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British Thoracic Society

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Peer review report

South East Scotland Adult CF Service

21 November 2014

1. Executive summary

Overview of the service

The Edinburgh adult cystic fibrosis (CF) centre provides care for adults with CF managed at Western General Hospital in Edinburgh, Ninewells Hospital in Dundee, Raigmore Hospital in Inverness and Dumfries & Galloway Royal Infirmary. Despite the significant logistical challenges posed by this large geographical area, the very enthusiastic, skilled and experienced team provides excellent care with good outcomes. However, several parts of the multidisciplinary team (MDT) are significantly under-resourced and this requires urgent attention. In particular, additional CF medical, specialist nursing, physiotherapy, psychology and pharmacy staffing is required to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)' recommendations. The most glaring gap in staffing is the complete lack of a dedicated CF social worker in any of the four hospitals, which puts additional strain on the already under-staffed CF MDT. We strongly recommend that appropriate CF social worker staffing be introduced to address this unacceptable situation, perhaps by exploring a joint appointment with a charitable organisation.

Good practice examples

- Experienced MDT providing excellent CF care in challenging geographical circumstances.
- Excellent links with the transplant team in Newcastle and a well-developed transition process.
- Good opportunities for patients to take part in cutting-edge research, in particular the UK CF Gene Therapy Consortium trials.

Key recommendations

- Urgent review of staffing levels is required within the existing CF MDT – in particular medical, specialist nursing, physiotherapy, psychology and pharmacy staffing require uplifts to meet the Cystic Fibrosis Trust's Standards of Care recommendations.
- The introduction of CF social worker staffing is urgently required – this would provide patients with the expertise of a dedicated social worker as well as reducing the burden placed on the existing under-staffed MDT.

Areas for further consideration

- Succession planning is required to replace the planned retirements of CF consultant staff, as well as cover for maternity leave at Western General Hospital. Opportunities for improved out-of-hours middle grade cover should also be explored at the Western General Hospital. The Edinburgh service is ideally placed to provide CF training for specialist registrars (SpR) aiming to fill future CF consultant vacancies and the CF MDT is very keen to fulfill this role.
- The creation of a CF clinical nurse specialist (CNS) post with a specialist interest in CF-related diabetes (CFRD) at Western General Hospital would provide additional support for the existing CF specialist nursing team. The recommended 1.0 whole time equivalent (WTE) uplift in CF specialist nursing staffing at Western General Hospital would support an increase in the provision of the existing homecare service.
- The food provision for inpatients at Western General Hospital was a frequent source of complaints and consideration should be given to improvements in this regard.
- The introduction of Wi-Fi access for CF inpatients at the Western General Hospital and Ninewells Hospital would improve the patient experience and is recommended.

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

Models of care

Summary

Good overall performance.

Multidisciplinary care

Summary

Good overall performance, however the identified deficiencies in MDT staffing need to be urgently addressed. An additional 1.0 WTE CF specialist nurse, 1.8 WTE qualified CF physiotherapist, 0.25 WTE CF pharmacist and 0.7 WTE CF psychologist staffing is required at the Western General Hospital to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)' recommendations. An additional 0.5 WTE qualified CF physiotherapist, 0.2 WTE CF pharmacist and 0.2 WTE CF psychologist staffing is required at the Ninewells Hospital to meet Standards of Care recommendations.

The lack of a CF social worker is a major concern and this needs addressing (elaborated in the 'Commissioning' section below).

Principles of care

Summary

Good overall performance.

Delivery of care

Summary

Good overall performance, however the risk matrix identified four main deficiencies:

- Inpatients in Dundee are only seen once weekly by a CF consultant, rather than twice weekly as recommended by the Cystic Fibrosis Trust's Standards of Care. We therefore strongly recommend that additional CF medical staffing be provided at Ninewells Hospital to allow inpatients to be reviewed by a CF consultant twice weekly.
- The lack of a CF social worker is a major deficiency and this needs addressing (elaborated in the 'Commissioning' section below).
- Insufficient CF pharmacist time is highlighted by the lack of availability of a pharmacist for inpatients and clinic visits in Edinburgh. As previously stated, the panel strongly recommends that an additional 0.25 WTE pharmacy time be provided at the Western General Hospital. There is no specialist CF pharmacist in Dundee and we recommend an additional 0.2 WTE pharmacy staffing be provided at Ninewells Hospital. There is no specialist CF pharmacist in Inverness or Dumfries & Galloway and the additional staffing in Edinburgh will help support these services.
- CF physiotherapy staffing requires an urgent uplift in line with the Cystic Fibrosis Trust's Standards of Care recommendations, particularly since CF physiotherapists are routinely required to provide cover for non-CF patients in Edinburgh and Dundee (see 'Commissioning' section on the next page).

Commissioning

Summary

The panel was very concerned that several members of the CF MDT were routinely expected to provide care for non-CF patients. This further reduces the already significantly under-resourced staffing available to provide care for CF patients. This impacts on the ability of the MDT to meet the Cystic Fibrosis Trust's Standards of Care and urgent action is required to reduce this unacceptable misuse of CF staffing. This particularly affects the CF physiotherapy staffing in Edinburgh and Dundee, teams that are already significantly short-staffed. In addition to being expected to provide cover for the cardio-respiratory team, the impact of the introduction of seven-day working further reduces the time that the CF physiotherapists have available to provide care for CF patients. This further limits their ability to participate in audit and research. In an attempt to compensate for this shortfall, the panel strongly recommends that additional CF physiotherapy staffing be provided in line with the Cystic Fibrosis Trust's Standards of Care recommendations as previously stated.

The review panel feels that the lack of a CF social worker available to any of the patients cared for by the Edinburgh adult CF service is a major deficiency. Although other members of the CF MDT (in particular the under-staffed CF specialist nursing team) do their best to provide this role, this does not adequately bridge the gap left by the lack of an appropriately qualified and registered specialist CF social worker. Initially a 1.0 WTE CF social worker is required in Edinburgh and this would go a long way to support CF patients cared for within all four hospitals. An additional 0.5 WTE CF social worker would eventually be required in Dundee to meet the Cystic Fibrosis Trust's Standards of Care recommendations. The panel recognises that social workers are not traditionally included within clinical teams in Scotland, but we strongly recommend that an innovative approach be taken to address this important issue. A model of care that is commonly successfully employed in England and Wales is that of a CF social worker being jointly funded by a charitable organisation. The panel suggests that if such appointments could be secured, this would be a trail-blazing initiative that would set an excellent example for other CF centres in Scotland to follow.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	Edinburgh 137 Dundee 45 Inverness 24 Dumfries 6

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		0	0
	Number and median(range) FEV1 % pred by age range and sex	16–19 years	6; 56.6 (30.43-78.32)	6; 60.81 (34.97-89.11
		20–23 years	7; 58.44 (16.27-122.1)	17; 61.53 (16.27-107.36)
		24–27 years	15; 54.67 (19.76-100.38)	13; 76.58 (26.32-100.17)
		28–31 years	15; 70.84 (19.75-102.44)	10; 73.52 (18.51-96.59)
		32–35 years	10; 61.63 (23.6-96.79)	4; 69.41 (67.67-92.8)
		36–39 years	5; 84.43 (50.69-122.81)	4; 47.65 (22.05-125.41)
		40–44 years	2; 57.62 (55-60.23)	3; 78.32 (61.15-128.28)
		45–49 years	5; 80.42 (59.83-92.97)	3; 95.33 (46.3-101.78)
		50+ years	5; 90.32 (90.03-90.61)	7; 66.6 (22.96-120.68)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	N=70, 28 (28%)	N=67, 31 (46%)
	Number of patients and % with BMI <19 split by sex	7 (10%	12 (18%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	65
	Number and % of patients with chronic PA infection on inhaled antibiotics	25 (38%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	51 (79%)
	Number and % of patients on chronic macrolide without chronic PA infection	27 (38%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

Edinburgh (183 patients)

There are three consultants based in Edinburgh (Dr Helen Rodgers, Dr Alastair Innes and Dr Maeve Smith), each of whom has 0.5 WTE directed towards CF (1.5 WTE total). CF inpatients are cared for on a one-in-three basis and all consultants have sufficient experience to carry out their CF roles. However, Dr Smith is currently on maternity leave, which places an additional burden on the remaining two consultants. At the time of peer review, there were no plans in place to provide maternity leave cover for Dr Smith beyond January 2015. In addition, Dr Innes is planning to retire within the next two years and succession planning is required to appoint a suitably trained replacement. It was suggested that Dr Innes may choose to return part-time, potentially partnering with Dr Smith when she returns following maternity leave, but this would still leave the CF consultants under-staffed. Currently Drs Rodgers and Innes cross-cover during periods of leave and feel that this works well, but the panel was concerned regarding continuity of cover during periods of unplanned absence eg sick leave.

- There is the facility for all inpatients to be medically reviewed seven days a week, if necessary.
- CF consultants carry out ward rounds at least twice a week in Edinburgh.
- There is a middle grade CF doctor, providing adequate daytime junior staff cover. However, there is limited middle grade cover outside of the normal working day, with CF patients being reviewed by a medical SpR if required out of hours. There is often a respiratory SpR on call at Edinburgh Royal Infirmary, but since they are based in a separate hospital, they are unable to physically review CF patients at the Western General Hospital.
- The Edinburgh adult CF centre is ideally placed to provide CF training for SpR's aiming to fill future CF consultant vacancies and the CF MDT is very keen to fulfill this training role.
- There is a clear centre director (Dr Rodgers).
- Medical clinicians attend either the ECFC or NACFC every year, as well as the BTS Winter meeting.
- There is representation at the yearly Cystic Fibrosis Trust Centre Directors Meeting.

Dundee (47 patients)

- Dr Rodgers travels to Dundee once per week (Thursday) to review the CF inpatients and see CF outpatients. CF inpatients are also reviewed at least once per week by a respiratory consultant (Dr Tom Fardon), who gained CF experience during his SpR training although is not a CF specialist. CF inpatients in Dundee are therefore only generally seen once per week by a specialist CF Consultant, which does not meet the the Cystic Fibrosis Trust's 'Standards of Care (2011)' recommendations. The CF MDT in Dundee feels well supported by Dr Rodgers and members know that they can contact the Edinburgh team if required. However the Dundee CNS team reported that they were not always able to clearly identify medical staffing support at the Dundee site for day-to-day decision-making. The panel was concerned that during periods of Dr Rodgers' leave, this risks further reducing specialist CF consultant input in Dundee. The panel suggests that additional CF specialist consultant input should be provided in Dundee. The panel was informed that a respiratory lecturer was due to start in May 2015, which may provide Dr Fardon with some additional support. The development of a CF nurse consultant post would be another potential way forward, but this would not replace the medical expertise provided by a specialist CF consultant.

Inverness (24 patients)

- Dr Hulks, a respiratory consultant with some CF training, manages any CF inpatients in Inverness and communicates with the Edinburgh team when required.
- Dr Rodgers or one of the other CF consultants travels to Inverness every three months to see CF outpatients (with physiotherapist, dietitian, pharmacist and CF nurse).
- Dr Hulks is retiring and succession planning is important to ensure that his replacement has sufficient CF training to manage the CF patients cared for in Inverness.

Dumfries & Galloway (six patients)

- Dr Little provides medical input for any CF inpatients (maximum one at any given time).
- CF patients that require specialist care are transferred to Edinburgh.

Areas of Excellence:

- Edinburgh service is well staffed (1.5 FTE) with very experienced clinicians and good clinical outcomes.
- Good involvement in research.
- Good links with paediatric and transplant centres.

Areas of improvement:

- CF inpatients in Dundee should ideally be seen by a specialist CF consultant twice every week.
- Out-of-hours and leave cover are concerns.
- Succession planning is a concern (Dr Hulks and Dr Innes are planning to retire in the next 24 months; maternity leave cover is not in place from January 2015).

Recommendations:

- Need ideally to provide additional CF consultant cover in Dundee.
- Lack of out-of-hours/weekend respiratory middle grade cover would ideally be addressed.
- Need to develop firm plans for replacing Dr Innes and Dr Hulks.

Specialist nursing

Edinburgh:

183 Patients 2 WTE

Introduction

The CNSs are members of the Cystic Fibrosis Nurses Association. They regularly attend Scottish network meetings.

