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British Thoracic Society

BIPRS

Peer review report

Churchill Hospital, Oxford adult CF service

15 January 2015

1. Executive summary

Overview of the service

A medium-sized service, historically slow to grow, apparently on the cusp of expansion in patient numbers. It is in a long overdue and exciting period of transition to new premises but this is not guaranteed. The move must include outpatient, inpatient and cepacia/abscessus facilities. Allocation appears “just enough” but potentially insufficient if expansion occurs. The team appears highly skilled, well qualified (including three non-medical prescribers), well organised and highly appreciated by their patients. On paper they have “just enough” staffing to manage but there is mission creep to bronchiectasis which is ill-defined, with gaps which are either not covered or covered by good will, and at John Radcliffe there is a risk that the service will be further subsumed by respiratory medicine and the acute take. Medical cover is consultant led and highly praised by patients but job planning does not recognise the time given during the working week, out of hours or for research. There is insufficient middle grade cover and no dedicated junior cover in the current arrangement which, if not addressed, will be unsustainable.

Good practice examples

- Consultant-led service with robust auditing, guidelines, attention to detail and a strong research profile.
- The peer review team repeatedly commented on the allied health professionals’ (AHP) commitment and going a second mile.
- Patients look past poor facilities and praise the team for communication, knowledge and their availability.

Key recommendations

- The move to John Radcliffe must include all elements of the service with adequate provision for *Burkholderia cepacia* complex (Bcc) and *Mycobacteria abscessus* patients.
- Care must be taken to ring fence the CF service from the acute work that will undoubtedly increase as Respiratory Medicine is integrated in the acute medicine service.
- Staffing levels and their ability to cross cover sickness and annual leave and freedom to attend international meetings needs to be addressed particularly dietetics, pharmacy and admin/clerical. The social worker (SW) post has been gestating for many months and should be actioned. It is noted that if appointed at 0.5 WTE this post will almost immediately be below recommended levels and the potential to release nursing and psychology time will not be fully realised.
- Staff grading appears inadequate. It is noted that some service leaders are banded below their peers within the Trust and peers in similar positions in other CF centres eg (in order) a lead dietitian at Band 6 with this level of experience and responsibility is inappropriate. The prescribing lead nurse appears to have wider responsibilities beyond CNS status that need to be reviewed to determine if appropriately funded by cystic fibrosis. The Band 5 nurse, if fulfilling a Band 6 role should be recognised as such. The lead physiotherapy grading and structure similarly needs to be reviewed.
- Equipment. There should be clear budgetary lines for provision of basic equipment, notably nebulisers, without access to which, choice of optimal inhaled prophylactic treatment is compromised. These should be funded and available to staff based on clinical assessment of need according to guidelines.

Areas for further consideration

- Training of staff and the creation of a pool of skilled ward nurses in the new premises is mandatory – will some nurses be transferred from the current ward? It is unlikely the CNS complement will have time to support the new ward for eg Portacath care for any length of time.
- Dedicated junior staffing should be considered as the new unit expands. It is noted that there is very little middle grade cover, there have been problems recruiting to Fellow posts historically and the unit provides little formal training for respiratory trainees in CF beyond a supernumerary attachment including one clinic; registrars are otherwise exposed as part of their routine ward work. A formal attachment, eg three months in the Specialist registrar training rota could be considered.
- Consequently the service is dependent on consultant staff, extended hours, unpaid on-call and weekends or run by non-specialists and juniors from without respiratory. This is unsustainable.
- Despite the hard work of team members there was a lack of 'resilience', in senior and junior medical cover, single-handed dietetic and pharmacist cover admin cover. The service has demonstrable weakness in covering annual leave or sickness and compromises the ability of members to attend meeting.
- Cleaning of inpatient and outpatient areas, segregation by staff, PPE wear etc will need to be reviewed, including cleaning staff on the ward.
- Additional requirements include computing and Wi-Fi access to support school and college, TV (which should be free) and recreational facilities, and exercise equipment. These are required as part of the service specification.

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

Models of care

Summary

The service has developed despite poor accommodation and relative lack of resourcing (recently improved) and seems to have well organised and thought-out protocols, referral links, joint clinics and transition arrangements. Integration within respiratory and infectious disease is good at one level but is necessitated by lack of base ward and junior and middle grade staffing placing heavy reliance on consultants for continuity of (medical) care.

Out-of-hours cover is largely non specialist, including non-respiratory and is commented on by patients. In the new unit a cohesive ward would provide a focal point for out-of-hours calls and triage; a general ward would be less able (diluted skills and less integration in the CF team) to manage this. Weekend cover within respiratory has been supportive and needs to be considered in the new place.

Multidisciplinary care

Summary

The MDT appears strong and cohesive, though there is lack of recognition of seniority and responsibility, dependency on single handed practitioners working beyond contracted hours and hence lack of resilience which will be unsustainable in the near future if growth accelerates as predicted.

The willingness to teach and participate in National interest groups by allied professionals is noted but there appears to be difficulty in attending eg European and American CF meetings.

All of the above appears to apply particularly to pharmacy and dietetic cover. It is noted that nursing staff cross cover empty posts, junior staff have been appointed as more senior staff could not be found and there have been delays in appointments compounding the problems and detracting from appropriate development within disciplines.

Space for the MDT is lacking, especially for SW and psychology who have neither office nor clearly defined area to see patients and, given the often private nature of their consultations, this should be addressed.

Principles of care

Summary

Audit suggested many clinics were not covered by a consultant, and the patients commented they hadn't seen a consultant but this was in the interregnum before WF was appointed and this has probably been addressed (it was noted even then patients were highly complementary when they did see a consultant) and there are gaps in annual review. It is noted that the availability of five OPD rooms gives opportunity to increase clinic segregation but one wonders how they will be covered by medics or AHPs.

Gaps in pharmacy and dietetic provision during annual leave and illness are unacceptable and need to be urgently addressed.

Delivery of care

Summary

Feedback is excellent in almost all regards.

The usual – car parking, food, waiting for pharmacy comments arise.

Further thought to infection control re *M. abscessus* and BCC and cleaning of rooms may be warranted (from observation) but patients comment hand hygiene and practices by staff appears good.

Commissioning

Summary

The unit currently provides a service which is obviously highly appreciated by patients and shows good outcomes. There are however elements of infrastructure and staffing which have caused some problems in further advancing the unit's growth and provision of an excellent service. The planned move of the whole service to new accommodation on the John Radcliffe site therefore presents both opportunities and challenges to the unit and Trust to ensure that the foundations are put in place for future growth and improvement. Therefore as part of the move the Trust's plans should make certain that:

- Staffing numbers and banding support a resilient structure that allows opportunities to grow the service safely and sustainably.
- Training of staff new to the service is well planned and timely.
- That the new physical infrastructure is organised to allow the most effective and efficient way to manage this cohort of patients including infectious disease unit (IDU) requirement.
- That systems and protocols such as out-of-hours access to advice are reviewed to ensure they are still effective in the new location.
- Patients should be fully involved in the development of the new facilities.
- That the service builds on the new physical proximity with the paediatric service, including further development of patient transition within the framework of a recognised programme such as 'Ready, Steady, Go'.
- Funding of the cystic fibrosis service should not be adversely affected by demands from other elements of the respiratory service.

