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Peer review report

South-East Scotland Paediatric Cystic Fibrosis service

25 June 2015

Fighting for a Life Unlimited

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1. Executive summary

Overview of the service

Experienced and dedicated staff operate across the network, providing high-quality care.

Unique elements:

- The 'CF Office' (Associate Specialist supporting cystic fibrosis nurse specialist [CFNS], excellent inter-disciplinary communication).
- Approach to exercise and cardiopulmonary assessment.

Inpatient facilities will improve with new hospital in Edinburgh.

The network needs a more consistent partnership approach; many models of network care exist at the moment and the annual review (AR) experience is variable.

Resources required:

- social work support across the network,
- more definition of the psychology role,
- more dietetic input,
- more pharmacy cover, and
- additional secretarial/admin support – currently 0.7 whole time equivalent (WTE) for 150 patients (recommended 1.0 WTE).

It may be appropriate for network partners to develop a clear understanding of the role of each partner (akin to a service level agreement [SLA]).

Funding arrangements are complex, but the children's commissioner wants to work constructively to ensure the sustainability of an excellent service.

If St John's is to continue to provide CF care then investment is required to support their local resources.

Good practice examples:

- Academic approach, illustrated by exercise physiology and contributions to international studies and national initiatives.
- Cohesive and positive work force, with a vision for taking the network forward.
- Patient-focussed approach, illustrated by the joined up thinking of the CFNS and other team members, in particular, the Clinical Associate. A constructive relationship with the commissioner.

Key recommendations:

Urgent requirements,

- access to nebuliser devices (clear long-term funding stream),
- clarification and protection of psychology time,
- a package for physio to provide exercise support,
- ensure protected pharmacy time, and
- dedicated space within the clinic for the team to administrate between patients.

A bigger piece of work will be developing a co-ordinated network approach.

Outcomes from this exercise should be:

- a clear strategy for St John's (developing a MDT approach to inpatient care),
- a network plan for increasing dietetic time (the dietetic deficit is in the Royal Hospital for Sick Children (RHSC) service where there is a 0.3 WTE shortfall to bring up to 1.0 WTE per 150 patients with CF),
- a network plan for data entry (dedicated Band 4 administrator or equivalent support, ie 0.5 EPA/two hours per week for a CF speciality doctor),
- a uniform network AR framework (based on the Edinburgh and Scottish Managed Clinical Network (MCN)),
- a solution across the network for dedicated social work support for families of people with CF (the input of the commissioner will be needed due to funding being across four different health boards),
- increasing CFNS time to sustain the network contribution of the hub team (1.0 WTE) ,
- a plan for Dumfries patients, and
- a plan to ensure dedicated physiotherapy support at each centre providing inpatient care.

Areas for further consideration:

- Once the network plan is established, a clear transitional care pathway needs to be developed that supports young people across the region. A common template for transition known as 'Ready Steady Go', derived in Southampton, is being proposed for those with chronic disease undergoing transition at RHSC or its network centres.
- All members of the CF multidisciplinary team (MDT) need to make plans for succession planning and this needs to be incorporated into the network solution.

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

Models of care

Summary

Edinburgh is a regional CF centre and provides the hub for a network of three clinics (Fife, Forth Valley and Borders).

Each network clinic has a distinct working relationship with the hub. This reflects:

- resources at the network clinic,
- geography, and
- local expertise.

At the peer review it was clear that the network partners would examine their model of care and look to a more consistent approach, enabling sustainable provision of quality care across the region.

Multidisciplinary care

Summary

On the whole the network is well served by experienced and highly skilled health professionals through the MDT. There are a few deficiencies, outlined in this report. The network MDT works together in a co-ordinated manner with hub staff reaching out to network clinics appropriately and vice versa.

Principles of care

Summary

The network provides a high level of excellent care. The principles of care are well voiced, but there may be a place for documenting this at a network level, as part of a SLA between the hub and the network clinic. This will be an important tool for ensuring and maintaining standards, although less necessary than networks that are funded through a Payment by Results (PBR) tariff. The network needs to do some work re-invigorating the transition plan for transfer to adult care.