Areas of Excellence:

- The CNS team communicates well and is a passionate, supportive and dedicated team, with an open environment for discussion within the MDT.
- Homecare, day case planning and clinic coordinating are all managed by the CNSs.
- Committed to undertaking service improvement audits – have audited the annual review and transition process.

Areas of improvement:

- Historically, availability of a nurse manager for CNS support and appraisals has been infrequent. In light of a recent allocation of a nurse manager this needs to be monitored.
- Development of the homecare service provided by the CNSs, which has been cut back due to staffing shortages.
- The CNSs are passionate about undertaking service improvements and contribute to ward nurse education but again this has been limited due to staff shortages.

Recommendations:

- Employment of additional CNS – 1 WTE to meet Standards of Care recommendation. 183 patients with 2 WTE is becoming increasingly more difficult to manage and has had a direct impact on the community care that can be offered and research time availability.
- Employment of social worker. Increasing demands are being made on the CNS's time with patient's psychosocial issues with no CF social worker provision.
- The CNSs acknowledge the employment of a UK CF Registry Manager has helped greatly with data collection but support for the planning of annual reviews may now need to occur as this has an impact on CNS time.

Dundee:

47 patients: 1.1 WTE

Two CF CNSs who work well together, offering support to the CF community. The CNSs are members of the Cystic Fibrosis Nurses Association, and one is secretary to the group. They regularly attend Scottish network meetings and national and international conferences.

Areas of Excellence:

- Flexible and adaptable working, adjusting to the needs of the CF patients under their care with high patient satisfaction.
- The CNSs are committed and passionate about their working role and are active members of the Scottish group and the CFNA.
- The CNSs are committed to expanding the service they provide: one CNS is currently undertaking the nurse prescribing course with plans for the other CNS to do the same.

Areas of improvement:

- Increased cross-communication with the CNS team in Edinburgh in order to promote continuing professional development and skill sharing.
- The CNSs feel they would like to forge links with the local hospice service and provide teaching to Hospice staff.

Recommendations:

- Identification of out-of-hours contact. The CNSs currently offer 24-hour patient phone contact. Presently they feel this is not being abused but has potential to occur.
- The CNS team feels well supported by the clinical lead at the Edinburgh site but there needs to be a process in place to clearly identify medical staffing support at the Dundee site for day-to-day decision making.

Inverness:

24 Adult patients :1 WTE

Well supported by the MDT. Lesley's role consists of supporting both paediatric and adult patients. Currently there is a consultant with a CF interest who is approaching retirement. The Edinburgh MDT provides an outreach in Inverness when approximately six to nine patients will attend. Leslie attends the Scottish CF CNS Group and acts as the Group's Chair.

Areas of Excellence:

- The CNS has been dedicated in continuing her professional development. She has completed her Master's Degree in Advanced Practice in Long Term Conditions.
- The CNS has shared policies and guidelines with the lead CF centre in Edinburgh.
- Due to the overlap in the service between paediatrics and adults, patients pending transition can be identified early and the process commenced.

Areas of improvement:

Recommendations:

- Workforce planning regarding replacement of the CF consultant in light of his pending retirement.
- Explore inpatient support for those admitted to Raigmore for intravenous antibiotics (IVABs), in line with the need for centre care.

Dumfries & Galloway Royal Infirmary:

Six patients: A small number of patients in a rural location. Patients are looked after by local physicians and travel to Edinburgh for OPD visits and annual review.

Areas of Excellence:

- A small team that communicates well.
- Rapid access for review is provided. A 'no delay' approach for patients to commence home IVABs.
- CF care provided by a well-qualified respiratory nurse specialist who attends CF education days twice a year.

Areas of improvement:

- The CNS would like to be able to establish more time, as required, for the support of the unwell and end-of-life patients within their own home.

Recommendations:

- Clinic letters from patients reviewed in Edinburgh can take up to three weeks to be received, which sometimes leaves the CNS seeking the information.
- Clinic space should be looked at more closely, as reported only one clinic room is available for patient review, not allowing cleaning and airing time post reviews.

Physiotherapy

Edinburgh team physiotherapy report

Staffing
The physiotherapy service provides 2.8 WTE qualified physiotherapists; 2.0 WTE Band 7 and 0.8 WTE Band 6. The funded staffing falls below that recommended; 4.6 WTE qualified physiotherapists. This significant shortfall is further compounded due to the frequent requirement of the Band 6 to provide cover for the cardio respiratory physiotherapy team. In working practice it is suggested that as little as 0.2 WTE Band 6 is provided to the CF team. The introduction of seven-day working is also a grave concern. The requirement of CF staff to cover weekend working and take time off from their current posts in lieu during the week will further impact staffing levels; ultimately resulting in an inability to adhere to the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

Inpatients
Despite the low staffing levels, inpatients are prioritised to ensure that all patients receive twice daily physiotherapy airway clearance reviews. The specialist physiotherapists attend ward rounds and MDT meetings regularly. Exercise provision for inpatients, however, falls below standard. Gym facilities are available both on the ward and within the outpatient department, but lack of staffing means that patients do not receive daily (Monday-Friday) exercise sessions.

Outpatients
All patients in CF clinic do have access to a physiotherapist at their appointment. Completing appropriate paperwork for annual review patients can be a challenge; staffing pressures dictate whether such tasks are performed. Whilst the team has worked hard to develop its community support, the service is inconsistent in what it can provide and thus patients may not get a weekly review when on home IV antibiotics. A staff uplift would facilitate service development in this area, which given the wide geographical distribution of patients, is a service that should be developed and enforced.

Professional development
The clinical specialist physiotherapists are members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and are active members of the Scottish Cystic Fibrosis Group. They regularly attend meetings both regionally and nationally.

Research and audit
Whilst the clinical specialists demonstrate a clear drive for research and audit, reduced staffing levels do have a significant impact upon their ability to undertake such activities. Staff uplift would facilitate progress in this area.

Areas of good practice:

- A highly motivated and passionate team which has great enthusiasm for developing the service.
- The physiotherapists have close links with the other satellite clinics. Sharing of knowledge and expertise is commonplace.

Recommendations for service development:
Whilst the CF Physiotherapists recognise there are staffing shortcomings it is essential that this is addressed by the physiotherapy managers. It is vital that an action plan is agreed by the clinical service and operational managers to address the following:

- The physiotherapy structure needs immediate review to meet the Cystic Fibrosis Trust's Standards of Care recommendations of 4.6 WTE qualified physiotherapists. With the current staffing levels, CF staff should not be expected to be involved in the seven-day working rotas as this would disrupt an already unstable infrastructure.

- The use of Band 2/3/4 assistant time should be considered to allow for duties to be taken from the clinical specialists that do not require that level of expertise.
- It is essential that CF time is protected and not used to cover the cardio respiratory medicine wards or bronchiectasis outpatient clinics.
- Protected time for service development, research and audit.

Inverness team physiotherapy report

Staffing
The physiotherapy service consists of 1.0 WTE Band 7 working Monday to Thursday, meeting Cystic Fibrosis Trust recommendations. However, this does not reflect the great geographical spread of patients and that visits to patients may take considerably longer than at other CF centres. Cover is provided by adult/paediatric physiotherapy teams at times when the CF specialist physiotherapist is absent. However, this is at a reduced level and does not incorporate exercise. Whilst the quantity of dedicated CF staff meets standards, the Band 7 is not protected and at times is expected to provide cross-cover for the medical wards.

Inpatients
Patients receive twice daily airway clearance and once daily exercise. However, this may reduce on occasions when the specialist CF physiotherapist is absent.

Outpatients
All patients are reviewed in clinic and at annual review. A robust MDT community service is provided, although the geographical spread of patients is very time demanding. Patients are given physiotherapy support when on home IV antibiotics.

Professional development
The clinical specialist physiotherapists are members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and are active members of the Scottish Cystic Fibrosis Group.

Research and audit
The specialist physiotherapist has undertaken research and is keen to develop the service further.

Areas of excellence/good practice:

- Dedicated Band 7 clinical physiotherapist who provides an excellent level of care for CF patients, both paediatric and adult.
- A robust MDT community support system is available for patients.
- The Band 7 has established excellent links with specialist CF centres and attended the biannual Scottish network meetings regularly.

Recommendations for service development:

- A review of staffing levels taking into account the time allocated to cover the geographical area. Consider with this the training of others to improve the level and quality of cover provided in the absence of the Band 7.
- Consider the employment of or use of existing physiotherapy assistants to cover exercise sessions for inpatients.
- Ensure time is allocated for non-clinical responsibilities including training others.

Dundee team physiotherapy report

Staffing
The physiotherapy service provides 0.6 WTE Band 7 and 0.2 WTE Band 6. Thus for two half days per week there is no specialist physiotherapy cover and working patterns result in an overlap of only two hours between the Band 7 and Band 6. Should patients require review they are seen by the respiratory medicine staff members. This falls below that recommended by the Cystic Fibrosis Trust. Further 0.5 WTE qualified physiotherapy should be invested into the team. The Band 6 physiotherapist is often required to provide cover on the respiratory medicine wards, further adding to the staff shortcomings. An increase of 0.5 WTE would ensure Monday–Friday specialist CF staff are available, and would allow for overlap between staff members to accommodate supervision and joint training.

Inpatients
All patients receive twice-daily airway clearance review as inpatients. Physiotherapists have capacity to attend ward rounds and MDT meetings. Unfortunately given the staffing levels, exercise provision for inpatients is variable. Not all inpatients would receive daily exercise.

Outpatients
Physiotherapy is provided for patients attending clinic and annual reviews. Community physiotherapy is provided for both airway clearance and exercise as required. Unfortunately time constraints limit the support patients receive whilst on home IV antibiotics. Whilst some patients are seen, there are inconsistencies on the frequency/amount offered, as other CF activities take priority. Patients on the transplant list are reviewed at home, within geographical constraints.

Professional development
The clinical specialist physiotherapists are members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and are active members of the Scottish Cystic Fibrosis Group. They regularly attend meetings both regionally and nationally. The lack of crossover of the working patterns of the Band 7 and Band 6 may limit the ability to undertake supervision, in-service trainings and clinical based learning.

Research and audit
The specialist CF physiotherapist has undertaken a lottery funded exercise project and intends to present findings nationally. However, they report that time for such work is limited due to clinical demands.

Areas of excellence/good practice:

- Motivated and keen to improve the service as demonstrated through research and Service Improvement projects.
- Adhering to the standards of care for clinic, inpatients and annual reviews.
- Works closely with the MDT and provides peer support between colleagues, including those at other CF centres around Scotland.

Recommendations for service development:

- The physiotherapy staffing levels and structure needs immediate review. An uplift of 0.5 WTE is recommended and the introduction of a Band 2/3 staff member should be considered. A Band 2/3 could provide support with exercising patients as an inpatient and other duties currently being undertaken by the qualified staff members.
- The home IV service needs review; physiotherapists should aim to see all patients when they are on home IV antibiotics.
- Staff to be given the time to undertake service improvement, research and CPD projects – this

would be helped by an improved staff framework.

Dietetics

Edinburgh peer review dietetics

The Edinburgh and Dundee services function as two distinct services with Edinburgh also caring for 11 patients in Dumfries. There are 15 patients in Inverness and these patients are seen a minimum of once a year by the Edinburgh dietitians. There is funding for CF dietetic hours in Inverness but this post has been vacant for two years and has recently been downgraded. The Edinburgh dietetic service consists of 1.3 WTE experienced (8 and 17 years) Band 7 dietitians (0.6 and 0.7WTE) and for 183 patients this would require 1.22WTE. A CF specialist dietitian is present in all clinics unless there is sickness or annual leave. Inpatients are seen daily where possible but if stable twice weekly. The dietitians attend one of the two ward rounds each week. The two dietitians cover the work load between them but in an emergency there would be cover from the dietetic department.

The dietitians are involved in the transition process but are keen to be more involved in the MDT process and parental education sessions. They are able to do home visits but this is very rare. The 11 patients in Dumfries attend clinic in Edinburgh and are encouraged to have admissions to Edinburgh but see the team in Dumfries.

The dietitians are members of the UK Dietitians CF Interest Group (UKDCFIG) but in Scotland there is an arrangement that a Scottish representative attends the meeting and feeds back to other dietitians working in cystic fibrosis. The dietitians have had opportunities to attend European and North American CF conferences and report the team is very supportive. They also participate in research and audit but feel they are not getting as much time as previously as they are called upon to contribute to general dietetic cover.