The service is currently at a crossroads and a well-planned and executed move is an essential part of taking the service forward. It is important that the commissioners visit after the move to review how it went and assess the impact on service provision and patients with the unit.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	93

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		N/A	N/A
	Number and median(range) FEV1 % pred by age range and sex	16–19 years	6; 85 (49.98–103.77)	6; 72.62 (55.83–101.68)
		20–23 years	9; 63.23 (20.94–135.13)	13; 46.09 (24.53–112.19)
		24–27 years	7; 66.46 (35.42–99.59)	3; 100.49 (1 set of data)
		28–31 years	10; 69.2 (19.06– 105.07)	3; 95.42 (61.97–110.96)
		32–35 years	4; 59 (38.48–95.36)	3; 75.59 (50.61– 109.12)
		36–39 years	6; 53 (33.41–99.31)	6; 83.99 (51.6–95.01)
		40–44 years	5; 33.3 (19.06–67.56)	3; 48.38 (31.77–64.99)
		45–49 years	0	3; 95.91 (59.67–132.15)
		50+ years	6; 73.04 (48.76–90.41)	0

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=53); 20 (38%)	(n=40); 21 (52.5%)
	Number of patients and % with BMI <19 split by sex	8 (15%)	7 (17.5%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	36 (39%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	29 (81%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	11 (31%)
	Number and % of patients on chronic macrolide without chronic PA infection	10 (18%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

Standards suggest consultant cover at 0.5 and 0.3 WTE for 75 and 1.0 and 0.5 WTE for 150 patients with middle grade cover 0.9 and 1.8 WTE respectively. After a recent uplift there 0.4 and 0.45 consultants with 0.1 supernumerary SpR cover. This level of staffing is just short of the standard for 75 patients but there are 108 patients currently and thus staffing is significantly short of recommendations and hence the consultants estimate they work 0.6 and 0.5 WTE in CF and up to 50 hours a week in the office excluding on call.

Middle grade cover is borrowed from respiratory. There are plans for four fellows, one of which will be C, funded from within CF and due to go to advert shortly but we understand recruitment has failed once to date. If recruitment fails the respiratory rota will be under pressure and daytime cover to the wards clinics and likely CF will be at risk.

The service is only medically viable because of integration with respiratory colleagues who admit patients in their name, manage them with their juniors and provide weekend ward rounds (overall excellent cover) but largely non specialist and WE cover is provided by goodwill from the CF consultants above this as needed. This needs to be carefully reviewed in the new place with new colleagues in the context of the acute medical take. Although the actual respiratory beds are only expanding from 22–27 including six CF, much respiratory medicine is currently managed by generalists and there is a risk this work will be gradually absorbed by respiratory medicine as outliers.

The Trust management made great claim for the contribution of CF to the respiratory research portfolio but Dr Will Flood has no research time in the job plan and the work is essentially free to the Trust and is unsustainable.

There appears to be a lack of transparency in the funding of CF which the consultants are trying to address. The operational service manager (Kathryn Hall) explained efforts were being made to clarify this and enhance CF funding. With Payment by Results (PbR) tariffs and Service Level Agreement (SLR), pharmacy data and fixed costs around staffing and a known 23% Trust overhead it should be possible to come up with a model onto which ward costs (will the hospital or the CF service pay for the beds and wards staffing they use (both models exist)?) can be mapped. The monthly meetings between consultants and service managers are considered good practice.

The bronchiectasis service is growing and it's not clear how this is supported, though there is 1 WTE money for nursing and 1 WTE physiotherapist (above the CF compliment). Care must be taken that the 'Cinderella' diagnosis in respiratory which has no clear funding stream does not erode CF capacity.

The service has grown slowly from 1999 to date at a net gain of five patients per year. The catchment area is large and competing centres include London, Birmingham and Southampton. It is not clear what the transfer rate from the children's centre would have been and it is not clear of the potential 18 paediatric patients this year how many will come to the adult service but with integration at the JR the likelihood is more will stay. The past trend may be informative with current numbers and banding allowing a predictive model for future growth. If expansion goes into double figures each year staffing and physical capacity in the new centre will be stretched very quickly (based on rule-of-thumb six beds per 100 patients).

Summary

Overall the consultants clearly lead and deliver a good service with support from a strong team. "Nursing support is excellent, that's how it works" (said about how the standards are maintained despite a lack of medical cover). Prior to the peer review there had been concern that the move

will not include the full service and result in two-site working. This would be unacceptable. On peer review day there was managerial optimism that the move will happen, including inpatient, outpatient and cepacia/abscessus provision and if this is so it undoubtedly has the potential to be beneficial. It is however also clear that they and their team have little spare capacity to manage the service, let alone integrate in to the new space and train clinic, ward and medical staff in the ways of cystic fibrosis. The impact of bronchiectasis, acute respiratory medicine and a larger bed pool with the acute medical take has the potential to be highly detrimental unless the service is ring fenced, especially if there is no (or a shared) base ward, and a culture integrating the ward specialist OPD CF team cannot be fostered.

Areas of good practice:

- Team leadership, patient feedback, availability and generally going the second mile.

Areas for improvement:

- Audit data suggests consultant presence in clinic and for AR feedback is poor. This was before Dr Flight started and may have been improved further by the increase in Dr Chapman's hours. However with five clinic rooms and an intention to increase the numbers of clinics to facilitate segregation, without additional consultant time, the consultant presence in clinic could actually be reduced.

Recommendations:

- Review job plan, the actual hours worked (it should be time sensitive), the out-of-hours cover, uplifted for the lack of middle grade staff (whose work the consultants will inevitably do) and recognise time contributed to research – especially if the Trust is going to promote this as an area of excellence.
- Delineate CF from bronchiectasis and acute respiratory medicine so that the funding and team effort are protected as best they can be – this will be crucial for sustainable resilience if numbers increase at the new forecast rate.

Specialist nursing

The clinical nurse specialist (CNS) establishment should be ~2 WTE for 108 patients, per the Cystic Fibrosis Trust's 'Standards of Care (2011)'. There are 3.2 WTE nurses in post. 1 WTE Band 7, 2 Band 6 nurses, each 0.6 WTE =1.2 WTE) a Band 5, 1 WTE joined the team in January. A decision to appoint an entry level nurse (Band 5) to a specialist nursing post was made following recruitment difficulties. There is 1 WTE Band 6 for bronchiectasis. All nurses cross-cover both services.

The CNSs facilitate care and management of patients with CF and non-CF bronchiectasis. The split between these specialities is not clear; the non-CF bronchiectasis workload appears significant. There is no facility for community care for patients. The hospital does not have shared care arrangements with other CF centres. The CNS's cross-cover each other for sickness, study leave or other absenteeism.

One of the team is a qualified non-medical independent prescriber (practising) and one is undertaking her exams. Only one of the CNSs has attended an ECFS conference in recent years; they have never attended a NACFC. The team members are active in local CF meetings and teach annually at Brooks University (cardiothoracic training). All are members of the CF nurses association, the lead nurse was, until recently, a regional representative of this group. The CNSs have undertaken some limited audits but not participated in research recently. Audit is planned for the future.

The team dynamic is difficult to establish. The nurses may work in some isolation. At least one nurse attends every MDT meeting. They see 100% of outpatient attendees. Their role in outpatients is the undertaking of spirometry and coordination of the clinic flow as well as being involved in direct patient care. Team members are working closely with diabetes nurses to further increase their knowledge.

The lead CNS has many managerial responsibilities, many of which appear historical including much social work type duties which will be relieved with the appointment of a new social worker. Many of these duties are undertaken in her own time and are likely to detract from her clinical responsibilities and in supporting her junior colleagues.

The nurses undertake a nurse-led bronchiectasis clinic and review patients on an ad-hoc basis to start IV antibiotics at home as required. They insert long-lines and coordinate the home IV programme. The lead nurse has significant involvement in budget planning, staff appointment and steering groups within the department and wider Trust.