Delivery of care

Summary

There are good written guidelines for all aspects of care and these have been appropriately updated. There is evidence of excellent delivery of care across the network and the dedication of the MDTs should be recognised. The guidelines should be incorporated into the network SLA.

Commissioning

Summary

The NHS Lothian Child Health Commissioner led the discussion and focussed on the leadership and clinical strengths as per the SWOT analysis.

It was disappointing that the Senior Managers and Child Health Commissioners from outside NHS Lothian (NHS Lothian includes Edinburgh RHSC and St John's Livingston) were not in attendance. It therefore made the meeting very difficult to conclude in terms of joined-up senior management discussion and assessment of senior manager leadership across the South East of Scotland CF network.

Overall there is a high clinical commitment across the region and Edinburgh NHS Lothian and partners provide a very good service for their children and young people, and there are many examples of effective multidisciplinary working at the specialist and shared care centres, although team members across all sites are not solely dedicated to CF work. This can create pressures within job plans for consultants and often requires the Lothian nursing team to work extra hours, especially if supporting the shared care areas.

Within Lothian there are pressures on inpatient beds that can sometimes lead to delays in admission and there is a worry that this is not being addressed within the footprint of the new Edinburgh Children's Hospital.

The South East of Scotland Children's Planning Group has responsibility for oversight of the national specialist delivery plan. Only Lothian members were present at the managers' meeting so again difficult to ascertain the role of the South East and Tayside Children and Young People's planning group in developing, growing and monitoring of the service.

Overall, analysis and discussion concluded there to be strong clinical leadership within NHS Lothian and the shared-care centres, but quite disparate senior management arrangements. These became evident when discussing issues within and across the services, for example the Paediatric AHP Services in Lothian, which are not managed with other services within the RHSC. Therefore, the RHSC Director was unaware of some of the service pressures that faced this group of staff and has no control of funding for these services, and was also therefore unaware of issues with backfill of posts and that efficiencies had been made, impacting on the services.

Recommendations

The SEAT Children's Planning Group requires a stronger focus on CF service delivery and quality improvement and to ensure the ongoing monitoring and review of the CF services, including the use of the Non Profit Distributing (NPD) investment and any subsequent disinvestment or erosion of investment due to efficiency savings and/or other service pressures including staff vacancies and maternity leave need to be addressed.

An agreed, consistent model of care and annual review (AR) process, compliant with the CF standards of care, is required to be implemented across all NHS Boards and hospitals within the South East network.

NHS Lothian should review the designated beds and configuration within the plan of the new children's hospital to ensure capacity and compliance with CF standards of care.

A staffing review across all of the CF service is required and a workforce plan must be agreed to ensure appropriate staffing to meet the CF standards of care.

There is variance of the model of care in the shared care centres. A single model needs to operate across all centres with the same level of support from the specialist centre reflected by patient numbers.

NHS Lothian may wish to review the management of paediatric Allied Health Professionals (AHP) services.

There is a huge reliance on the specialist Cystic Fibrosis Nurse (CFN) service to fulfil what is perceived to be the social worker role. This may be consistent with 'Getting it Right for Every Child', the national policy in Scotland and lead professional model of care, but recognition of the additional demands on the nurses needs to be considered and a support infrastructure introduced to enable them to undertake these additional responsibilities.

NHS Lothian is required to address the issues that cause delay in recruiting to posts, such as the maternity leave cover of the specialist CFN.

NHS Lothian is required to review the CF lead consultant job plan and ensure skill mix to support CF patient data management.

Practical issues around supply of equipment, such as nebulisers, need to be urgently addressed.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	117 total for centre: 95 Edinburgh; Forth Valley 22.