There have been changes to food service over the last two months and this has proved limiting. Patients can now only choose from the main menu. There are snacks available funded by the CF Unit and staff will go to the canteen for food but this has to be paid for. Patients have a small fridge in their room but no kettle. The ward ‘kitchen’ is in need of refurbishment and delays in doing this are limiting snack provision.

They have 11 patients who are enterally tube fed and 52 patients with cystic fibrosis-related diabetes approximately 40–50% of these ‘carb count’. There are four diabetic clinics each year and all patients are seen once a year. This is an area for development and they feel they could improve communication and relationships.

Areas of good practice/excellence:

- Enthusiastic, dedicated and motivated team with commitment to professional development
- Clear nutritional pathways and many diet sheets/resources.

Areas for improvement:

- Concerns highlighted about food provision which would be helped by a kitchen refurbishment
- Review CFRD service provision.
- Dietetic input to patients in Inverness.

Recommendations:

- Review impact of general dietetic cover on CF service and prevent dilution of CF dietetic service by ensuring a clear funding stream and ring fencing dietetic monies.
- Greater involvement in the MDT transition process and education.
- There is a need for a diabetes nurse specialist with a special interest in CFRD to help streamline the service to patients with CFRD, to support the dietitians and ensure timely initiation of

treatment.

- Review nutritional management of patients in Inverness in view of longstanding dietetic vacancy. Review banding of the post and ensure appropriate training and clinical supervision in place in view of the complexity of patients.

Dundee peer review dietetics

The Edinburgh and Dundee services function as two distinct services with Dundee caring for 47 patients. The Dundee dietetic service is well staffed with 0.6 WTE experienced (10 years) Band 7 dietitian and for 47 patients this would require 0.3 WTE. A CF specialist dietitian is present in all clinics but there is minimal cover for sickness or annual leave. There is a low in patient turnover with patients being seen up to three times a week by the CF specialist dietitian but general cover can be provided on non-working days or for annual leave/sickness. There is an MDT handover after clinic which the dietitian attends but she does not attend a ward round. Able to provide home visits and can do AA at home.

The dietitian is involved in the transition process with paediatric patients attending adult clinic twice a year from 13–14 years and a joint home visit before transfer. The dietitian is a member of the UKDCFIG but in Scotland there is an arrangement that a Scottish representative attends the meeting and feeds back to other dietitians working in CF. The dietitian has had the opportunity to attend European CF Conferences and has in the past submitted an abstract.

Food provision is good with cooked breakfast, a choice of menus, additional snacks and vouchers available for the Metropole Café. Patients have a small fridge in their room.

There are three tube feeders and nine diabetic patients. There is no CFRD clinic but patients are referred to a dedicated DM consultant and DNS but this could benefit from being streamlined to provide more timely intervention.

Areas of good practice/excellence:

- Enthusiastic, dedicated dietitian with commitment to professional development.
- Clear nutritional pathways and many diet sheets/resources.
- Shared office with physiotherapists and nurses, so there is good communication and good peer support within the team.
- Bespoke service with home visits and practical skills training.

Areas for improvement:

- Review CFRD Clinic.

Recommendations:

- Review and streamline provision for CFRD cover.

Pharmacy

Pharmacist provision at the Edinburgh adult CF service is 0.75 WTE; this also includes outreach cover for Inverness, which is provided as an ad hoc basis. The pharmacist does not attend all four Inverness clinics per year. For the total number of patients attending these clinics (201) the Cystic Fibrosis Trust's 'Standards of Care (2011)' recommends 1.0 WTE.

There is no provision by the CF pharmacist for the patients who attend Dundee (46 patients) other than by bleep/telephone access. Dumfries patients (six) have access to the pharmacist when attending at Edinburgh.

The pharmacist attends regional, national and occasionally international meetings and conferences, and maintains all mandatory training and personal development.

Strengths:

- The pharmacist is a highly valued member of the MDT who is resourced to attend weekly MDT, ward rounds, in patient reviews and some clinics (pseudomonas).
- Being an independent prescriber is a great benefit to the MDT and patients, especially during clinic appointments.
- The pharmacist carries out annual reviews on all patients, and produces many policies and procedures relating to medication issues and also patient information leaflets.

Areas for Improvement:

- Attend all outpatient clinics not just the pseudomonas clinic.
- Transition clinics could benefit from pharmacist input to avoid potential problems which may arise after transition.
- There is no cover during absences, other than by bleep.

Recommendations:

- Increased staffing is required for both Edinburgh (up to 1.0 WTE) and Dundee (up to 0.2 WTE) sites in order to meet the Cystic Fibrosis Trust's 'Standards of Care (2011)'.
- The appointment of a Band 7 pharmacist (respiratory) would protect the CF pharmacist time, and could also deputise during leave.
- Increase technician support would also be of benefit, as they could manage supply issues, releasing pharmacist time for audits etc.

Psychology

The Edinburgh adult CF service has a 0.8 WTE clinical psychologist (CP) who covers Edinburgh and provides outreach to Inverness (visiting four times per year) and Dumfries (through patients attending the centre in Edinburgh). For this total of 201 patients the Cystic Fibrosis Trust's 'Standards of Care (2011)' would recommend staffing of 1.5 WTE. In Dundee (46 patients) there is 0.1 WTE CP compared to the recommendation of 0.3 WTE. Both services are understaffed. Suitable leave cover is in place in Edinburgh but not Dundee. The CP in Dundee is currently on maternity leave and plans for cover need finalising.

In Edinburgh, the CP is a UK Psychosocial Professions CF Group (UKPPCF) member and the Scottish representative on the committee. They attend committee meetings and study days as well as the Scottish CF Psychology Group but have yet to attend an international conference. In Dundee the CP is a UKPPCF member and has attended some local CPD events but has yet (six

months in post) to attend any national/international events.

Strengths for Edinburgh:

- CP is well integrated, attending all inpatient and outpatient discussions (although not covered when on leave) and involved in service development (transition and annual review).
- CP is respected and utilised by the whole team eg reflective groups for ward based nursing staff currently being set up.
- There is good involvement of CP in transition through regular meetings with paediatric colleagues and the running and evaluation of parents' evenings.

Strengths for Dundee:

- The role of the CP is welcomed by the team with enthusiasm for joint working and the majority of inpatient and outpatient discussions are attended.
- Despite limited resources the CP offers face-to-face annual review where possible.
- The CP works flexibly to respond to the needs of both inpatients and outpatients.

Improvements for Edinburgh:

- The annual review process is based on paper screening with no option for face-to-face. It relies on patients returning the completed questionnaire. Data is not available for the response rate and this process could be reviewed and better evaluated. This is an on-going piece of work currently being undertaken.
- Adult diagnosis and fertility/parenthood are areas where psychology is not routinely involved. Examination of any service development needs for these groups would be useful.

Improvements for Dundee:

- The provision is currently very reactive with not enough time for standardised processes or planned input at key life stages.
- No capacity for involvement in audit, research or service development.

Recommendations:

- Increased CP staffing is required for both the Edinburgh (additional 0.7 WTE) and Dundee (additional 0.2 WTE) sites in order to meet the Cystic Fibrosis Trust's Standards of Care. This would allow greater CP input into research and service development and enable more standardised involvement at other key life stages (eg diagnosis and planning for parenthood). Resources such as computer access and desk/storage space are also needed to support the post in Dundee.
- In order to provide equitable care for patients across all sites greater integration and skills sharing between the CPs will be invaluable, this is currently being established. In particular service developments around transition and the annual review made in Edinburgh could also be considered in other sites.
- The addition of social work input to both teams would strengthen the psychosocial provision to patients and be an invaluable resource for the multidisciplinary team.

Social work

Western General Hospital, Edinburgh

- This is a large and busy clinic at the centre of a network of hospital services providing care and support to adults living with CF, through shared care and outreach arrangements. In Edinburgh, the team care for approximately 180 adults with cystic fibrosis.
- There is no CF social worker in post with whom to liaise but I was able to gather information from the available documentation and to discuss the team's work with specialist nursing staff and the team's clinical psychologist.
- It is clear that this is a skilled and committed team, whose considerable body of knowledge and experience in CF care allows them to respond creatively to the needs of individual patients, working flexibly across disciplinary boundaries and often drawing on, or directing others towards, external resources (eg the Butterfly Trust). They clearly have excellent intra-team communication and high expectations of what they will offer to patients and families.
- Despite their passionate and patient-focused approach and their willingness to go the extra mile for those in their care, the team recognises it is not possible entirely to bridge the gap left by the absence of an appropriately qualified and registered specialist social worker. This absence means that patients cannot be supported by the truly multi-disciplinary team envisaged in the Cystic Fibrosis Trust's Standards of Care, which is recognised, in its plurality of perspective, to be in the best interests of patients and their families. It deprives the team of the contribution to its collective conversation and development which could be offered by a suitably qualified and experienced social work member and inevitably puts undue pressure on other, already stretched, team members.
- It is strongly recommended that the necessary steps are taken to allow the recruitment and integration into the team of a 1.0 WTE CF social worker, in line with best practice and the expectations of the Cystic Fibrosis Trust's Standards of Care.

Ninewells Hospital, Dundee

- This is a 'satellite centre' attached to the service at the Western General Hospital in Edinburgh, serving approximately 46 adult patients living with cystic fibrosis. It has weekly clinics and supports its own admissions.
- There is no CF social worker in post with whom to liaise but the review panel was able to gather information from the available documentation and to discuss the centre's work with specialist nursing staff and the team's clinical psychologist, who joined them in March 2014 but is available for only a half day per week (to coincide with clinics and to see those patients in greatest immediate need).
- Service members give some of the credit for the high quality of communication it achieves and maintains to the compact nature of the service, being a smaller group of patients and professionals (though covering a wide geographical area). This in turn is seen as integral to the flexible and responsive service offered by all team members, recognised as a major strength in the effort to address the practical and emotional support needs of patients, either directly or often by referral/signposting on to other agencies (including the Butterfly Trust which is, in certain circumstances, able to offer local support with practical issues).
- Despite the skilled and patient-centred work of the team, members were able to acknowledge that it is not possible entirely to bridge the gap left by the absence of an appropriately qualified and registered specialist social worker. This addition would not be about seeking to exclude, but rather to augment and extend, the provision of emotional support by existing team members, as well as developing the availability of 'in-house' practical advice and support.

- The absence of a specialist social worker means that patients cannot be supported by the truly multidisciplinary team envisaged in the Cystic Fibrosis Trust's Standards of Care, which is recognised, in its plurality of perspective, to be in the best interests of patients and their families. It deprives the team of the contribution to its collective conversation and development which could be offered by a suitably qualified and experienced social work member and inevitably puts undue pressure on other, already stretched, team members.
- It is strongly recommended that the necessary steps are taken to allow the recruitment and integration into the team of a 0.5 WTE CF social worker, in line with best practice and the expectations of the Cystic Fibrosis Trust's 'Standards of Care'.

Raigmore Hospital, Inverness

- This service has close links to the team in Edinburgh and works to a shared care model, supporting approximately 24 adults living with cystic fibrosis. Its members have experience of working across the age range.
- The cohesive local provision is supported by quarterly outreach clinics from the Edinburgh team, including the clinical psychologist as there is no CF psychology service based in Inverness. The team works in a highly collaborative way to support patients and their families.
- There is no CF social worker in post with whom to liaise but I was able to gather information from the available documentation and to discuss the centre's work with the CF nurse specialist.
- The CF nurse specialist, working in close cooperation with her colleagues, occupies the role of 'navigator', using well-established local knowledge and networks to help patients link in to the most appropriate external resources, from local charities to hospice services across the region. In thinking about the impact of this, it was made clear that the size of the service and the ability to 're-route' people to other sources of support meant that this additional input was managed without undermining the primary roles of individuals within the team.
- Despite the skilled cooperative team approach, promoting resilience and resourcefulness amongst patients in addressing a wide range of needs, it was acknowledged that the contribution of an appropriately qualified and registered specialist social worker, based within the Edinburgh team but reaching into the local service, would be useful for patients and alleviate some of the pressure for team members, extending the provision of emotional support, as well as the availability of 'in-house' practical advice and assistance.
- It is strongly recommended that the necessary steps are taken to facilitate the contribution of a CF social worker to the team at Raigmore, via the recruitment by the Edinburgh centre of a suitably qualified and registered worker, in line with best practice and the expectations of the Cystic Fibrosis Trust's Standards of Care.