The ward nursing team cares for patients with a variety of respiratory conditions and has excellent experience in the management of patients requiring non-invasive ventilation. The team members are committed to caring for patients with cystic fibrosis, but feels that they would benefit from greater teaching and support, especially with regards to managing challenging behaviour.

Areas of good practice:

- The positive feedback from the patient satisfaction questionnaire is undoubtedly a reflection of the high standard of nursing care and personalised service received despite the poor facilities available to the team.
- The lead nurse appears pivotal in the management of the CF service. She has significant involvement in budget planning, staff appointment and steering groups within the department and wider Trust.

Areas of improvement:

- Improve outpatient clinic organisation. There is a requirement for greater community support for patients when at home. This will help enhance the care for patients receiving IV antibiotics at home, end-of-life care and for patients for complex psycho-social issues.
- The junior grade of some of the CNS team and a lack of educational opportunities causes concern and should be supported.
- Improved teaching and support of ward nurses via visible presence on the ward and study day.
- Ward nurses should be encouraged and facilitated to attend ward rounds and MDMs to enhance their involvement in patient care.

Recommendations:
The CNS establishment should undertake a job-mapping exercise to review its workload and establish the ratio between CF and non-CF bronchiectasis. This could be used to develop a business case for CNSs in non-CF bronchiectasis and ensure CF is adequately staffed. The impact of the non-CF bronchiectasis workload is not clear and there should be greater role definition.

A review of the lead nurses' managerial responsibilities should be undertaken to establish the appropriateness of some of her duties and ensure her time is best spent in direct patient care and the support of her junior colleagues.

The CNSs should have identified time and resources to increase their educational awareness and their professional profiles. Specifically they should be encouraged and supported to attend both ECFS and NACFC conferences where they are presenting their own audit and research.

Admin Support

1.0 WTE admin support available. Clearly very organised as it books clinics and annual reviews, and is responsible for all data inputting into Port CF. No annual leave cover is available and so no data inputting can occur when the data manager is absent.

Recommendation:

- Review of admin support time available to provide, as a minimum, leave cover. As the clinic increases in size, so an increase in admin support will be required.

Physiotherapy

The adult cystic fibrosis physiotherapy team is funded to staff 2.58 WTE for 104 patients. This essentially meets the national guidance for physiotherapy staffing. The team also covers the growing bronchiectasis service and is funded for 1.0 WTE Band 6 to deliver this. The team comprises of 5 qualified members of staff with 1 x 0.58 Band 7, 1 x 0.6 Band 6 (static), 1x 0.4 Band 6, 1x 1.0 Rotational Band 6 and 1.0 Band 6 (Bronchiectasis). There is also funding for an additional 0.24 WTE Band 6 to support musculoskeletal physiotherapy provision. This is in the process of recruitment. The team provides inpatient care, clinic reviews, annual reviews, outpatient sessions and a limited homecare service for patients with end-stage complex disease. Daily Band 3 time is available (0.4 WTE) to assist in the delivery of individualised exercise programmes. Annual leave and sick leave cover is provided from within the team.

The team is actively involved in CF MDT meetings and ward rounds (and therefore has input into all aspects of patient management) and also try to hold regular physio team meetings to discuss individual patients.

The team is actively involved in the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) with the Band 7 currently serving as Treasurer and a Band 6 as Membership Secretary. Attendance at ACPCF meetings and committee meetings is therefore excellent. Static members of the team have also been able to attend the ECFS in June 2014. Opportunities are available for research, and funding has been secured for a telemedicine project, however implementation of this is difficult due to clinical pressures.

The Band 7 has audited many aspects of the physiotherapy service (see submitted docs) which demonstrate that the standard of care being delivered is high. This is reflected in patient feedback. The Band 7 is also driven to make service improvements, the most innovative of which is the development of a Band 3 post to provide daily supervised exercise sessions for patients. The Band 7 is also a non-medical prescriber. Provision of appropriate nebuliser equipment is challenging as no dedicated budget is available.

Areas of good practice:

- Highly specialist and knowledgeable team led by a dedicated Band 7, delivering excellent and individualised care.
- Excellent level of physio input for patients on home IVs and at weekends.
- Innovative use of Band 3 role in delivery of a daily exercise programme for in-patients.

Areas of improvement:

- Designated budget for nebuliser equipment – specifically eFlow nebuliser units and consumables.
- Involvement in research.
- Local teaching and service development currently compromised by staffing pressures due to vacancies and increasing pull of the bronchiectasis service on physiotherapy time.

Recommendations:

- This is a growing service and therefore PT staffing should continue to track the nationally recommended staffing levels. In addition, grading of the more senior staff should reflect the level of leadership required to deliver continued service developments and facilitate research, as well as the management of an increasing team and patient caseload.
- The team should be encouraged to become more involved in research as there are excellent opportunities available but again, this will need to be supported by appropriate staffing.
- A review of the PT input into the bronchiectasis service would determine the extent to which PT time is being pulled away from CF and identify any staffing requirements for that service.

Dietetics

There is currently 0.6 WTE (three days a week) Band 6 dietitian dedicated to CF at the Oxford adult centre. There should be approx 0.7 WTE for 108 patients of which most are full care. A small amount of bronchiectasis patients are also seen by the CF dietitian. For two days of the week no specialist CF dietitian is available. There is some support from a dietetic support worker. No formal cover for annual/study leave etc. High priority inpatients and urgent home enteral feeding patients' enquiries are covered by a non-CF Band 6 dietitian. Approx 6-7% have gastrostomy tubes. Mean BMI is 22.8kg/m2. Annual assessments are split into two parts, and seen by the dietitian at one part at least. The dietitian attends weekly MDT meetings and clinic. 93% of inpatients seen at least twice a week. CF ward rounds are not always possible to attend. Actively involved in the key life stages with care planning at MDT meetings. Dietitian has experience of working in CF paediatrics, which is helpful in the transition process. They attended European CF conferences in 2010 and 2011, and the regional CF meeting yearly since 2008. Also a member and current secretary of the Dietitians' Cystic Fibrosis Interest group and attends bi-annual meetings.

Service improvements/audits for last five years:

- Developed locally-based carbohydrate counting education (INSIGHT) of CFRD patients.
- Audit of vitamin D levels and an algorithm developed as a result of this to optimise patients' vitamin D levels.
- 24hr food service provision – three menus and snack boxes available.

Areas of good practice:

- Inpatient and outpatient service provision and attendance at MDT meetings/clinics despite limited cover.
- Diabetes education – carbohydrate counting, – Vitamin D supplementation and optimisation.

Areas of Improvement:

- Food provision. It's likely the move to John Radcliffe site will improve this, with a larger canteen and retail food outlets.
- Collaborative diabetes care planning and dietary education for in and outpatients
- Dietitian availability for inpatient/outpatient service & full cover for annual leave etc.

Recommendations:

- Improved food provision and facilities for CF patients and CF MDT (office environment/IT).
- Increased funding to enable full service provision and review of skill mix and banding (a lead dietitian in CF service with this amount of experience would be considered appropriate to be banded at 7).
- Continued support and focus on research/audit/education/training and conference attendance.

Pharmacy

The clinical pharmacy service funded by the CF centre comprises 0.5 WTE Band 8a pharmacist. The size of this clinic falls between the historic recommendations of 0.5 WTE pharmacist for 75 patients and 1 WTE for 150 patients (this figure does not include homecare provision). The large scope of practice within the CF service and commitments to the respiratory service suggest that 0.5 WTE is insufficient to meet the increasing demands of the CF service.