			Male	Female
FEV_1	Number and % of patients with FEV_1 <85% by age range and sex	0–3 years	0	0
		4–7 years	2 (14%)	2 (28%)
		8–11 years	4 (29%)	0
		12–15 years	5 (35%)	3 (44%)
		16+ years	3 (21%)	2 (28%)

Body mass index (BMI)	Patients with a BMI percentile <10th centile on supplementary feeding	(n=4); 3 on supplementary feeding

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	9 (10%)
	Number and % of patients with chronic PA infection on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	9 (10%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	5 (56%)
	Number and % of patients on chronic macrolide without chronic PA infection	11 (13%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

There has recently been some succession planning owing to the retirement of an experienced senior consultant. The Edinburgh hub is well served with a mix of experience and skill sets. Four consultants provide CF care in the hub along with non-career grade doctors – there is a specialty doctor for CF at both RHSC and Forth Valley – as well as local consultant input. There is a need for more dedicated CF time in their job plans. This will be even more of an issue with reconfiguration of the provision of network care if more time is required for supporting the network clinics. This should be a key factor in any business case for future development.

Specialist nursing

Edinburgh Paediatric CF Centre Peer Review of CF Nursing Services

The Edinburgh Paediatric CF Centre is made up of five clinics:
West Lothian: 20* patients
Borders: four patients
Fife: 32 patients
Forth Valley: 25–29 patients
Edinburgh: 78 patients (*including the 20 at West Lothian)

Total number of patients - 147

Edinburgh – Royal Hospital for Sick Children

Areas of strength/opportunities

- There are 78 full care patients and 69 shared care patients with 2 whole time equivalent (WTE) nurses.
- Both nurses (Band 7) are well qualified (Registered Nurse (RN) children. BSc, MSc) and are extremely experienced in nursing and cystic fibrosis. They are both nurse prescribers. They are members of the Cystic Fibrosis Nurses Association (CFNA; one as a committee member), CF Managed Clinical Network (MCN) Scotland and have attended relevant local, national and international meetings and conferences. Both nurses have presented at local, national, and international meetings several times during their time working with cystic fibrosis.
- The CF multi disciplinary team (MDT) is a robust team that provides good peer support and is easily accessible. The CF CNSs share an office with the Associate Specialist Doctor, which is a great advantage.
- They attend CF MDT clinics both at the centre and in the outreach clinics, as well as having their own nurse-led clinical reviews. Their time is divided between hospital- and community-based care and supporting the outreach clinics. They run the home intravenous (IV) service and are responsible for organising the treatments and reviewing progress during treatment.
- They report an excellent working relationship with the CFN in Fife with weekly contact, but feel the working relationship with the nursing team in Forth Valley is less well established.
- It is hoped that links can be expanded upon with Forth Valley team in the areas of peer support, in-service training and joint working.

- Recent audits – New Born Screening parent experiences, Totally Implantable Vascular Access Device (TIVAD). They are educators – mentoring trainee nurses, team away days, parent evenings, national CF Nursing events.

Areas of improvement/concerns

- For the number of patients on full and shared care, 2 WTE nurses would seem appropriate. However, this is already a drop in establishment from a few years ago and 1 WTE nurse has been on maternity leave for several months. Some of these hours have now been backfilled, but there is fear that pressures will mean the full hours will not be replaced when the nurse returns from maternity leave. If this were to happen it would put a great strain on the CF nursing service and make it difficult to maintain the service to Edinburgh's full care patients and the support to the shared care clinics.
- Lack of social worker and admin support mean the nurses spend time doing tasks outside the nursing remit. If the appropriate support was available they would have more time to address the areas identified as weaknesses.
- The four patients that live in the Borders and the cover provided for the patients in West Lothian (St John's) are only manageable because the Edinburgh nurses live in those areas. This would not be sustainable if these nurses did not live in those areas.

Borders General Hospital

Areas of strength/opportunities

These patients are looked after by the Edinburgh CF Nursing team. Recently, there has been allocation of a Paediatric Community Nurse to each of the four patients at the Borders.