Dumfries & Galloway Royal Infirmary

- This hospital provides a CF service to six to eight patients from within a wider respiratory team. Patients are seen at the centre in Edinburgh at least once annually and more frequently as the complexities of their situation requires. This is in addition to the monthly clinics and home support offered by the team locally. Psychology support is offered in Edinburgh or by telephone, with referral on to local resources where this is most appropriate.
- There is no CF social worker in post with whom to liaise but I was able to gather information from the available documentation and to discuss the centre's work with the Specialist Respiratory Nurse and the psychologist in Edinburgh.
- The local service cooperates closely with colleagues at the centre in Edinburgh to offer the advantages of local provision with the benefits of a large centre service. The shared care arrangements are perceived as working well for patients.

- Excellent communication is vital in ensuring a quality provision, drawing on local resources including (on occasion) the knowledge and advice to team members of the wider respiratory team's social worker and a benefits advice worker who can attend respiratory MDT meetings if needed.
- Despite the resourcefulness of staff in connecting patients with support locally and from Edinburgh, it was acknowledged this does not entirely bridge the gap left by the lack of contribution from a dedicated CF social worker, appropriately qualified, experienced and registered. It was felt that this would give patients access to "the right information at the right time", with a continuity as their condition progresses. Whilst the respiratory nurse specialist felt that limited CF numbers meant that the extra workload remained manageable, it was an element in making it hard to meet the demand in her own wider role. It was also seen as being a missing aspect in their multidisciplinary working (the value of which she has experience of in the wider respiratory team setting).
- It is strongly recommended that the necessary steps are taken to facilitate the contribution of a CF social worker to the work at Dumfries, via the recruitment by the Edinburgh centre of a suitably qualified and registered worker, in line with best practice and the expectations of the Cystic Fibrosis Trust's Standards of Care.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male			5	6	3	2	
Female		2	9	4	3	1	2

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	28	6	2	0
From the ward staff	16	6	1	0
From the hospital	18	12	5	0

Areas of excellence:

1 Overall care of CF team – feel like family/excellent team.

2 Availability of staff members – all supportive/see any time.

3 Cross-infection segregation – straight into rooms for O/P.

Areas for improvement:

1 Food – horrendous/awful.

2 Car parking – not enough.

3 Ward – patient side rooms are not consistent in cleaning.

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

The Western General 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%	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	Y	Y	
	% 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	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Green	Green	

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	

3.3 Complications	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
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%	Amber	Amber	

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	
	% 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	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red No social worker.	Red	

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a social worker for inpatients	100%	Red No social worker.	Red	
	% availability of a pharmacist at clinic	100%	Amber	Amber	
	% availability of a pharmacist for inpatients	100%	Amber	Amber	
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	<1	
5.2	Number of clinical incidents reported within the past 12 months	<1%	<1	<1	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all Shared care services	100%	Green	Green	

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Western General Hospital 183 patients
Consultant 1	0.5	1	1	0.5
Consultant 2	0.3	0.5	1	0.5
Consultant 3			0.5	0.5
Honorary consultant				-
Staff grade/fellow	0.5	1	1	1
Specialist registrar	0.4	0.8	1	
Specialist nurse	2	3	5	0.95 + 0.525 + 0.525 = 2.0
Physiotherapist	2	4	6	1 +1 + 0.8 =2.8
Dietitian	0.5	1	2	0.6 + 0.7= 1.3
Clinical psychologist	0.5	1	2	0.8
Social worker	0.5	1	2	
Pharmacist	0.5	1	1	0.75
Secretary	0.5	1	2	1
Database coordinator	0.4	0.8	1	1

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 Western General Hospital	
Number of active patients registered (active being patients within the last two years)	219 total network
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	Edinburgh 137 Dundee 45 Inverness 24 Dumfries 6
Median age in years of active patients	28
Number of deaths in reporting year	1
Median age at death in reporting year	54

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	12 (8.5%)
	20–23 years	24 (18%)
	24–27 years	28 (20%)
	28–31 years	25 (18%)
	32–35 years	14 (10%)
	36–39 years	9 (7%)
	40–44 years	5 (4%)
	45–49 years	8 (6%)
	50+ years	12 (8.5%)

Genetics	
Number of patients and % of unknown genetics	11 (8%)

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=70, 28(40%)	n=67, 31(46%)
Number of patients and % with BMI <19 split by sex	7 (10%)	12 (18%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	4 (57%)	7 (58%)

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; 56.6 (30.43-78.32)	6; 60.81 (34.97-89.11
	20–23 years	7; 58.44 (16.27-122.1)	17; 61.53 (16.27-107.36)
	24–27 years	15; 54.67 (19.76-100.38	13; 76.58 (26.32-100.17
	28–31 years	15; 70.84 (19.75-102.44	10; 73.52 (18.51-96.59)
	32–35 years	10; 61.63 (23.6-96.79)	4; 69.41 (67.67-92.8)
	36–39 years	5; 84.43 (50.69-122.81)	4; 47.65 (22.05-125.41)
	40–44 years	2; 57.62 (55-60.23)	3; 78.32 (61.15-128.28)
	45–49 years	5; 80.42 (59.83-92.97)	3; 95.33 (46.3-101.78)
	50+ years	5; 90.32 (90.03-90.61)	7; 66.6 (22.96-120.68)

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	24
	24–27 years	28
	28–31 years	25
	32–35 years	14
	36–39 years	9
	40–44 years	5
	45–49 years	8
	50+ years	12
Number of patients with chronic PA by age group	16–19 years	3
	20–23 years	13
	24–27 years	15
	28–31 years	12
	32–35 years	8
	36–39 years	3
	40–44 years	4
	45–49 years	3
	50+ years	4

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	13 (10%)
Number and % of *cenocepacia*	5 (39%)
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	7 (5%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	1 (1%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	7 (5%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	44 (32%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	12 (9%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (1%) with PH; 1 (1%) 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	10
Number of patients receiving lung, liver, kidney transplants in previous three years	7

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	37
	20–23 years	175
	24–27 years	261
	28–31 years	101
	32–35 years	43
	36–39 years	41
	40–44 years	7
	45–49 years	28
	50+ years	140
Number of days of home IV therapy in reporting year split by age group	16–19 years	103
	20–23 years	343
	24–27 years	562
	28–31 years	417
	32–35 years	125
	36–39 years	106
	40–44 years	21
	45–49 years	119
	50+ years	84
Total number of IV days split by age group	16–19 years	140
	20–23 years	518
	24–27 years	823
	28–31 years	518
	32–35 years	168
	36–39 years	147
	40–44 years	28
	45–49 years	147
	50+ years	224

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=98); 48 (49%)
If not on DNase, % on hypertonic saline	7 (7%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	65
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	25 (38%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	51 (79%) with chronic PA; 27 (38%) without chronic PA

Appendix 4

Patient survey

Western General Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male			5	6	3	2	
Female		2	9	4	3	1	2

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	23	9	3	1
Communication	19	14	3	1
Out-of-hours access	10	8	4	3
Homecare/community support	7	8	2	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	24	10	2	1
Waiting times	18	7	6	1
Cross-infection/segregation	23	14	0	0
Cleanliness	23	11	3	0
Annual review process	20	11	5	0
Transition	6	6	2	0

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	8	6	3	1
Cleanliness	6	8	5	1
Cross-infection/segregation	11	7	1	0
Food	0	6	9	4
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	12	5	1	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	8	7	2	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	14	7	1	0
Availability of equipment	13	9	1	0
Car parking	3	12	9	7

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	28	6	2	0
Of the ward staff	16	6	1	0
Of the hospital	18	12	5	0

Comments about CF team/hospital

"Fantastic service from a very dedicated team first class treatment."

"I wouldn't be alive without them. I feel like part of a family."

"Everyone helps me no matter how ill and makes me feel as welcome as you can be in hospitals. Great."

"I keep getting told from my GP that I have missed appointments; this has happened three times. I am not getting any appointment letters etc (my address is correct)."

"Don't see much hand washing between seeing patients (coming and going out of room during clinic)."

"Outpatient clinic visits – frequently spend long times waiting for member of care team to come to see you. Outpatient appointments/reminders could be sent by text/email to save some postage/ paper."

"I feel numbers of patients there are to the number of staff are not correct. However I am aware of cuts, but there is too much work load for staff which results in poor communication between staff."

"Never been inpatient so can't comment on most questions. Only written communication is appointments, have asked for clinic letters but told no. Feel sometimes that doctors don't listen to me. Haven't really gelled with team after four years."

"Having had a very successful transplant three years ago, my needs now are a lot less, but when I do need things, on the whole I think the CF team are amazing, in particular the CF nurses, especially since the introduction of the texting. Pre-transplant my main relationship was with the physio team and they could not have been more helpful or accommodating, with house visits numerous times a week. Without our CF team I would be lost. They are extremely helpful, will always see me when I need seen. There is a new doctor who I'm not sure fits into this team well."

"I really can't speak highly enough of my CF team. The level of care I've received my whole life has been excellent. It also really helps that most of the team have remained the same for so long as it helps build a trusting relationship."

"The food from the kitchens is awful. I don't even bother to order any. Sometimes the bathrooms aren't cleaned out properly prior to next patient – other people's face cloths, shower gel etc, even urine samples waiting to be removed!"

"The CF nurses are excellent they get to know you as an individual and are flexible about arranging/ re-arranging appointments."

"Overall service at the Western is amazing, especially CF nurses. Nothing is too much bother. Only issue is recently no registrar available after five weekends. Would be better if we could have own CF ward as sleep sometimes difficult due to elderly patients. Would also mean more nurses who understand CF and the patients. Parking would be extremely difficult if didn't have blue badge. Food generally good only occasionally inedible. Sometimes only physio available once a day at weekend. Not usually a CF physio. Side rooms are kept very clean."

"Cannot fault the level of care provided by my CF team, they are fantastic. Ward are also very good."

"The CF team are always helpful and very efficient."

"The CF nurses are kind, reassuring and so easy to talk to. They work very hard and provide a fantastic service."

"A very friendly atmosphere and a very approachable and helpful team."

"Cannot comment on the ward as I have never been."

"Only problem is car parking space not enough disabled spaces."

"I've always felt cared for genuinely with friendly staff 100%."

"I am satisfied with everything you do for me."

"The CF nurses provide a great level of service and go out their way to help."

Appendix 5

Patient/parent interviews

Edinburgh adult peer review – patient telephone interviews

(Including Western General Hospital/Edinburgh, Ninewells Hospital/Dundee, Raigmore Hospital/ Inverness, Dumfries & Galloway R.I.)

Patient A attends Western General Hospital, Edinburgh and at Dumfries & Galloway Royal Infirmary (R.I.). At outpatient clinic she feels she sometimes waits along time (up to 40 mins) without seeing a member of the CF team, but she does see the full multidisciplinary team (MDT). Patient A considers segregation measures are "brilliant" at clinic. The feels that, in all, the CF team at Edinburgh is very good and she had excellent support on issues around pregnancy. She added that her medication is picked up for her at outpatient clinic at Western General Hospital whilst she remains in clinic.

Patient A explained that the CF team's communication is good and that they return her calls within 24hrs; she phones the ward for immediate response.

Patient A described her outpatient experience at Dumfries far less positively – "the doctor just asks me how I am and doesn't check things... it's very vague". She does not get to see a dietitian or specialist nurse, although Patient A explained there is a physiotherapist but added, "but no one sees her". Patient A felt the nurse was keen to get the service "more up and running" at Dumfries & Galloway R.I.

Annual review: Her annual review takes place at Edinburgh where she sees the whole MDT and has x-ray, lung function, DEXA scan and liver CT scan. The outcome of her annual review is fed back to her in a written report which she said was "a new thing", although she only received it six months after annual review with a form to fill in to clarify what had been covered in the annual review.

Patient A described the inpatient experience as "terrible" and explained that she didn't see the doctor during the whole admission, nor was a follow-up appointment made post-discharge. When asked about the ward staff's understanding of CF at Dumfries, Patient A felt that "staff do not understand CF or the importance of medication timings", adding, "I have a set routine".