The pharmacist is very highly committed, and despite being 1 WTE, works many additional unpaid hours per week to sustain the service. The pharmacist attends one CF MDT and one CF clinic per week and is available by bleep for further clinics, advice and – as in independent prescriber – to prescribe home IV antibiotics (there is a home IV antibiotic service for infusions supplied in elastomeric devices) and non-IV homecare medicines. The pharmacist is involved in the annual review and transition clinics. All inpatients on the dedicated respiratory ward are reviewed twice daily; outliers are reviewed at least at the beginning and end of their admission.

There is limited additional support – a Band 7 pharmacist supports half a day per week to attend a respiratory consultant ward round; there is no CF cover when the pharmacist is on leave. Ward cover is provided by a junior pharmacist with no provision for CF MDTs, clinics or generating homecare prescriptions. Therefore, if a patient has had a nebulized drug trial, they must wait until the pharmacist returns from leave to have a supply established.

All high cost drugs (HCDs) have already been repatriated from primary care; prescriptions are written by the pharmacist, however, there is no administrative support. Homecare prescribing takes approximately 7.5 hours of the pharmacist's time per week.

The pharmacist has been involved in audits (eg adherence to nebulized/inhaled therapy), and guideline generation and update. The pharmacist has been instrumental in writing the original 'Oxford CF Guideline' which has been an invaluable resource. The pharmacist is involved in horizon scanning, training other pharmacists in the management of CF, and finance reporting. The pharmacist is a member of the UK CF pharmacist group and has attended the annual meeting but has not had the opportunity to attend other national or international conferences.

Areas of good practice:

- The pharmacist is clearly a very committed individual who is driving the pharmacy service for CF forward despite competing demands on time.
- Early repatriation has occurred bringing all HCD prescribing in-house.
- Patients can contact the pharmacist by email to order CF medicines or with any queries.

Areas for improvement:

- There is insufficient cover for annual leave to sustain the service which has been established.
- There should be a contingency plan for homecare in the absence of the CF pharmacist to prevent delay in access to HCDs.

Recommendations:

- Staffing levels to be reviewed – there is a clear need to increase the amount of ring-fenced pharmacist time for CF. Consideration should be given to what additional support is required for respiratory to sustain the service to patients with CF (eg Band 7 pharmacist).
- Rate of growth of service will be important to determine if 0.5 WTE 8a also needs to increase to 1 WTE for cystic fibrosis.

Psychology

- The service has a 0.8 WTE Band 8C clinical psychologist in line with recommended standards for the patient population (0.7-0.8 WTE).
- The psychologist is a member of the UKPP-CF and attends the national conference and adult CF study days.
- The psychologist attends MDT meetings, CF business meetings, annual reviews and transition clinics and meets all new patients (transition and late diagnoses).
- Psychology referrals are received from MDT members and patients are able to self-refer. Inpatients and outpatients are seen within one week of referral. Occasionally patients are referred on to other community mental health services and are then reviewed by the CF psychologist.
- Informal consultation/support is provided to the MDT as well as more formal staff training (for example motivational interviewing). Research projects exploring treatment burden and young adult's experience of transition have been completed.

Areas of good practice:

- The psychologist is a highly experienced clinical health psychologist and the psychology service is very well integrated in the MDT, of which it is a valued part.
- The psychologist screens all patients at annual review, providing excellent opportunity for psychological issues to be identified.
- There is no waiting list and patients are seen quickly.

Areas for improvement:

- There is no dedicated space for therapy or staff supervision to occur. Clinic space to see outpatients can be limited and is under increasing pressure. The psychologist is based within a busy, open plan office and there is no quiet or private space for consultation, staff support/ supervision or confidential telephone conversations.

Recommendations:

- Psychologist to attend an international CF conference.
- Dedicated space for therapy as well as private space to offer staff supervision. A quiet space for confidential or sensitive telephone conversations and reflection.

Social work

Currently there is no social worker in post in the CF team but the decision to appoint one has been made and agreed. The team are now waiting for a job description and a banding level to be agreed. The options are between a Band 6 or 7. This will be decided through consultation with other CF teams and their recommendations and experiences. The post is for a 0.5 WTE role.

In the meantime, the social work role falls on CNS team and the psychologist to offer their experience and skills to perform the tasks usually carried out by a social worker.

Areas specific to a social work role such as coordinating a safeguarding situation or a vulnerable adult issue are handed over to the hospital Safeguarding lead, which means communication and details are not concentrated within the team.

For all other social work related issues the CNS team will cover these with the knowledge that they have in areas such as benefits, housing, employment and annual reviews to name just a few. This will not be in any way comprehensive enough to support a large group of adult CF patients, amongst whom will be patients with complex needs and considerable support as the nurses have their own roles and responsibilities to meet. Ultimately there are issues that the nurses are unable to deal with either due to time constraints or other pressures. In these cases, patients are sign posted to the appropriate professionals outside the team.

This CF service would benefit from a dedicated social worker, as recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)' as an integral part of the CF team, bringing with it time and expertise which are considerably more difficult to provide from other under resourced areas within the team.

Recommendations:

- Recruitment of qualified social worker as per the Cystic Fibrosis Trust's Standards of Care to contribute to development of transition, annual assessment and specialist key life stages support.
- Consultation with other centres on how to achieve this.
- In the meantime, careful thought and close management need to be given regarding social work issues to ensure that the patients are properly supported.'

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	2	0	4	7	4	3	2
Female	1	1	5	3	3	0	0

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	25	4	5	0
From the ward staff	9	9	4	2
From the hospital	10	13	6	1

Areas of excellence:

1 Accessibility – advise from CF team
2 Communication from CF team
3 Outpatients – cross-infection

Areas for improvement:

1 Inpatients – food/ward/cleanliness
2 Communication between staff and patients
3 Hospital building and parking
4 Doctors – continuity and sharing knowledge with other consultants

6. Appendices

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

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

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

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

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

Churchill Hospital

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	
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%	Red	Red	This figure should improve with added consultant hours already in place.

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	Safe – yes. Effective – no.	No	Safe, not effective, lacks resilience.
	% 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	But attendance at ECFS and/ or NACFF conferences appears patchy.
	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	Very impressive folder.
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's Standards of Care	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	But a close run thing and, if no middle grade, suggests reliance on nurse-led clinics.
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Red	Amber	The impression given was this is already improving with two new appointments in diabetes.

3 Principles of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
3.1 Infection control	% of patients cared for in single en suite rooms during hospital admission	100%	Green	Green	
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	Beware as there are only six rooms in John Radcliffe for 108 patients and rising – already averaging 4–6 and up to 9 admissions.

3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Red Minimum turn around 48hrs.	Unknown	The service was expected to move in-house in Jan 2015 and has not (Feb).
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	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	See 3.7.
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	N/A	N/A	
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%	Amber	Amber	See 3.5. It is arguable that in adults with normal results this frequency is unnecessary.