- The experience of the Community Nurses with such small numbers will be limited and mean they will not be working at an appropriate level. Therefore the centre nurses will need to continue to be the named CF specialists in nursing for this group of patients. The Community Nurses can act on direction from the Centre Nurses, but would need to feed back to them for appropriate course of action. Since initial discussions it seems that the Community Nursing Team have communicated to the CFCNS that they can only provide provision of supplies to the CF patients in their area.
- Nursing staff caring for inpatients need to be kept up to date and be experienced in caring for children with CF. This is difficult to maintain with small numbers. It may be more appropriate for all inpatient care to be provided in the centre.

Fife – Queen Margaret Hospital Dunfermline and Royal Victoria Hospital Kirkcaldy

Areas of strength/opportunities

- Fife has 0.6 WTE CF nursing cover for 32 patients. This is just below the recommended ratio of 1:50 patients, where 0.64 WTE would be required. She works closely with the centre CFCNSs and they cover in her absence. However, as stated previously, this is only sustainable because one of the CFCNSs lives in Fife. Since this nurse has been on maternity leave, cover has been more difficult.
- The Fife nurse is well qualified in nursing (RN child, BSc Nursing and is about to embark on the online CF course). To maintain her knowledge and skills she regularly attends the CFNA meetings and has applied for funding to attend her first international meeting (NACFC). She also attends the Scottish Nursing and MDT meetings. She is involved in organising a Scottish study day for ward nurses (adult and children) and has collaborated with the centre nurses on the new born screening audit – 10 years parental experience.
- The nursing service is split roughly 50:50 between home and hospital care. The home IV service is nurse-led, being initiated for the first two doses in hospital and subsequent reviews at home. Ad hoc nurse clinic reviews are arranged for interim checks or acute problems. Specialist nursing support for inpatient care is provided by daily review by the CFN on her working days. There is a CF resource folder on the ward and the centre nurses are available for verbal advice.
- The local CFN practises independently, but benefits from close liaison with CFCNSs in Edinburgh as well as liaising closely with the local consultant with a respiratory interest (Dr Aniruddhin), the local home-visiting service and local AHPs (physiotherapy, dietetics and psychology services).
- The nurse knows her patients well (an advantage of a small caseload) and seems well aware of her limitations and when she needs to seek advice from her more experienced colleagues. She has weekly contact with the centre nurses.

Areas of improvement/concerns

- The members of the MDT are scattered across various bases (up to a 30-minute drive apart), which puts constraints on the service.
- Funding for equipment is a struggle to identify.
- Lack of social worker and admin support mean the nurse spends time doing tasks outside of the nursing remit. If the appropriate support were available she would have more time to address the areas she has identified as weaknesses.
- Growing patient numbers are stretching the nursing resource and need to be considered in future planning.

Forth Valley Royal Hospital

Areas of strength/opportunities

- Forth Valley has 0.6 WTE CF nursing cover for 25-29 patients (slight variation in numbers given from clinic and centre). This is in line with the recommended ratio of 1:50. This 0.6 WTE is officially split 0.4 WTE and 0.2 WTE between two Paediatric Community Nurses who both have patients without CF in their caseload. However, the feeling is that in reality they split the caseload 50:50. There is a nurse available throughout the working week and they cover each other for absence. The 0.4 WTE nurse has a team leader remit as part of her role. She is well qualified in nursing (Registered Sick Children's Nurse (RSCN), Community Children's nurse, Post Graduate Certificate in Education, Diploma in Counselling). The 0.2 WTE Band 6 is the Complex Respiratory Nurse working in the Paediatric Community Team. She also has a wealth of qualifications and experience in nursing (RGN, RN Child, Specialist Practice Degree in Paediatric Intensive Care, Neonatal Course and 1 module at MSc level). They attend Scottish nursing and MDT meetings but have not attended UK or international meetings. They are both members of the CFNA but have not been to a meeting; neither has completed the CF course.