Homecare: This patient does not currently require/receive home care. She explained that she gets help "with the renal issues" and added that "it would be nice to have bloods tests at home", as opposed to having to make an early start to travel to hospital for them.

Patient B attends Raigmore Hospital, Inverness for all his CF care. At outpatient clinic he is ushered straight into a side room on arrival where the CF MDT come to him – the CF team rotate between patients – and spiro takes place in the same consultation room. Patient B sees the whole MDT. He has been offered the chance to see a clinical psychologist but felt he didn't need to; nor has he accessed the social work services. He did feel that he would prefer to see the dietitian when needed rather than automatically as a matter of course at each outpatient clinic.

Patient B is happy that the CF team listens to him during consultations and makes decisions with him rather than dictating to him. He hasn't needed to use the hospital pharmacy and feels that his local high street pharmacy is disorganised.

Patient B's last inpatient ward admission was over three years ago, to a respiratory ward. He had "no issues with the care on the ward and IVs were given on time or pretty close to on time". He described the ward food as "edible", adding "well, it's hospital food". He was sometimes given high calorie snacks on the ward and had "a lot of food brought in by family".

Annual review: This is offered to Patient B each year at Raigmore Hospital. His last annual review was this year where he saw the whole MDT including the psychologist. All his annual review tests, he explained, are carried out at Raigmore Hospital, except the DEXA scan which is performed at another site, a 15-mile drive away.

Homecare: Patient B does not receive homecare, nor does he feel he needs it.

Good practice:

- "The CF team are always there on the telephone when I need them."
- Good feedback and updates on treatments from the CF team.
- Helpful team which gives him encouragement.

Area for improvement:

- "Raigmore needs a dedicated CF unit... I always have to go to a different clinic/different part of the hospital."

Patient C attends Raigmore Hospital, Inverness. He was happy with the segregation measures in place at outpatient clinic – "You wait in the hallway where there are four or five seats; at the other clinic 20 seats. If the team catches you you're put straight into a side room'. Patient C attends quarterly clinics, when the CF team from Western General Hospital attends. At clinic, Patient C explained, the MDT rotates (with spirometry equipment) between patient consultation rooms, adding that "there is good hand hygiene".

Patient C considers the decision making by the CF MDT very good – decisions made with the patient. He added: "They recognise I have good understanding… The CF team listen and are interested and give very good explanations." Patient C remarked that he sees the doctor, physiotherapist, dietitian and clinical nurse specialist (CNS) every visit and the psychologist is "often about", but he was not aware of a social worker in the service; he feels he has no need for social worker support. Patient C added: 'The team are always at the end of an email... no communication issues there." He also had no issues with hospital pharmacy arrangements. Patient C described "a good local relationship between GP and hospital team", and he explained that he emails the CNS for IV ancillaries which are then posted out/received in 24–48hrs.

Annual review: Patient C is offered annual review each year, although his latest one is long overdue – May 2013. This, he explained, was no fault of the team/service, but more due to the patient's own diary commitments. Annual review normally takes place at Raigmore, including OGGT, exercise test, DEXA scan, liver CT scan, x-ray – pulmonary function tests separate. He usually sees the nurse, and physiotherapist at annual review, not necessarily the doctor. His annual review is reported back via informal email with more formal feedback at his next outpatient clinic appointment.

Homecare: Patient C has to mix his own IVs which he administers himself at home via portacath. His wife is trained to flush his port, although he explained that if need be a CNS would make a home visit for this. He gets his Tobramycin levels checked at his GP surgery, or he can go to Raigmore Hospital for this.

Patient D attends Western General Hospital, Edinburgh. She reported good segregation measures in place at outpatient clinic ("always directed into a private consultancy room"), although there is a general waiting area. Patient D referred to good use of hand gels and good hand hygiene, with equipment wiped down between patients. She assumes the doctors wash their hands between each patient as she doesn't always see.

Patient D sees the whole MDT at clinic, apart from a social worker whose work is covered by the nurse specialist; she has access to the psychologist. She is happy with her CF team's advice and explanations at clinic and she feels that decisions are made with her rather than for her. "We always plan and discuss treatments, they always ask me if I'm ok with suggestions/ recommendations. I ask questions!"

Patient D referred to pharmacy experience as being "a long wait" in the past, but now the pharmacist calls down and collects medications and returns them to Patient D in clinic.

Patient D is offered an annual review each year. She hasn't had her latest annual review for one and a half years due to being on IVs each time, although she has had OGTT and DEXA scan. She explained that the team tries to fit in all tests on the same day, on the same site. She would see all the MDT at annual review, apart from a social worker. Annual review outcome is reported back by letter which Patient D explained "started this year and they ask you to take the letter to next clinic to discuss it." Prior to the written format, Patient D explained annual review feedback was verbal.

Inpatient care: Patient D described "quick admission" to the ward when she's needed it and "there always being a bed made available for someone with CF". She was last treated on the ward in summer 2014, in an en suite side room on the respiratory ward. She explained that on that occasion quite a few nurses were on holiday, replaced by bank nurses who she felt worked more slowly and were not allowed to access portacaths. Patient D referred to the regular ward staff as "really wonderful, very knowledgeable and experienced". She was far less positive about the catering on the ward, describing it as "really bad". She lost 4kg during last admission, she feels "definitely down to the food". However, she mentioned snacks being available including chocolate, scones and cheese and biscuits.

Homecare: She has to mix her own IV antibiotics at home. The CNS makes a home visit mid course of IVs. Her Tobramycin levels are checked after three to four doses, either at home or on a visit to the ward. A CNS used to do a home visit to flush Patient D's portacath, now however she ties in port flushes with regular outpatient clinic appointments every four weeks.

Good practice:

- "Love my CF team. I was late diagnosed but the team supported me well as it was difficult at first. They are easily accessible and let me ask questions."
- They always make an inpatient room available for CF patients.
- Only 24 hour wait max before starting home IVs.

Area to improve:

- Catering on the ward – the food.

Patient E attends Western General Hospital, Edinburgh. She finds segregation measures at outpatient clinic excellent and much better than her previous CF centre's measures. She is ushered straight to a side room in the Edinburgh clinic where she is happy with hand hygiene measures. She sees all the MDT except the physiotherapist (she is post-transplant) and she is not sure if there is social work support as she turns to the Butterfly Trust for this purpose.

Patient E is happy that the CF team discusses decisions on treatments with her and rather than dictating to her, adding, "I ask lots of questions". The nurse specialist rings the pharmacy, collects medicines and returns them to Patient E at clinic, negating any wait at pharmacy.

Inpatient care: Patient E can be admitted generally within a few hours of ringing up. She referred to the weekend admission situation though as "a nightmare" since they changed policy. Admission is to an en suite side room every time, with an exercise bike in the day room. She described the experienced nursing staff as "excellent", but added that there are some inexperienced nurses. Timing of medications she felt is not always the best, adding, "you have to ask for it and doctor writes up medications without consulting me, so it's not always the nurses' fault."

Patient E described the food on the ward as "horrendous", so she eats snacks and gets her husband to bring in sandwiches.

Homecare: Patient E returns to Western General Hospital for blood tests, although she's now trying to get the GP surgery to do them.

Good practice:

- Segregation measure at the CF unit.
- Knowledge and respect between patients about segregation/cross-infection.
- Hard working and understanding nurses, ward nurses – "they (the CF team) are like friends and make you feel welcome and safe".

Areas to improve:

- Food on the ward.
- Car parking, which she doesn't feel is secure enough.
- Superficial cleaning of ward side rooms in most admissions.
- Provide more fans in side rooms as windows don't open far or at all.
- Provide Wi-Fi and a TV remote control handset for each side room.

Patient F attends Western General Hospital. She describes segregation at clinic as good, she is sent straight to a consultancy room, door shut and she sees good use of hand gels and wiping down of equipment. Discussions about and decisions on her treatments are with her rather than for her – "they're always absolutely great". Patient F sees all of the MDT at clinic, apart from a social worker (she doesn't want to see any social worker), but she thinks there is one. She explained that CF consultant is now a permanent post which she feels is much better than the previous lack of continuity due to different doctors.

Annual review: Patient F is offered annual review each year and she has had some of her annual review already for this year. All her assessments take place at the Western General Hospital and a written report is sent to her afterwards; this she explained is a new method of reporting back to patients which she prefers.

Inpatient care: Her last ward admission was between one and two years ago. It was easy to get admitted and to an en suite side room. She noticed quite a lot of new ward staff. She felt that although the ward side rooms are deep cleaned between CF patients, she would prefer that this should also happen after use by medical patients/other respiratory patients. Patient F felt that treatments were generally on time, but that in the evenings IVs were sometimes given quite late. Her view of the ward food was: "It's alright, not too bad for hospital food... and I can get some extra snacks."

Homecare: No homecare provided, or in Patient F's view needed. She attends Western General Hospital for port flushes; team text or ring Patient F to come in, but she's confident that the nurse would do a home visit for this purpose if necessary.

Patient F has found the retirement of Professor Greening and some other changes worrying. She is also concerned about what she described as "no doctor cover after 9pm".

Good practice:

- "Fabulous care."
- "Very caring team. Feels like a 'little family'".
- "You know you can get hold of them when ever needed."

Area for improvement:

- Consistency with room cleaning – ward patients' side rooms

Patient G attends Western General Hospital. Outpatient clinic segregation she described as "fine" with different clinics for different bugs. She gets as much time as needed to discuss matters with the CF team and decisions are always only made after agreement with her, with good explanations, sometimes after further clarification. She sees the whole MDT available or at least has access to all who are available. She rarely has to wait for more than an hour at pharmacy. She can get hold of the CF team when needed by telephone/answer machine and call back.

Inpatient care: Patient G's last admission was in early summer 2014. Admission to the ward was quick and easy – "the same each time", she remarked. She feels the knowledge of ward nursing staff used to be better, and that they're now learning on the job. She added, "There are always some knowledgeable ones though and they're good at listening." She felt the timing of medications was usually good, though IVs are sometimes late in the evenings due, she felt "to a shortage of staff". She added, "They are very committed nurses, rushed off their feet." Patient G described the ward food as "appalling" in terms of quality, presentation, adding it's "bland and over/under cooked", so her daughter brings takeaways in for her.

Annual review: Every year annual review is offered. Patient G receives a written report of her review outcome. She said she'd never had a liver scan and "they've stopped giving me a DEXA scan."

Homecare: Patient G goes to Western General Hospital for bloods and port flushes. She has to mix her own IV antibiotics at home.

Good practice:

- Communication from the CF team.
- "Quality of care is excellent. They have kept me alive and I feel secure."

Areas for improvement:

- Food on the ward.
- Provide WIFI on the ward.
- Improve level of ward nurse staffing.

Patient H attends Western General Hospital, Edinburgh. He feels segregation measures and hand hygiene is good at this centre's outpatient clinic and the clinic flows well, although some days are busier. His spirometry takes place in the consultancy side room where he remains throughout the clinic appointment; the CF team rotates between patients. He is happy that his CF team's decisions on treatments are made with him rather than simply for him and he does not have a long wait at pharmacy. Sometimes he picks up pharmacy medications from home next day.

Inpatient care: Patient H was happy with the staff's knowledge of CF and his requirements particularly on the ward. He added that "they do all they can to help me and medications are always on time". He referred to the ward as "spotlessly clean", remarked that the ward food is "ok and the dietitian provides extras". His longest wait for admission was 24 hours.

Annual review: Patient H is offered annual review each year, with one coming up soon. His assessments are all done the same day and he sees the whole CF team. His DEXA scan and liver CT scan are carried out when he is an inpatient on the ward. The annual review outcome letter is sent to him one month after his review.

Homecare: Patient H has to mix his own IV antibiotics at home. He returns to his CF centre in Edinburgh for flushes and three-monthly outpatient appointments.

Good practice:

- Helpful team.
- Always available to contact and they ring back within two hours if on answer machine.