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% 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	Current standards for OPD letters is 48 hours - see below.
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	It is doubtful these will be maintained if dependent on current admin staffing levels.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	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	Single-handed dietitian without cover from colleague without CF experience, which suggests this will not be the case in holidays and is unsustainable.
	% of patients reviewed by a CF specialist dietitian a minimum of twice during an inpatient stay?	100%	Green	Green	
	% availability of a clinical psychologist at clinic	100%	Green	Green	Single-handed practitioner – see above.
	% availability of a clinical psychologist for inpatients	100%	N/A Is available as required.	Green	Documented short waiting time and good capacity but no A/L cover.
	% availability of a social worker at clinic	100%	Red Funding identified.	Red	Long delay in appointments already noted and commented on.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a social worker for inpatients	100%	Red. Funding identified.	Red	
	% availability of a pharmacist at clinic	100%	Green	Green	Single-handed practitioner with non-specialist back up by phone when away.
	% availability of a pharmacist for inpatients	100%	Green	Green	As above.
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%	1	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	5	Red	But very good reporting and governance structure – good practice.
5.3 End-of-life care	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all Shared care services	100%	N/A	Green	

Appendix 2

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Oxford Service 104 patients	Estimated deficit
Consultant 1	0.5	1	1	0.41	0.2
Consultant 2	0.3	0.5	1	0.45 (recent uplift)	0
Consultant 3			0.5		N/A
Staff grade/fellow	0.5	1	1		0.6 Red
Specialist registrar	0.4	0.8	1	0.1	0.6 Red
Specialist nurse	2	3	5	2.32	0
Physiotherapist	2	4	6	2.54	0
Dietitian	0.5	1	2	0.6	0
Clinical psychologist	0.5	1	2	0.8	0
Social worker	0.5	1	2	0	0.6 Red
Pharmacist	0.5	1	1	0.5	At risk
Secretary	0.5	1	2	1.0	Combined, at risk.
Database coordinator	0.4	0.8	1	0.0	See above.
Physio Assistant (Band 3)				0.4	
Clinical Support Worker				1.0	

Appendix 3

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre Churchill Hospital, Oxford	
Number of active patients registered (active being patients within the last two years)	98
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	93
Median age in years of active patients	28
Number of deaths in reporting year	1
Median age at death in reporting year	47

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	12 (13%)
	20–23 years	22 (23%)
	24–27 years	10 (11%)
	28–31 years	13 (14%)
	32–35 years	7 (7%)
	36–39 years	12 (13%)
	40–44 years	8 (9%)
	45–49 years	3 (3%)
	50+ years	6 (7%)

Genetics	
Number of patients and % of unknown genetics	12 (13%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=53); 20 (38%)	(n=40); 21 (52.5%)
Number of patients and % with BMI <19 split by sex	8 (15%)	7 (17.5%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	4 (50%)	5 (71%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		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	6; 85 (49.98-103.77)	6;72.62 (55.83-101.68)
	20–23 years	9; 63.23 (20.94-135.13)	13; 46.09 (24.53-112.19)
	24–27 years	7; 66.46 (35.42-99.59)	3; 100.49 (1 set of data)
	28–31 years	10; 69.2 (19.06- 105.07)	3; 95.42 (61.97-110.96)
	32–35 years	4; 59 (38.48-95.36)	3; 75.59 (50.61- 109.12)
	36–39 years	6; 53 (33.41-99.31)	6; 83.99 (51.6-95.01)
	40–44 years	5; 33.3 (19.06-67.56)	3; 48.38 (31.77-64.99)
	45–49 years	0	3; 95.91 (59.67-132.15)
	50+ years	6; 73.04 (48.76-90.41)	0

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	12
	20–23 years	22
	24–27 years	10
	28–31 years	13
	32–35 years	7
	36–39 years	12
	40–44 years	8
	45–49 years	3
	50+ years	6
Number of patients with chronic PA by age group	16–19 years	4
	20–23 years	5
	24–27 years	5
	28–31 years	3
	32–35 years	3
	36–39 years	9
	40–44 years	4
	45–49 years	1
	50+ years	2

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	2 (2%)
Number and % of *cenocepacia*	1 (1%)
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	9 (10%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	17 (18%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	17 (18%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	38 (41%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	17 (18%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	3 (3%) with PH; 2 (2%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	7
Number of patients referred for transplantion assessment in previous three years	15
Number of patients receiving lung, liver, kidney transplants in previous three years	4

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	72
	20–23 years	104
	24–27 years	200
	28–31 years	108
	32–35 years	10
	36–39 years	40
	40–44 years	5
	45–49 years	0
	50+ years	20
Number of days of home IV therapy in reporting year split by age group	16–19 years	167
	20–23 years	834
	24–27 years	304
	28–31 years	360
	32–35 years	69
	36–39 years	213
	40–44 years	143
	45–49 years	56
	50+ years	36
Total number of IV days split by age group	16–19 years	239
	20–23 years	938
	24–27 years	504
	28–31 years	468
	32–35 years	79
	36–39 years	253
	40–44 years	148
	45–49 years	56
	50+ years	56

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV1, % predicted <85% (ie below normal) on DNase	(n=69); 35 (51%)
If not on DNase, % on hypertonic saline	2(3%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	36 (39%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	29 (81%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	11 (31%) with Chronic PA; 10 (18%) without

Appendix 4

Patient survey

Churchill Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	2	0	4	7	4	3	2
Female	1	1	5	3	3	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	21	11	2	1
Communication	19	7	5	3
Out-of-hours access	3	11	9	4
Homecare/community support	9	9	1	2

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	19	11	1	3
Waiting times	14	10	5	2
Cross-infection/segregation	20	11	2	1
Cleanliness	15	15	3	2
Annual review process	14	13	7	0
Transition	8	6	2	1

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	6	8	5	4
Cleanliness	3	10	6	4
Cross-infection/segregation	9	9	2	3
Food	0	8	4	9
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	15	5	2	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	7	9	4	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	14	8	1	0
Availability of equipment	14	15	2	1
Car parking	3	6	11	11

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	25	4	5	0
Of the ward staff	9	9	4	2
Of the hospital	10	13	6	1

Comments about CF team/hospital

"When my CF got to the point when transplant was now or never, the CF staff and ward staff together supported me through it. However sometimes there were issues, but usually ironed out. Recently I haven't used the CF team to their full potential due to receiving my bilateral lung transplant in April 12. However, I always feel I can ring the nurses, dietitian, physios or members of the team for help and advice. My health has seen me be supported by other NHS institutes as well."

"Continuity of doctors appalling – rarely see a consultant. Outpatients disgusting, also day care ward. Not enough clinics."

"Overall the care provided by the Churchill has been excellent. There has been a long delay in recruiting the replacement for Dr Bennett and this has meant that other doctors have seen me rather than one of the two CF consultants – not ideal."

"I have access to a fantastic team and have never had any problems."

"Hospital bed availability is often an issue – long wait for bed to be available. Care on ward as inpatient less good than care as outpatients due to other demands on staff eg other patients need their time. Parking is a disaster – pleas to use park/ride lost on me as I need to be there for a specific time and then leave to come home."

"They are great – always find time for me and very supportive and friendly. They're like another family to us patients – makes everything that little bit easier. Doctors are excellent in their care and advice too."

"I feel that the cepacia patients do not get the care, the time and support that the other CFs receive, especially patients on J12."

"I feel listened to and cared for at the CF unit (outpatients) at the Churchill. I like it that if the doctors don't know about something they are not afraid to say so, ask what I think and so on. It is all well organised and all the team are very kind."

"CF team are great but the hospital is way behind the times. Free Wi-Fi for patients is a must as it allows us communication to the outside world. Food is shockingly poor."

"Our CF team are just the best, can call them anytime and it doesn't have to be about CF, they are a magnificent emotional support group as well as fantastic in their CF role."

"The team are superb sometimes the ward staff are less rigorous in their attention."

"When admitted to the John Warin ward and not Geoffrey Harris, you are very isolated and out of the loop and really seem to be forgotten about. Lack of communication between doctors and ward on procedures. A very bad experience!"

"You have in my opinion missed an important question regarding the rooms on the CF ward; our rooms have non opening windows that overlook a waiting room. Being in hospital in summer is unbearably hot and like a green house. It is not conducive for any respiratory patient."

"Very happy so far."

"Excellent. Cannot state the improvement on my old centre."

"Team hospital are great. You can ask about everything and they answer. They are really helpful and friendly."

