		MRSA patients are cared for on one of our outlying ward rooms. W6 has ensuite facilities, whilst the two CF rooms on W1 share a bathroom.
What facilities are provided for those with <i>B. cepacia</i> ?		As above, care is provided on outlying wards, usually W6 for these patients.
What facilities are provided for those with other complex microbiology?	Yes	
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	However, special infection patients are unable to visit the CF ward.

Additional comments

The CF centre has been campaigning hard for the past two years for the middle floor of the centre to be converted to a 16-bedroom all ensuite ward facility (plans have already been drawn up). This area has been vacant for this period whilst efforts have been made to obtain suitable funding to move this forward. A decision is still awaited with regard to this. However, there has been much support from the Chair of the Board which continues as it will be impossible to care for a growing, ageing CF population with only seven beds and only one of these ensuite for non-special infection CF patients.

	Hospital name	University Hospital Llandough
	Yes/no/number/N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	All parking at this hospital site is free of charge
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	However, no two patients would be booked to attend radiology or DEXA scan on same date/time and both departments would be informed prior if it so happened that two patients with CF needed investigations around same time so that adequate provision could be made to ensure cross-infection control measures were not compromised. We have very close links with both departments and work together to slot patients in appropriately.
Do patients have to wait at pharmacy for prescriptions?	Yes	All patients advised not to wait in the pharmacy waiting area if there is a queue, to avoid any potential risk of sitting next to another CF patient.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/feedback boxes?	Yes	

Appendix 7

Panel members

Stephen Bourke*

Alison Morton

Blaithin Odea

Keith Thompson

Alison Gates

Tanya Cavany

Claire Nelson

Penny Martin

Lynne O'Grady

Sophie Lewis

Dominic Kavanagh

Consultant

CF Specialist Dietitian

CF Specialist Psychologist

CF Specialist Pharmacist

CF Specialist Physiotherapist

CF Specialist Nurse

Specialised Planner

CF Specialist Social worker

Head of Clinical Programmes

Clinical Care Adviser

Clinical Care Adviser

Royal Victoria Infirmary, Newcastle

Leeds General Infirmary, Leeds

Kings College Hospital, London

Royal Brompton Hospital

Churchill Hospital, Oxford

Castle Hill Hospital, Hull

Welsh Health Specialised
Services Committee

Papworth Hospital, Cambridge

Cystic Fibrosis Trust

Cystic Fibrosis Trust

Cystic Fibrosis Trust

*Clinical lead

Attended on day in **Bold**.

cysticfibrosis.org.uk

© Cystic Fibrosis Trust 2015. Registered as a charity in England and Wales (1079049) and in Scotland (SC040196). A company limited by guarantee, registered in England and Wales number 3880213. Registered office: Cystic Fibrosis Trust, 2nd Floor, One Aldgate, London EC3N 1RE.