- They spend roughly 25% of their time in home care and 75% in hospital-based care. Home care is more frequent with younger patients. Once the families become more experienced, most problems are managed by phone contact outside of clinics.
- The CFNs lead the home IV service. Only patients with TIVADs have home IVs. All others would have full courses of IVs in hospital.
- The Forth Valley nurses participated in the CF nurses survey of families affected through newborn screening and in the regional psychology study as part of the network's research and audit activity.
- The MDT has a close working relationship.
- The two named nurses cover each other for absences and have telephone or email contact with the centre nurses for support if needed. They also do joint visits with the centre nurses where required.
- Joint clinics are every three months, giving the opportunity for nurse supervision. However, the local nurse often reviews the patients with the consultant rather than using the time for nurse supervision and collaboration. Nursing guidelines and protocols are derived from national, Cystic Fibrosis Trust and Edinburgh guidance.
- The CF nurses have a close working relationship with the ward matron and ward nurses. They will visit inpatients daily and have a regular Friday handover of potential issues that may occur over a weekend. They are in the process of producing a 'patient passport' to include treatment regime, information and results, which will enhance care for all patients.
- The nurses are organising a parents evening: Family Education Evening.
- Transition to adult care is led by the centre, although patients do not engage well in this.

Areas of improvement/concerns

- Lack of social worker, psychology and admin. support mean the nurses spend time doing tasks outside the nursing remit. If the appropriate support were available they would have more time to devote to the nursing tasks.
- As the nurses work from within the Community team it feels as though they are part of the local Community team over being part of the CF team. They would benefit from the CF part of their role being more of an extension from the CF centre nursing team so that standards of care and knowledge would be more robust and in line with Centre guidance and therefore National Guidance.
- There is a need to secure funding to attend continuous professional development (CPD) outside of Scotland.
- They need to work with the centre nurses to change the transition process in an attempt to improve patient participation with the process.

Overall themes and recommendations

- Lack of secretarial, social work and psychology support mean the nurses spend time on tasks outside nursing remit. They struggle to manage the level of nursing support that is needed. This could be rectified with appropriate admin., social work and psychology establishment.
- Although the nurses reported that the inpatient nursing care was satisfactory in each hospital they all highlighted ward staff education was acking due to time constraints. They felt if they did have more spare time this is one of the areas they would use it for. Freeing up more specialist nursing time for ward staff education is important.

- The model of shared care differs between the centre and clinics. There are long-standing CF nursing networks between the specialist centre and the Fife service. The relationships between Edinburgh and Forth Valley are less well-established with ongoing development of peer support, in-service training and joint working. Guidelines/protocols may not be being interpreted the same at the centre and local clinic. The centre CNSs work very closely with the CF Nurse in Fife but don't feel they work closely enough with the CF Nurses in Forth Valley. Although they acknowledge that there are advantages to the nurse knowing first-hand what the medical team are saying to the patients, they feel they should get the opportunity to pair up with the nurses in the joint clinics for supervision and collaboration.
- There are gaps in the transition process from paediatric to adult care. Again, the process differs in each clinic. Some patients are asked to attend transition clinic at the paediatric centre where they haven't been before, as all the shared care is done locally. They will then transfer to the adult centre in Edinburgh. It isn't perhaps surprising that they are poor attenders to the transition clinic at the paediatric centre. There are always going to be variables that mean one system will not be ideal for all; there may be scope for looking at the transition process and making some adaptations, which could lead to higher engagement.

Physiotherapy

Edinburgh Royal Hospital for Sick Children (RHSC)

There is an established and very experienced team working at this CF Centre.

They provide full care to patients who attend RHSC and shared care to the patients attending the Network hospitals.

The physiotherapy staff at RHSC cover other conditions as well as CF, ie other complex respiratory patients. They are responsible for inpatients, outpatients and also see patients in the community. Following a previous review appropriate staffing was provided in relation to the number of full care and shared care CF patients. Since that time further re-organisation has meant that 1 WTE has been taken away from the establishment. This has meant that the Band 8a has had to sometimes plug this gap, becoming involved more extensively involved in patient treatments rather than in the specialised roles of an experienced Band 8a. It has also meant that at busy times exercise for patients has had to be prioritised out

Cover to the patients on the wards is to the required standards and patients are treated as frequently as necessary both during the week and at weekends.