"Run-down buildings, parking expensive, can be difficult to find parking. Good CF team who care."

"I have full confidence in my CF team and the best care possible."

"A really caring and committed CF team who are realistic about the treatment demands. Very supportive."

"Having had a lung transplant I do not visit the hospital as often as I did."

"The CF team are great at supporting me at home, very friendly."

"The CF unit is in a very old part of the hospital and is not up to standard. The ward does not always implement instructions given by the CF team and communication when an inpatient is poor. Food is appalling and does not support the needs of a CF patient."

"Always seen promptly and all questions answered during clinics."

Appendix 5

Patient interviews

Patient A

Patient A found the segregation measure fine at the Churchill Hospital's CF centre. He added that staff are "good at keeping us away from each other and quick to get us into cubicles."

Patient A usually sees all the multi-disciplinary team (MDT) at clinic and has spirometry in the same room, though out of choice he doesn't see a dietitian (as he's pancreatic sufficient), or psychologist. He feels very much involved in the joint decision making on changes to treatments. He cited waiting at pharmacy as a problem sometimes due to his length of wait.

Annual review: Patient A is offered annual review each year and had his last one in spring 2014. He sees the whole MDT at annual review and explained that his DEXA scan takes place at the John Radcliffe; all other assessments at the Churchill. Outcome of annual review is fed back to Patient A by letter and verbally at his next clinic – "Letter with full list of data, levels etc…same as GP version".

Inpatient care: Patient A's last admission he described as "not easy… a three to five-hour wait". He's always admitted to an en suite side room on the Geoffrey Harris ward. He described the ward nurses' knowledge of CF as "reasonable... agency staff not as switched on as senior staff". He felt that medications were given on time.

Although Patient A doesn't feel a need for physio on the ward he has use of an exercise bike, usually when admitted.

Patient A described the food on the ward as "rubbish... hospital food, very poor in terms of taste, presentation and portions". However, he did add that he could order a lunch box.

Homecare: Patient A has home visits from the clinical nurse specialist (CNS) for Tobramycin levels.

Good practice/positive comments:

- The quality of nursing staff and consultants.
- Flexibility of response from team – ie availability of outpatient clinic slots at short notice.

Areas for improvement/less positive comments:

"Car parking is horrendous – the other side of the hospital, so you have to walk right through the hospital."

"Not a comfortable or welcoming building – ie an aged building."

"It's a (long) walk from anywhere to the outpatient clinic and ward."

Patient B

Patient B is happy with segregation measures at the Churchill's adult CF unit; "they always put us straight into rooms at clinic". He felt that some staff and patients use the hand gels more than others and he sees those he needs to see amongst the MDT at outpatient clinic.

Patient B didn't feel that decisions on his care are always made with his view in mind, adding "There's an endemic opinion that 'I know better'" rather than taking his view into full consideration. Patient B felt the collection of medications from pharmacy was a slow process, adding, "nurses put tickets in early as much as possible, but I still end up waiting at times… and cross-infection's a risk there".

Annual review (AR): Patient B is offered AR every year and has had it this year. He doesn't receive a written annual review report, but has a consultation two weeks later with the consultant or the team will phone if urgent issues arise. He sees all of the MDT at annual review.

Inpatient care: Patient B waited several days to get a bed on the John Warin ward. He said he usually gets an en suite side room, but it depends on the ward you're admitted to. He added "They do try to isolate you." Describing the nursing care on the Geoffrey Harris ward, Patient B explained: "They are keen on doing what they've been told to do… not that knowledgeable about CF, but imagine senior nursing staff have better insight into CF."

Referring to the timing of his medications on the ward, Patient B described them as "not on time… sometimes after midnight… it's frustrating and tiring". Patient B described the ward food as "excellent, the hospital menu and extras". In terms of exercise, Patient B referred to the hospital gym and said they didn't mind him walking around as exercise, or using a stepper provided in his room.

Homecare: Patient B requires no home visits. He attends the Churchill Hospital for his Tobramycin levels. He doesn't require PEG/NG feeds.

Good practice/positive comments:

"CF team always there, a phone call away."

"Warm and friendly atmosphere which makes my wife happy/comfortable" – ie at ease.

"The Churchill Hospital location is convenient."

Areas for improvement/less positive comments:

"To improve internal communication and communication with patients – Dr Chapman has already instigated efforts to improve this."

"There should be more consultation (sharing of knowledge) between specialists from other CF centres to solve patients' treatment issues."

Patient C

Patient C felt that segregation measures at Churchill are really good and that staff adhere strictly to the use of hand gels and encourage patients to as well. She sees the whole MDT at clinic and has spirometry in the same room as consultations, adding: "It's perfect, and they get you a drink."

Patient C felt that decisions on treatments are made very much with her view in mind, adding: "They and I know what's best… I'm good at questioning and they are too." Referring to waits at pharmacy to pick up medications prescribed, she said, "I can wait a while, but it's pretty much within half an hour."

Annual review: Patient C is offered annual review each year, the last one in summer 2014. All her assessments take place at the Churchill, apart from her DEXA scan at nearby Nuffield Hospital. The outcome of her annual review is reported back at the next clinic appointment and a letter follows.

Inpatient care: Patient C is usually admitted the same day as the outpatient clinic appointment, into an en suite side room on the Geoffrey Harris ward. In terms of the ward staff nurses' understanding of CF, she added: "It depends on who you get... sometimes not given correct doses, though totally on time, in fact bloods are taken very early sometimes."

Patient C said she hated the ward food which she described as "basic", but added, "there's a special menu for CF patients each day – lunch time and dinner time".

Patient C described exercise opportunities in terms of the exercise bike, but added that the exercise took place under a glass cover facing onto a waiting room/area, so that there's no air and consequently it's hot in summer and cold in winter.

Homecare: Patient C has a Portacath, goes to the Churchill every six weeks for check-ups and port flushes. CNS does home visits for her Tobramycin levels. She has no supplementary (NG/PEG) feeds.

Good practice/positive comments:

- "Fantastic staff who listen."
- "Good infection control and segregation measures."
- "Quick admission to the ward."

Areas for improvement/less positive comments:

- Improve ward facilities to improve circulation of fresh air.
- "Employ someone (housekeeper?) to make snacks/drinks especially in the evening, or provide somewhere patients can do this safely."

Patient D

Patient D goes regularly to the Churchill for her CF care. She explained that the clinic team always ensures patients are not kept waiting at reception, but are directed straight to a side room. She sees the whole MDT or has access to them at clinic – she mainly goes to see the physio, but can see the dietitian, nurse, psychologist and presumes there is a social worker but hasn't been told about one. She feels that the discussion around her treatments are "very inclusive" so she feels fully involved in decisions. The pharmacy experience is generally ok, usually waiting 30–40mins, but sometimes much less when the CF nurse may have taken prescription to pharmacy early.

Annual review: Patient D is offered annual review each year and has had this year's annual review. She sees the whole MDT, has all assessments at Churchill, apart from DEXA scan at the Nuffield Hospital, and receives a letter reporting back outcomes of the annual review.

Inpatient care: Speed of admission is "hit and miss" according to patient D. Christmas last year she couldn't get admitted and "struggled on at home". Sometimes she has to wait in the day care unit from the morning until admission around 5–6pm (the Geoffrey Harris ward). On one occasion, had to be seen on the head and neck injury ward for her CF care due to shortage of beds – "not a good experience".

Patient D felt that staff nurses on the Geoffrey Harris ward have "ok" knowledge of CF, some better than others and some don't understand – eg the need for blood sugar monitoring two-hour post meal. She said it depends on the nurses and the handover as to how good the care is.