Patient I attends Ninewells Hospital, Dundee. He described the service as "generally very good", but added that, "over the last two years everything seems budget-constrained – resources, appointments – all allocated in short blocks and insufficient". He described the CF nurses as "excellent", adding that "everyone in the team is excellent". He explained that the service did not have its own consultants; that Edinburgh consultants travel each Thursday to Dundee and he sensed that "decisions are made by the Edinburgh team". Patient I felt that the team overlooked patient stress caused by the dilemma of home IVs versus inpatient IVs. He felt sometimes that the patient's opinion is not taken seriously enough. He sees the physio and dietitian at every outpatient appointment, and he described pharmacy in terms of "long waits".

Annual review: Patient I is offered an annual review* each year, given a date and assessments are staggered. He doesn't see the whole team at annual review. He thinks a written report is sent to his GP, but he as a patient doesn't receive a report: "Only if there's a problem, they let me know."

*DEXA scan at Ninewells, liver CT scan at Edinburgh.

Inpatient care: Patient I has had inpatient care at Ninewells (two years ago) and he felt "bounced around wards". He felt the ward staff don't understand the significance of CF, only some rooms are en suite. At Edinburgh he said he stays in the same room for the whole admission; all rooms en suite.

Patient I felt that timing of treatments was better at Edinburgh than Ninewells, but still not always on time. He felt that the nurses' knowledge on the ward was very good at both Edinburgh and Ninewells.

Patient I didn't have a problem with hospital food, although he said there's not enough of it and presentation could be better. He explained that the dietitian can arrange extra snacks (Mars bars etc).

Homecare: Ninewells nurses make home visits or phone to check how he is. Edinburgh nurses visit or ask him to attend hospital for Tobramycin levels. Patient I felt it wasn't always easy to contact CF nurses at Ninewells and that there is an "established protocol" and won't answer after 5pm – he will phone Edinburgh. He can't always get through due to nurses being busy and based on the ward.

Good practice:

- Clean unit/ward and good hygiene standards – Edinburgh.
- Availability of equipment is good at Edinburgh Western General Hospital.
- Knowledge of staff is good at Ninewells, Dundee.

Areas to improve:

- "Too restricted by protocol" at Ninewells; patient feels treated as doing wrong if stepping outside of this.
- Improve cleanliness of the ward at Ninewells – dirty showers and loose tiles lying around in showers.

Patient J attends Ninewells Hospital, Dundee for all his CF care. He feels the CF team take as much care as possible to segregate patients at outpatient clinic, with separate side rooms, team rotate between rooms and hand washing is robust.

Patient J sees the whole MDT at clinic, with access to a psychologist, although he is not sure if there's a social worker. He felt it depends on the situation as to how much the CF team make or share the decision making with him on treatments – eg recent need for Gastrografin, but the patient didn't want to come into hospital; preferring to stay at home for the treatment. CF team allowed the first week at home. By contrast, if not well enough to complete IVs at home, this patient feels his team make the decision for him to stay in hospital until well enough for discharge/completing course at home.

Patient J likes the pharmacy pick up arrangement. Staff from clinic collect his medication from pharmacy and return it to him in clinic before his appointment has finished.

Annual review: Patient J is offered annual review (A/R) each year, though can't remember when he last had annual review earlier this year. All his A/R assessments are at Ninewells, DEXA scan and liver CT scan usually same day. Annual review is reported back to him either by phone, text or in writing, depending on health status at the time.

Inpatient care: Patient J has IV treatment three times a year. He described ward staff on ward 3 as "amazing" and added, "all the nurses know me as a person". He explained that treatments are given on time, he's given a fridge for medications/foods in his en suite side room and nurses will bring food from Tesco for him. He asks for admission to ward 3, though the last two occasions he had been admitted to ward 42/Infectious Diseases, with an en suite side room – "they do their best" and treatments are given on time here too. He receives physio every day on both wards, though not the usual CF physio at weekends.

Patient J described the ward food as "edible/hospital food and a bit tasteless", adding though that the CF team can bring something in from outside for free, plus chocolate and crisps from the snack trolley and sausages for breakfast which he likes. He receives vouchers for free food from the hospital cafés.

Homecare: He felt he doesn't really require home care or receive it, though the nurse will make an annual visit if needed, or post IVs/check nebuliser etc.

Good practice:

- Cross-infection procedures.
- Quality of care.
- Helpfulness of the CF team – "They go out of their way to help me."

Area to improve:

- Improve home monitoring eg introduce home monitoring of sputum microbiology, which the patient had heard of.

Patient/parent interviews peer review day

Ninewells Hospital Dundee

Male patient of 31 years of age was diagnosed at birth and has attended Dundee all his life. He lives with his partner about a 20-minute drive from the hospital or one hour by bus; generally he drives to appointments.

Areas of excellence:

- The CF team is fantastic and do as much as possible to make the stay bearable, the physiotherapist travels to his home for visits and he has IVs at home. It would be nice to have a permanent CF doctor for inpatients.
- The team is always on call; he could call the mobile number at any time.
- The dietitian has travelled to his home to cook and try out new recipes with him.

Areas for improvement:

- Parking charges, there are a few disabled bays near the main parking area with no ticket machine nearby.

- If restricted to ward the food is poor and portions are small. The vouchers issued can help, he can have a cooked breakfast with these.
- No Wi-Fi and the TV signal is not great and there is no remote control.
- The room can be too hot.
- All vending machines stock sugar free drinks.
- Shared shower room, he does wonder how clean it is, what condition the last user had and can only assume it has been cleaned properly between patients.

Western General Hospital

Patient One

Female patient of 29 years of age was diagnosed at five months old. She lives with her partner approximately 25 miles from the hospital. If she is well enough she will drive to the hospital for appointments, if not her mother will bring her in. She has great support from her family and her partner. Her local hospital is Forth Valley; however she prefers to come to Western General as there are better facilities.

Areas of excellence:

- The room has a fridge for use and a TV.
- Good communication with the team, she can always call, if she leaves a message they will always return her call in good time.
- The dietitian has been very helpful; patient has been peg feeding for the last few months.
- The consultants listen and she has built up a good rapport with Dr Tasiou who she feels is very thorough. The ward staff are also very helpful and always ask if she needs anything, they go above and beyond and she receives 1:1 care from the nurses.
- Recliner chair in room – her mother/partner can stay overnight.
- Can have extra snacks; crisps, sweets, drinks; these are kept on the ward. She can also pick extra food from the menu.
- Open visiting hours.
- IV access and admittance, she will call the team can be admitted within two days, once improving she can be sent home to complete treatment.

Areas for improvement:

- Hospital food is very bland, lacking taste and child size portions.
- Vending machines only sell sugar free drinks.
- Parking – patient has a blue badge so it is not too bad for her; however it can be horrendous for visitors, especially if they all arrive at once.
- Outpatients – clinic waiting times for team to visit the clinic room. She has waited four hours before with no distractions, no phone signal or Wi-Fi.

Patient Two

Male patients of 26 years of age, he was diagnosed at six months old. He is in full time employment as a data manager, fortunately his employers are supportive, and he can work flexibly and has a dongle so that he can work from his hospital bed. He has recently moved in with his

partner, he moved away from his parents' home at the age of 18 years. He lives a 15-minute drive from the hospital; he can also use door-to-door public transport.

As a child he grew up in Slough and attended Wrexham Hospital. He attended Raigmore Hospital, Inverness, for eight years before transitioning to Western General. He also lived in Oxford for one year and attended the Churchill Hospital.

Areas of Excellence:

- Facilities are fantastic.
- Although the food is not very appetising, he can order extra snacks. The menu is set, however he can ask for additional extras to his dinner or if he prefers an alternative, they usually supply what he requests.
- The physiotherapist visits at least once a day.
- CF mobile calls are returned within 48 hours.
- He can be admitted within one day.

Areas for improvement:

- Annual review – requires more visits to hospital for each test prior to the Annual review. He needs to take time of work for each appointment, this usually means taking half a day for each appointment.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Western General Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	
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?	No	Height and weight measurements currently taken in one room. Only a 20-minute gap is left between patients. We have suggested that height and weight measurements should be taken in each patient's consulting room.
Where are the lung function tests done for each visit?		In each patient's consultation room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	TVs, magazines and books are available.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	A diabetic clinic is run out of the diabetic department – again, patients are seen in single rooms.
Transition patients – can they get tour of outpatients' facilities?	Yes	Transition takes place over the course of a year. Patients get the opportunity to meet the whole of the MDT before they transition from paediatrics.
Transition/new patients – do they get information pack?	Yes	The pack contains information about the hospital, service, staff and travel options.

Environmental walkthrough: ward

Ward name: 54

Microbiology status: Pseudomonas, MRSA, Cepacia

		Hospital name	Western General Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Not dedicated CF ward	The ward is suitable for CF patients and was designed around the needs and care requirements of patients with cystic fibrosis.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		11	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Showers in all rooms – there is no bath.
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	Lockable bedside cupboards are provided.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Freeview television is provided.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	There is a relative's room with a sofa bed and en suite. There are reclining chairs in the patient's bedrooms which are also used by visitors to sleep on.
Visiting hours – are there allowances for CF patients/families out of normal hours?			Open visiting.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	There is a fridge in each side room.
What facilities are provided for teenagers?			Wii, PlayStation and all rooms have a DVD player.

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	There is a gym on the ward and a moveable exercise bike that patients can use in their side rooms.
What facilities are there to help with school and further studies?	None	
Is there a relatives' room?	Yes	
What internet access is there?	None	The service has received complaints from patients regarding this.
What facilities are there to enable students to continue to work and study?		Nurses liaise with universities when a request for course work extensions are required, for example.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Parts can be washed in washing up bowls (specifically used for this purpose) and water can be emptied down a sink in the sluice room.
What facilities are provided for those with MRSA?		Barrier nursed – gloves and aprons used. A sign is placed outside the patient's room. Patients are cared for in a separate part of the ward.
What facilities are provided for those with *B. cepacia*?		As above.
What facilities are provided for those with other complex microbiology?		As above.
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	Yes	

Additional comments

- The urgent need for Wi-Fi internet access to be available for patients to use whilst staying in the hospital was highlighted to the service's management.
- There is a room which is known as 'the pantry' with kitchen equipment in it which urgently needs refurbishing. This room requires far more storage space and a larger fridge.

Environmental walkthrough: Other

	Hospital name	Western General Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Parking is extremely limited. Patients and their visitors often find it problematic getting a parking space.
Other hospital areas		
Clear signage to CF unit and/or ward.	No	There is some signage but this could be clearer. It would be helpful if there was clearer signage on route to the departments starting much closer to the lifts.
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	
Do patients have to wait at pharmacy for prescriptions?	No	Prescriptions are given at outpatient appointments or dispensed on the ward.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	Patients and their families mainly go direct to the MDT to verbally voice any comments or feedback. A formal complaint process is in place.

Ninewells Hospital, Dundee

Overview of service

Ninewells Hospital acts as a satellite centre for the Edinburgh adult CF service, with approximately 47 patients. Dr Rodgers travels to Dundee once per week (Thursday) to review the CF inpatients and see CF outpatients. CF inpatients are also reviewed at least once per week by a respiratory consultant (Dr Tom Fardon). The Dundee MDT also consists of a small but experienced CF specialist nursing, dietetic, physiotherapy and psychology team. Patients are seen in the outpatient clinic and are admitted to Ninewells Hospital if they require inpatient admission, although may be transferred to Western General Hospital if they need more specialist care.

Staffing levels within certain disciplines fall well below those recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)'

CF physiotherapy – an uplift of an additional 0.5 WTE CF physiotherapist staffing is recommended, as well as the introduction of a Band 2/3 staff member to provide support with exercising patients.

CF pharmacy – the creation of 0.2 WTE CF pharmacy staffing is recommended.

CF psychology – an increase of 0.2 WTE CF psychology staffing is recommended.

CF social worker – there is currently no CF social worker available for patients in Dundee and we strongly recommend the creation of a 0.5 WTE post to meet the Standards of Care recommendations.

The risk matrix highlights two areas in which the Dundee team are failing to meet targets:

1. Inpatients are only seen once per week by a specialist CF consultant compared to the expected frequency of twice weekly. We therefore recommend that thought should be put into ways that additional CF specialist consultant input could be provided in Dundee.

2. Patients are unable to be reviewed by a CF social worker in clinic or as an inpatient because no such post exists. We strongly recommend that this deficiency be addressed as previously stated.

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

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%	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	Y	Y	
	% 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	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related-diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	N/A No joint clinic in Dundee	N/A	

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	

3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Green	Green	
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 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	Amber. Seen weekly	Amber	
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	

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	
	% 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	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	N/A	Red	No CF social worker.

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a social worker for inpatients	100%	N/A	Red	No CF social worker.
	% availability of a pharmacist at clinic	100%	Green	Amber	No CF pharmacist in post in Dundee.
	% availability of a pharmacist for inpatients	100%	Green	Amber	No CF pharmacist in post in Dundee.
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%	Green	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	Green	Green	
5.3	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%	Green	Green	

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Ninewells Hospital
Consultant 1	0.5	1	1	0.2
Consultant 2	0.3	0.5	1	0.2
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.4	0.8	1	
Specialist nurse	2	3	5	0.55
Specialist nurse				0.55
Physiotherapist	2	4	6	0.6 + 0.2 =0.8
Physiotherapist				
Dietitian	0.5	1	2	0.6
Clinical psychologist	0.5	1	2	0.1
Social worker	0.5	1	2	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

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 Ninewells Hospital, Dundee	
Number of active patients registered (active being patients within the last two years)	219 total network
Number of complete annual data sets taken from verified data set (used for production of the Annual Data Report 2013)	45
Median age in years of active patients	26
Number of deaths in reporting year	0
Median age at death in reporting year	NA

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	7 (15.5%)
	20–23 years	12 (27%)
	24–27 years	7 (15.5%)
	28–31 years	7 (15.5%)
	32–35 years	5 (11%)
	36–39 years	2 (4%)
	40–44 years	0
	45–49 years	0
	50+ years	5 (11.5%)

Genetics	
Number of patients and % of unknown genetics	1 (2%)

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=22; 7 (32%)	n=23; 11 (48%)
Number of patients and % with BMI <19 split by sex	5 (23%)	3 (13%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	5 (100%)	2 (67%)

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	2; 88.88 (79.65-88.1)	5; 46.77 (29.5-66.28)
	20–23 years	6; 66.47 (15.38-84.86)	6; 68.98 (34.52-85.69)
	24–27 years	4; 56.42 (15.11-63.17)	3; 92.01 (78.7-109.84)
	28–31 years	3; 48.75 (23.84-80.93)	4; 81.48 (52.28-96.39)
	32–35 years	4; 72.13 (33.82-81.93)	1; 61.57
	36–39 years	2; 79 (73.43-84.48)	0
	40–44 years	0	0
	45–49 years	0	0
	50+ years	1 (no data)	4; 60.55 (44.96-76.14)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	7
	20–23 years	12
	24–27 years	7
	28–31 years	7
	32–35 years	5
	36–39 years	2
	40–44 years	0
	45–49 years	0
	50+ years	5
Number of patients with chronic PA by age group	16–19 years	2
	20–23 years	4
	24–27 years	4
	28–31 years	3
	32–35 years	1
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	3 (7%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (2%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	2 (4%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	10 (22%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	6 (13%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH; 1 (2%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	4
Number of patients receiving lung, liver, kidney transplants in previous three years	1

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	0
	20–23 years	21
	24–27 years	56
	28–31 years	0
	32–35 years	33
	36–39 years	28
	40–44 years	0
	45–49 years	0
	50+ years	0
Number of days of home IV therapy in reporting year split by age group	16–19 years	112
	20–23 years	77
	24–27 years	28
	28–31 years	42
	32–35 years	79
	36–39 years	28
	40–44 years	0
	45–49 years	0
	50+ years	56
Total number of IV days split by age group	16–19 years	112
	20–23 years	98
	24–27 years	84
	28–31 years	42
	32–35 years	112
	36–39 years	56
	40–44 years	0
	45–49 years	0
	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=36; 15 (42%)
If not on DNase, % on hypertonic saline	5 (14%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	14 (31%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	13 (93%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	10 (71%) with chronic PA; 10 (32%) without

Patient survey

Ninewells Hospital name Dundee

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	1	2	5	6	0	1	0
Female	2	1	10	0	0	2	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	25	5	0	0
Communication	23	3	4	0
Out-of-hours access	20	5	3	1
Homecare/community support	22	4	3	0

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team	19	9	1	1
Waiting times	17	5	4	1
Cross-infection/segregation	19	8	1	0
Cleanliness	22	7	0	0
Annual review process	20	6	3	0
Transition	13	4	3	1

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	7	10	3	0
Cleanliness	11	6	2	1
Cross-infection/segregation	10	7	1	1
Food	2	4	7	6
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	11	2	6	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	10	4	4	1

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	17	3	1	1
Availability of equipment	16	8	1	1
Car parking	10	10	4	3

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	25	2	2	0
Of the ward staff	10	9	2	0
Of the hospital	15	9	1	2

Comments about CF team/hospital

"Good outpatients, poor inpatients."

"Excellent team."

"Absolutely outstanding service – goes above and beyond to help/advise. Would be lost without their outstanding service."

"Super service that goes a long way to me keeping as well as I can."

"My CF team are ok but they are not very good at listening to me."

"CF team are great, very helpful and understanding. I was just diagnosed about two years ago so a big shock for me.

"Excellent clinic, very friendly and very approachable. Dealt very sensitively at all times."

"I cannot rate the care and service I receive from all of my CF team highly enough - they are so kind and compassionate."

"Never had reason to complain. The staff are always there to help and explain my meds and care in every detail to me. Food is made better by vouchers given by CF team."

"Happy to assist with any needs/help. Good listeners."

"The waiting time for an appointment could be reduced as the appointment has to be done one to two months in advance."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Ninewells Hospital Dundee
	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	NTM and other microbiology patients are seen at separate clinics. NTM patients are never seen on the same day.
Do patients spend any time in waiting room?	No	On arrival the patient checks in at reception and is then sent directly to the clinic room. The reception staff are aware of the CF patients. The only time that patients could wait there is if they had a physiotherapy appointment, however they never knowingly have two patients waiting together.
Is there easy access to toilets?	Yes	Two toilets.
Where do height and weight measurements take place? Is this appropriate?		Separate height and weight room; patients have to come out of their rooms for this, coordinated by the staff. The scales are covered to assist in cross infection precautions.
Where are the lung function tests done for each visit?		In clinic room.
Are clinic rooms appropriately sized?	Yes	Four clinic rooms are available for use, three are used for clinic and these are all clean, well equipped and of a good size.
For annual review patients, are any distractions provided?	No	Patients would bring own.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	No	The diabetes nurse comes to the clinic. Some patients prefer to use their local diabetic nurse facility.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	From paediatrics.

Environmental walkthrough: ward

Ward name: Ward 3 and Ward 42

Microbiology status: 3 (Respiratory) 42 (Infectious Diseases)

		Hospital name	Ninewells Hospital Dundee
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Total 21	6 side rooms in ward 3; priority given to CF patients. 15 side rooms in ward 42.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	No	All rooms in ward 42 have full en suite facility with wet room. One room in ward 3 has a shower.
Do CF patients have to share any bathroom facilities?		Yes	Ward 3 – others would have to share a shower room which is monitored, aired and cleaned in between patients; a sign on the door (red/ green) indicates if the room is ready for use. There is also good patient awareness.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	There is a lockable cabinet in the room for which the staff have the keys.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Freeview with integrated DVD. All rooms are equipped with these.
If no, are there any concessions for CF patients?		N/A	
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	There are recliner chairs and Z beds available.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Flexible. The decision lies with the staff, dependant on patient needs.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	A fridge can be put in the room and temperature monitored regularly by the dietitian.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?		Portable DVD Player, Wii, PS, DS, Selection of DVDs. TV.
Is there access to a gym or exercise equipment in the rooms?	Yes	Portable weights, pedals, gym-balls available for rooms. Use of a very large physio gym; this is shared with prosthetics and cardio rehab. Fully equipped with bike, cross trainer, trampets, multi-gym, 4+ therapy tables.
What facilities are there to help with school and further studies?		Patients usually pre co-ordinate their study work, parents will also liaise with college.
Is there a relatives' room?	No	Can use of the day room although not a designated room. This has seating and a TV.
What internet access is there?	None	Patients have to bring in their own Wi-Fi connection (dongle).
What facilities are there to enable students to continue to work and study?	None	Patients would bring in their own IT equipment and Wi-Fi connection.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Sinks in rooms.
What facilities are provided for those with MRSA?		Would follow policy guidelines.
What facilities are provided for those with *B. cepacia*?		Would follow policy guidelines.
What facilities are provided for those with other complex microbiology?		NTM patients would be put in Ward 42 – negative pressure room
Are patient information leaflets readily available on ward?		General leaflets on rack. CF information is given on request.
Transition patients – can they get a tour of ward facilities?	Yes	Patients will receive written information from paediatrics about the adult service. There is a well-established programme in place. They will have a joint home visit from both team members.

Additional comments

- Ward 42 – all side rooms are of a good size with en suite facility and well equipped; all have a wall-mounted TV with integrated DVD.
- Ward 3 – all side rooms have their own toilet, however some patients would have to share the shower room. The shower is cleaned and aired in between patients and the patients would know if the room is available to use by the large green or red sign on the door.

Environmental walkthrough: Other

	Hospital name	Ninewells Hospital Dundee
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Car parking for CF/respiratory patients, a short walk to the outpatients. £2.10 for 3 hours. Concession for inpatient relatives, CNS issue document to take to parking attendant who then issues a scratch card style free pass. There is one free bay for dropping off patients (20 minutes)
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To ward from main entrance, however not so clear from outpatients at rear of building. Staff would escort patients to ward etc.
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?		Visits to DEXA and radiology are all planned and pre-booked. Radiology – large waiting area, seating for 8+ with individual changing rooms. Radiology is located in the clinic area; if the visit is unplanned there is also radiology for general patients in another part of the hospital. Pharmacy seating for 8+, fair size area.
Do patients have to wait at pharmacy for prescriptions?	No	Patients do not wait, collections are made by CNS. Also, the CNS has a drug cupboard for the issue of oral antibiotics on ward and prescriptions are issued by GP. Alternatively, visits would be pre-planned.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	No	No PALS – use Butterfly Trust. Some CF information on walls, leaflets can be issued on request. Parent group which can offer support to parents/carers/partners.
Are there patient comment/ feedback boxes?	Yes	Improvement tree – on ward reception wall – post it notes can be anonymously put on tree with patient comments. Patient surveys are regularly carried out.

Additional comments

- The team has produced a CF education app suitable for Google play store/android/iBook. So far they have had 1,000+ downloads.

Raigmore Hospital Inverness

Overview of service

The Edinburgh adult CF service provides an outreach service for Raigmore Hospital, caring for approximately 24 CF adults. Dr Hulks, a respiratory consultant with an interest in CF, was due to retire soon after the peer review and succession planning is required. Dr Rodgers travels to Inverness once every three months to see CF outpatients. Patients are admitted to Raigmore Hospital for inpatient care but are transferred to Western General Hospital if they need specialist inpatient care.

Staffing levels within the CF MDT generally fall within those recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)', although as with the rest of the service there is currently no CF social worker available for patients.