Patient D felt the food on the ward was "terrible" – ie restricted choice, bizarre combinations of food (doughnuts provided at breakfast as calorific extras). Her husband has had to bring in microwave ready meals to ensure she maintains weight.

Patient D referred to exercise opportunities on the ward as "generally very good" – ie "they take you on walks along the ward and outside the hospital and provide the exercise bike each day if you are up to it". She added, "The physios are very good and also at the weekend due to good handover."

Homecare: Patient D mixes her own home IVs, but explained that in the last 18 months a homecare package has been available for SOME IV drugs – eg Colomycin, but not Meropenem or Tazobactam. Her Tobramycin levels are checked at the Churchill or at the GP surgery.

Good practice/positive comments:

- The quality of the physiotherapy team for outpatients and inpatients.
- Communication on day care is good (also team is reachable by phone, text, and generally responds the same day).

Areas to improve/less positive comments:

- Communication on ward (for family) from respiratory consultants needs to be better.
- Facilities need massive improvement – "we're on a condemned ward".

- Parking needs improving.
- Ward food needs improvement – the dietitians do their best to secure improvements and additional snacks but communication can get lost between dietitian and kitchen – eg baked potato and cheese comes back as a "baked potato and a hunk of cheese".

Patient E

Patient E felt that segregation at outpatient clinic is very good. He had never seen room cleaning between patients, but assumed this happens. He felt clinic staff are good at using hand gel, but has only been asked a couple of times to use the gel himself. He added that "the staff wipe down equipment". Patient E sees, or has access to, all members of the CF MDT, who rotate between patient rooms, but felt he didn't need to see the pharmacist. He felt that overall decisions made by the CF team about his treatments are done so with his view in mind, adding: "they are good at listening to my concerns, although the physios' approach can be too blunt on occasion."

Annual review: Patient E is offered annual review each year and had his last annual review in the summer. He sees or has access to the whole MDT, but his diabetes and liver specialists see him at separate clinics during the year. His annual review is reported back to him via written report/letter "a few weeks" after the first part of his annual review. A copy is sent to his GP. He rang the CF team over a concern relating to something mentioned in his annual review and would have preferred to have been telephoned about it for reassurance. Patient E felt that communication with his CF team/service is very good – "they make a real effort even if busy to make time for me and usually ring me back within two hours".

Inpatient care: Patient E explained that he's always admitted same day, but sometimes to a different ward from the Geoffrey Harris ward when beds are full. This causes Patient E anxiety as he explained different rules apply on different wards to self-medicating and it presents problems for visitors/family looking for him. He added that only once has he not been accommodated in an en suite side room, and then he was transferred to such a room as soon as possible.

Patient E felt that the CF knowledge/understanding of staff nurses on the Geoffrey Harris ward was "pretty good" although not as in depth as clinic staff, but better than on other wards he'd been on where he felt nursing staff's understanding of CF and his requirements was "really poor".

Patient E described the timing of medications as "pretty good, barring emergencies" on the Geoffrey Harris ward, but on other wards he spoke of four to five-hour delays to IVs on occasions. He said he did not usually take exercise on the ward as, when well enough to do so, he'd complete his IVs at home and exercise at home. However, he acknowledged that the physio team offers use of the running machine and exercise bike in the gym.

Patient E described the food on the ward as "pretty good, good portions, no extras offered". He takes his own snacks into hospital.

Homecare: Patient E has home IVs which he mixes himself. He mentioned that if he's not well enough to be assessed mid-course the CNS has offered to make a home visit – so far he felt this hasn't been needed.

Good practice/positive comments:

- "CF team are very good. They treat me as an individual, listen, pay attention and understand the significance of my issues."
- "CF team are quick to see me if I need treatment started – ie they find me a bed quickly."

Areas for improvement/less positive comments:

- Car parking – "It's atrocious. If not arriving early in the day you can wait 30 mins for a parking space, seems to have got worse since the redevelopment."
- "Physiotherapists' approach when making points to me on occasions – ie not so blunt."
- "Need for more evidence of cleaning rooms between patients."

Patient interviews on peer review day

Patient one

Male patient 43 years old. Admitted to hospital in October 2014.

Lives two miles from the hospital and travels to appointments by car, gambling on parking arrangements by parking illegally in the hope of not getting a ticket, up until now he has been successful. There are no direct bus routes to the hospital.

Areas of excellence:

- Consultant is outstanding and can be contacted at any time.
- Physiotherapist is always at hand and he has good communication with her, always receives treatments twice daily.
- Technical expertise from team.
- Safe surroundings
- Hospital very local to home.

Areas for improvement:

- Staff shortages/low staff levels at times.
- Handover of staff takes place between 7.30–9pm, during which time he cannot have any treatments.
- Communication when short staffed.
- Other disruptive patients on ward.
- Food serving times are too early, lunch at 12.30pm dinner at 5.30pm, after which is a long period of time until next meal. His wife brings him in home cooked meals as after being an inpatient for so long the menu is now lacking variety for him. The special CF diet menu offers no exciting choices.
- Smoking at the hospital main entrance- the patient likes to go out for a walk, smokers congregate at the main entrance and there are cigarette stubs all over the floor near a bench where he sits.
- Exercise bike available for use is in the MDT room which is accessed via a four-bed bay.
- The bathroom is too cold to have a shower, there is a hole in the wall behind the toilet, which only requires filling.
- The corridors are freezing cold.
- He requires more blankets in winter as the room is cold; he also brings in his own fan from home for when the room is too hot.
- If he is having treatment when the cleaners do their rounds, his room will then miss cleaning, he will have to ask for his room to be cleaned, there appears to be no rota.
- Cleaners will not knock, just walk in to clean bins, lack of privacy.

He thinks the move to John Radcliffe Hospital will be beneficial as long as the facilities are appropriate to cystic fibrosis.

Patient Two

Male patient 19 years old. Lives in Reading and his journey to hospital takes 40 minutes. He moved over from care at the Royal Brompton and has only been with Oxford for a couple of months. He has been admitted to the John Warin ward (infectious diseases) he has *M. abscessus* and is on day six of his stay of six weeks. He does feel quite isolated in his room with only his grandmother as daily visitor and contact with his friends via social media. He has brought in his own IT for use

When asked if he would be interested in having contact with other CF patients via the Cystic Fibrosis Trust's social media channels, his direct answer was "no"; he would however be interested in finding out how to be more involved in drug trials in the future.

Areas of excellence:

Food is quite good and he is fairly happy with it so far.

- He is happy with his present room, he refused the original room offered as it was very basic and would have to have an external bathroom allocated for his use.
- The consultant is excellent.
- He receives physiotherapy twice daily.
- He has been offered weights to keep in his room for exercise, however he is not interested and prefer his IT games.

Areas for improvement:

- Parking is an issue, his grandmother has to walk a long way from the car park when visiting daily.
- TV charges for use during his six-week stay are £315.
- The Wi-Fi connection is intermittent and frequently loses connection.

Patient Three

Interviewer spoke with Patient Three via telephone. A male of 28 years old. He lives between Reading and Newbury and it takes one hour to drive to hospital, his mother or girlfriend usually drive him in. He does not know if there are concessions for inpatient parking.

Areas of excellence:

- The consultant and staff are amazing! He is a complicated case with airway restriction and highly infected, having IVs for three months, he felt completely informed of his condition and treatment by his consultant and team.
- Geoffrey Harris ward, only good experiences whilst an inpatient and the facilities are good.
- He can leave the ward and visit the coffee shop or go into Headlington to have a break from his room.
- Mobile contact 24/7, always a rapid reply rate if he leaves a message.
- The move to John Radcliffe is a positive and welcome change

Areas for improvement:

- Parking is an issue. Recently for an IV review it took his mother 45 minutes to find a parking space.
- He does not feel that his CF "unique dietary" requirements are catered for and these could be improved. His parents bring him food in and staff are not opposed to takeaways being brought in.
- Outpatient buildings are old and tired and lacking space, he feels that there is a risk of cross-infection.
- Temperature varies dramatically throughout corridors and rooms, very cold in areas.