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 Raigmore Hospital Inverness	
Number of active patients registered (active being patients within the last two years)	219 total network
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	24
Median age in years of active patients	26
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	5 (21.5%)
	20–23 years	6 (25.5%)
	24–27 years	2 (8%)
	28–31 years	3 (12%)
	32–35 years	0
	36–39 years	1 (4%)
	40–44 years	1 (4%)
	45–49 years	3 (12.5%)
	50+ years	3 (12.5%)

Genetics	
Number of patients and % of unknown genetics	4 (17%)

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=9, 5 (56%)	n=15; 5 (33%)
Number of patients and % with BMI <19 split by sex	0	3 (20%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	0	2 (67%)

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	1; 63.57	4; 59.32 (25.55-81.28)
	20–23 years	2; 65.9 (49.59-82.21)	4; 67.75 (47.71-88.53)
	24–27 years	1; 69.78	1; 110.54
	28–31 years	2; 62.29 (only 1 set of data)	1; 56.77
	32–35 years	0	0
	36–39 years	0	1; 66.75
	40–44 years	0	1, 42.5
	45–49 years	1; 66.63	2; 42.5
	50+ years	2; 34.54 (30.33-38.74)	1; no data

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	5
	20–23 years	6
	24–27 years	2
	28–31 years	3
	32–35 years	0
	36–39 years	1
	40–44 years	1
	45–49 years	3
	50+ years	3
Number of patients with chronic PA by age group	16–19 years	0
	20–23 years	5
	24–27 years	0
	28–31 years	2
	32–35 years	0
	36–39 years	1
	40–44 years	0
	45–49 years	3
	50+ years	3

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (4%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	2 (8%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	0
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	6 (25%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (4%) with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	1
Number of patients receiving lung, liver, kidney transplants in previous three years	0

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	56
	20–23 years	21
	24–27 years	0
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	1
	45–49 years	0
	50+ years	14
Number of days of home IV therapy in reporting year split by age group	16–19 years	28
	20–23 years	121
	24–27 years	0
	28–31 years	48
	32–35 years	0
	36–39 years	0
	40–44 years	50
	45–49 years	42
	50+ years	70
Total number of IV days split by age group	16–19 years	84
	20–23 years	142
	24–27 years	0
	28–31 years	48
	32–35 years	0
	36–39 years	0
	40–44 years	51
	45–49 years	42
	50+ years	84

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=19; 6 (32%)
If not on DNase, % on hypertonic saline	4 (21%)

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	14 (58%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	8 (57%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	11 (79%) with chronic PA; 4 (40%) without

Patient survey

Raigmore Hospital, Inverness

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

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	7	2	0	0
Communication	7	0	1	1
Out-of-hours access	4	3	1	0
Homecare/community support	5	3	0	0

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	1	2	0	0
Cleanliness	2	1	2	0
Cross-infection/segregation	3	2	0	0
Food	1	2	1	1
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	3	0	0	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	2	1	0	0

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	6	1	1	0
Availability of equipment	6	2	0	0
Car parking	4	3	1	0

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	7	2	0	0
Of the ward staff	5	2	1	0
Of the hospital	4	4	1	0

Comments about CF team/hospital

"It would be good to receive a report after your annual review, detailing the results."

"My CF team are amazing. The care I receive is excellent."

"Not much consistency in dietitian care, they always change."

"They do a great job. Not a fan of seeing the dietitian all the time as I say the same thing every time. Would be better if they were only at clinics when you had an issue or wanted information."

"Always available when needed and keep regular contact. Feel supported to maintain healthy lifestyle."

"I love them, they do their very best to look after me and make life easier for me whenever possible. Like family! They really care; especially the nurses, couldn't do it without them."

"We are very lucky to have the nurses who provide a fantastic second to none service. Abeley supported by the rest of the team."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Raigmore Hospital, Inverness
	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?	Yes and no	The first 3 patients arrive and all go into separate rooms. If there is a delay at the clinic, the second group of patients ie the 4th slot patient may have to wait for a short time in the waiting area but away from other CF patients and other patients.
Is there easy access to toilets?	Yes	There are toilets in all clinic areas and at the main entrance to the hospital.
Where do height and weight measurements take place? Is this appropriate?	N/A	There is a prep room in the diabetes centre and in the main outpatient the scales are outside the clinic rooms.
Where are the lung function tests done for each visit?		In the individual clinic rooms where the patient is for the clinic.
Are clinic rooms appropriately sized?	Yes	With chairs, plinth, window, hand washing facilities, computer and screen and telephone.
For annual review patients, are any distractions provided?	No	There is very little time during annual review days where patients are not with a member of the team. However, we encourage them to bring their own entertainment, just in case.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Diabetes centre. The CF diabetic patients tend to come at the end of the diabetes clinic to give them more time and only one CF patient per clinic. We only have 3 diabetics on treatment at the moment.
Transition patients – can they get tour of outpatients' facilities?	Yes	We do this are part of the transition process in paediatrics.
Transition/new patients – do they get information pack?	Yes	We are unique in NHS Highland insofar as the CF nurse, dietician and physio all serve both children and adults. The inpatient/outpatient setting and the doctor are the big changes. We have planned transition process for each patient over a period of two years. All young people and their parents receive the Cystic Fibrosis Trust's leaflet on transition.

Environmental walkthrough: ward

Ward name: Ward 11 Raigmore Hospital, Inverness

Microbiology status: All

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	A range of equipment
What facilities are there to help with school and further studies?	Yes	There is a teacher on the children's ward who is available to help with school work. Colleges usually liaise with the young person directly.
Is there a relatives' room?	Yes	
What internet access is there?	–	3G signal throughout hospital. Internet is sometimes a problem. 4G coming later this year.
What facilities are there to enable students to continue to work and study?	Yes	The can use their laptops on the ward. Many have bought dongles to connect to the internet.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	To clean their equipment. Not to sterilise. Most take it home to sterilise.
What facilities are provided for those with MRSA?	Yes	Single side room. Last to be seen on ward round. Last for CF physio, dietitian and also at the physio gym.
What facilities are provided for those with *B. cepacia*?	Yes	Single side room – usually if possible on separate wing of ward, ie different nursing staff. As above for all else. No cepacia patients at present in caseload.
What facilities are provided for those with other complex microbiology?	Yes	Negative pressure room.
Are patient information leaflets readily available on ward?	No	CF team provide leaflets.
Transition patients – can they get a tour of ward facilities?	Yes	We take them to the adult ward on a couple of occasions as an integral part of the transition process.

Environmental walkthrough: Other

	Hospital name	Raigmore Hospital, Inverness
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	No	All car parking spaces are free. Disabled spaces close to ward areas, and outpatients. Also a drop off area at main entrance to hospital.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	All ward areas clear at all entrances. Ward 11 (Chest Unit) has its own entrance.
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	In radiology there is a waiting area for segregation. Patients do not usually have to go to pharmacy but if needed there is a waiting area for them. Bone density scans organised to ensure no two CF patients on the same day. There is however a waiting area where the patients can sit away from other patients in any case.
Do patients have to wait at pharmacy for prescriptions?	No	We usually ask for the prescriptions to come to the ward area for collection. The pharmacy is at the other end of the hospital from the ward.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	We also have an on-site Citizen Advice Bureau.
Are there patient comment/ feedback boxes?	Yes	In all ward areas and clinics, also at main entrance to hospital.

Dumfries and Galloway Royal Infirmary

Overview of service

The Edinburgh adult CF service provides an outreach service for Dumfries & Galloway Royal Infirmary, with approximately six CF adults. Staffing levels within the CF MDT generally fall within those recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)', although as with the rest of the service there is currently no CF social worker available for patients.

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 Dumfries & Galloway Royal Infirmary	
Number of active patients registered (active being patients within the last two years)	219 total network
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	6
Median age in years of active patients	26
Number of deaths in reporting year	0
Median age at death in reporting year	0

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	1(17%)
	20–23 years	0
	24–27 years	3(50%)
	28–31 years	1 (17%)
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	1 (17%)
	50+ years	0

Genetics	
Number of patients and % of unknown genetics	0

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=1, 1 (100%)	n=5, 2 (40%)
Number of patients and % with BMI <19 split by sex	0	3 (60%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	0	2 (67%)

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	0	1,99.53
	20–23 years	0	0
	24–27 years	1, 76.37	2, 67.6 (45.63-89.56)
	28–31 years	0	1, 79.7
	32–35 years	0	0
	36–39 years	0	0
	40–44 years	0	0
	45–49 years	0	1 (77.61)
	50+ years	0	0

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	1
	20–23 years	0
	24–27 years	3
	28–31 years	1
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	1
	50+ years	0
Number of patients with chronic PA by age group	16–19 years	1
	20–23 years	0
	24–27 years	3
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	0
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (17%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	0

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	1 (17%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	3 (50%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	0
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	0 with PH; 0 without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	0
Number of patients referred for transplantion assessment in previous three years	0
Number of patients receiving lung, liver, kidney transplants in previous three years	0

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	14
	20–23 years	0
	24–27 years	54
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
Number of days of home IV therapy in reporting year split by age group	16–19 years	0
	20–23 years	0
	24–27 years	30
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0
Total number of IV days split by age group	16–19 years	14
	20–23 years	0
	24–27 years	84
	28–31 years	0
	32–35 years	0
	36–39 years	0
	40–44 years	0
	45–49 years	0
	50+ years	0

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=4; 2 (50%)
If not on DNase, % on hypertonic saline	0

Chronic antibiotic therapy (ref: 1.22 Annual Data Report 2013)	
Number and % of patients with chronic PA infection	4 (67%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	2 (50%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	4 (67%) with chronic PA; 1 (50%) without chronic PA

Patient survey

Dumfries & Galloway Royal Infirmary

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

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	0	1	1	1
Cleanliness	1	1	1	0
Cross-infection/segregation	1	1	1	0
Food	2	1	0	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	0	2	1	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	0	1	0	2

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	2	1	0	0
Availability of equipment	2	1	0	0
Car parking	1	1	0	1

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	0	2	0	1
Of the ward staff	0	1	2	0
Of the hospital	0	0	3	0

Comments about CF team/hospital

"I think both need to be a bit more supportive at times and wards should be upgraded for CF patients with TVs, Wi-Fi etc instead of having to pay for TV which is really expensive especially if in for a long time. Dumfries hospital needs a specific ward for cystic fibrosis."

"The treatment received during weekends is poor as all CF specialists are off. I also feel communication between infirmary needs to be improved."

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Dumfries & Galloway Royal Infirmary
	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?	Yes...	…but minimal as far as possible. We aim for long appointment times with gaps and small numbers on each clinic.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	In the clinic room
Where are the lung function tests done for each visit?		Spirometry performed in clinic room. If PFTs required then arranged with separate visit to PFT lab.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?		Not applicable – shared care with annual review and investigations conducted at central unit.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Most diabetic care is provided via central unit.
Transition patients – can they get tour of outpatients' facilities?	Yes	
Transition/new patients – do they get information pack?	Yes	Not specifically for Dumfries & Galloway R.I. but will get information regarding transition in the central unit. Small numbers locally and easier to arrange to meet and discuss.

Environmental walkthrough: ward

Ward name: Respiratory

Microbiology status: All

		Hospital name	Dumfries & Galloway Royal Infirmary
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Respiratory ward.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		5	
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	
Can you use mobiles?		Yes	
If there is a television, is the service free?			Currently under revision – TV provided in family room.
If no, are there any concessions for CF patients?			Free Wi-Fi via public network throughout hospital.
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?			Predominantly open visiting.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?			Not relevant for current patients.

	Yes/no/ number/ N/A	Notes/comments
What facilities are provided for teenagers?	No	
Is there access to a gym or exercise equipment in the rooms?		As above.
What facilities are there to help with school and further studies?	Yes	
What internet access is there?		Free Wi-Fi public network.
What facilities are there to enable students to continue to work and study?		As above.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?		Single rooms with en suite.
What facilities are provided for those with *B. cepacia*?		Not relevant at present.
What facilities are provided for those with other complex microbiology?		Single rooms with en suite – close liaison with central team and microbiology on site.
Are patient information leaflets readily available on ward?	No	Specific information is provided by central unit but can be obtained locally as required/ requested.
Transition patients – can they get a tour of ward facilities?	Yes	

Environmental walkthrough: Other

	Hospital name	Dumfries & Galloway Royal Infirmary
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Specific area of car park for patients and visitors, together with numerous spaces for those with disability.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Small hospital so navigation not an issue and location of respiratory service is well known to patients.
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	
Do patients have to wait at pharmacy for prescriptions?	No	Prescriptions are arranged through the ward and prepared for collection via the ward.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?		Not applicable.
Are there patient comment/ feedback boxes?	No...	...but information regarding complaints/ feedback etc is clearly highlighted on posters through the hospital.

Appendix 7

Panel members

Edward Nash*	Consultant	Birmingham Heartlands
Jill Taylor	CF Specialist Pharmacist	Royal Victoria Infirmary, Newcastle
Rachel Massey-Chase	CF Specialist Psychologist	Kings College Hospital
Rebecca Heise	CF Clinical Nurse Specialist	Kings College Hospital
Alison Morton	CF Specialist Dietitian	St James's University, Leeds
Charlotte Rose	CF Specialist Physiotherapist	Northern General, Sheffield
Paul Forbes	Social Worker	Barnardo's Orchard Mosaic
Lyn Hutchison	Senior Programme Manager	NHS National Services Scotland
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
Andrew Sinclair	Quality Assurance and Control Manager	Cystic Fibrosis Trust

*Clinical lead for peer review

cysticfibrosis.org.uk