Generally the patient would be reluctant to move away from his present team and stated that if they moved he would probably have to follow them.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Churchill 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)	No	Small cramped area with 25+ seats. Patients do not wait here.
Do patients spend any time in waiting room?	No	On arrival patients are taken for H&W and then to clinic room.
Is there easy access to toilets?	Yes	Both male and female.
Where do height and weight measurements take place? Is this appropriate?	No	On arrival patients are taken to reception office, behind reception desk and can be in view of other patients.
Where are the lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	Yes	Rooms are very dated, shabby and in need of a total update and refurbishment.
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?	N/A	Joint clinic.
Transition patients – can they get tour of outpatients' facilities?	Yes	If required.
Transition/new patients – do they get information pack?	Yes	

Additional comments:

- There are five rooms for clinic use. Appointments are staggered, 8-10 patients attend each clinic. Décor is dated and shabby.
- The lung function laboratory is off the corridor close to outpatients department.

Environmental walkthrough: ward

Ward name: Geoffrey Harris

Microbiology status: Respiratory

		Hospital name	Churchill Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable. The ward is in the newer part of the hospital, however it is a long walk from the outpatients.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		10	
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	Each room has a lockable bedside cabinet.
Can you use mobiles?		Yes	
If there is a television, is the service free?		No	Purchase by top up card. Minimum of £5 for eight hours.
If no, are there any concessions for CF patients?		No	
Are there facilities to allow parents/ carers/partners to stay overnight?		No	Patients would have to bring in their own camp bed, there is sufficient space in the room for this.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	CF patient families are not restricted to hours.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?			Fridge only in room. No access to microwave.
What facilities are provided for teenagers?		No	

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Patients can have an exercise bike in their room. They are taken to the physiotherapy gym with the therapist by appointment.
What facilities are there to help with school and further studies?		None
Is there a relatives' room?	No	MDT room is the only room that can be used for private meetings.
What internet access is there?		Wi-Fi, however the connection is periodic and depends on where you are in the hospital.
What facilities are there to enable students to continue to work and study?	None	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sink in room.
What facilities are provided for those with MRSA?		Patients would be admitted to the John Warin ward (Infectious Diseases).
What facilities are provided for those with *B. cepacia*?		Patients would be admitted to the John Warin ward (Infectious Diseases).
What facilities are provided for those with other complex microbiology?		Patients would be admitted to the John Warin ward (Infectious Diseases) or other ward depending on infection.
Are patient information leaflets readily available on ward?	Yes	Various leaflets displayed. CF leaflets can be given on request or directed to External website.
Transition patients – can they get a tour of ward facilities?	Yes	If requested CNS would give a tour.

Additional comments

- Total of 108 patients.
- There have been a maximum of 11 patients admitted at any one time to the ward, however this amount is not usual.
- The ward is situated in the newer part of the hospital on level 2, access can be gained by stairs or lift.
- Inpatients is getting busier due to patients ageing.
- The day room can be accessed via two of the four bay rooms, which is off putting for patients to use as they have to walk through either ward passing patient beds.
- Some of the rooms have a window view to outside with opening windows. The other half of the rooms have a view to an atrium, with windows which cannot be opened and a view of a waiting area at the level below. The rooms are equipped fit for purpose, however they are very bland in decor.
- The top-up machine for the TV service on the ward was not working during the visit, the recommended machine to top up was quite far away from the ward.

Day Case Unit

- This is used for annual review, IV urgent cases and 'bug'-infected patients attend clinic here.
- The reception area is not always manned, there is a notice to inform a number for the patient to call on arrival, and the area appears quite deserted.
- There is an outside seated area for use, this looks unkempt and in need of renovating. The MDT room is opposite the outside area where the team can see who is arriving at the DCU. The waiting area has six seats and there are three side rooms for CF use. The rooms are very dated, have very draughty, rotten windows and in need of updating.
- The MDT room is very cramped and hot, too small for all the team at once. Not all the team can access IT at all times.

Physiotherapy gym

Situated in the DCU, facilities are: cross-trainer, exercise bike, treadmill. These have been donated by a local gym that closed down. Also has a trampette, exercise ball, free weights and table tennis. All equipment is cleaned after use and labelled as clean for future use. This gym is a very basic facility, very drab, shabby decor and in need of updating.

John Warin - Infectious Diseases

Situated in a separate building near to the out patients. Reception area houses a large waiting area. The rooms are of an older style, equipped and fit for use. Not all rooms have their own toilet, this can be allocated for personal use.

John Radcliffe Hospital

A move is scheduled for May 2015. Visiting this hospital was a total contrast to the Churchill Hospital, the proposed ward is located on level five accessed via four lifts. There are a total of 20 beds, all with en suite wet-room/shower; the rooms are located on two sides with the entrance in the middle, housing 10 rooms each side. There is a relatives' room with seating, TV and own toilet cubicle with sink. The ward also has a treatment room, ample storage rooms, MDT room, sluice room at each side and secretary office. The team is hoping to be allocated a designated area with six en suite rooms.

- The pharmacy is located near the main entrance, this is a very open area ideal for prescription collection on the way out.
- The outpatient area is a very large, bright, spacious and modern area with a vast amount of seating and a main reception desk.
- The clinic rooms are a dramatic improvement to the Churchill clinic rooms, they are well equipped and bright. The team is not yet sure which part of the outpatients facility will be allocated to them for use.

	Hospital name	Churchill Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Inpatients can get a reduced price and would park in the staff car park. Pay and display can be flexible and attendants are aware that appointments can over run, staff can contact the parking attendant to arrange this.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	General respiratory signage, clear from old entrance at back of hospital. Not clear from new main entrance, which can be a very long walk.
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?		Pharmacy – script is taken by team and collected by patient on way out. Radiology – staggered appointments, which works well if patients arrive on time. Separate waiting rooms for ultrasound, x-ray and CT scans, all of a good size in a newer part of the hospital. DEXA – not likely to meet other patients, one per month.
Do patients have to wait at pharmacy for prescriptions?	No	There is a separate room which could be used to isolate patients if they needed to wait.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	Manned office near new main entrance. Advertised throughout hospital on walls.
Are there patient comment/ feedback boxes?	Yes	Red boxes. In outpatients, DCU and on ward.

Additional comments

- Parking charges; up to 30 minutes free. One to two hours – £1.40, two to three hours – £2.80, three to four hours – £5.60, over four hours – £7. Lost ticket charge £7. Parking is free overnight if arriving after 8pm and leaving before 8am. Disabled bays – free parking.

Appendix 7

Panel members

Dr Frank Edenborough*	Consultant	Northern General Hospital
Keith Thompson	CF Pharmacist	Royal Brompton Hospital
Catherine O'Leary	CF Specialist Psychologist	Wales Adults CF Service
Mark Butler	CF Clinical Nurse Specialist	London Chest Hospital
Melanie Powell	CF Specialist Dietitian	London Chest Hospital
Tracey Mathieson	CF Specialist Physiotherapist	Kings College Hospital
Zoe Dallow	CF Social Worker	Heartlands Hospital
Sian Summers	Commissioning	Wessex, South Region
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Jacqueline Ryan	Executive Assistant	Cystic Fibrosis Trust

*Clinical lead for peer review

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