Current total WTE for CF physiotherapy at RHSC is 1.5 WTE as compared with the recommended levels for a centre this size of approximately 3 WTE:

- Ward-based rotational physio 0.5 WTE for CF.
- Senior physio (outpatient) 0.5 WTE for CF.
- Senior physio (acute and community-based) 0.5 WTE for CF.

There is always a physiotherapist present at clinic. A physiotherapist from RHSC attends all the clinics at the Network hospitals ensuring that Network children are reviewed by RHSC twice a year except for Borders General where only the doctor and nurse attend.

There is excellent networking in this region with support and education provided to all the hospital physiotherapists within the network.

There is opportunity to attend meetings and conferences at national and European level.

Areas of excellence:

- Networking and training.
- Exercise testing, exercise prescription, exercise referral scheme to local facilities.

Areas for improvement:

- Following reorganisation leading to the loss of 1 WTE physiotherapist time, physiotherapy cover has dropped to half of the recommended levels.
- Access to inpatient gym facilities is limited, however this will be remedied in the new hospital.
- There is some involvement in Research and Audit, however there is a lack of time available to allow this to be at a significant level.
- Funding for nebulisers is an ongoing challenge.

Recommendations:

- There should be investment to support sufficient staffing and skill mix for physio to provide exercise support and to ensure that exercise sessions on the wards are carried out and could also follow this important aspect of CF treatment into the community. Investment in staffing would also allow appropriate involvement of physiotherapists in research and audit.
- The establishment of a funding stream for nebuliser equipment, promixin and dry powder inhalers is needed.

Fife

Queen Margaret Hospital, Dunfermline and Victoria Hospital Kirkcaldy

The 32 patients looked after at this hospital are cared for by 16.5 hours of physiotherapy time, shared by two physiotherapists. However, both physiotherapists carry an additional caseload which can take priority over their CF caseload.

Outpatient clinics are at Queen Margaret's Hospital in Dunfermline and patients requiring IV therapy are admitted to Victoria Hospital in Kirkcaldy. The majority of regular planned IVs are done as home IVs.

There are no inpatient paediatric physiotherapy services within the children's ward at Victoria Hospital Kirkcaldy. Patients requiring to be seen will be seen by the adult physiotherapy team at Victoria hospital for acute admissions and only in the acute phase. Once stable, treatments are expected to be carried out by families. Therefore, the frequency of daily treatments does not meet national standards and is not equitable with the specialist centre (RHSC Edinburgh).

Weekend treatments are done by families and not the adult physiotherapy team unless identified by the consultant as needing physiotherapy input. This is also not equitable with the specialist centre (RHSC Edinburgh) or with agreed national standards

The physiotherapy department gym facilities within the Victoria hospital are good, but there are no available trained staff to support CF patients to use these facilities when an inpatient.

Physiotherapy staffing equates to 0.45 WTE, however using the quota equation of 1:50 then the staffing should be 0.64 WTE.

Areas of excellence:

- A physiotherapist present at every clinic.
- Committed and enthusiastic staff.
- Networking with other physiotherapy staff ensuring CPD.

Areas for improvement:

- The provision of inpatient physiotherapy care in accordance with current standards.
- It is important that the budget for nebuliser provision is ring fenced.
- Equity with RHSC to free gym membership.

Recommendations:

- Physiotherapy treatments need to be provided at least twice a day, week days and weekends for patients on the ward by appropriately trained and experienced physiotherapists.
- The provision of dedicated clinical hours to promote exercise for IV patients in hospital and in the community and also to do some routine physiotherapy treatments for those on planned IVs.
- The establishment of a funding stream for nebuliser equipment, Promixin and dry powder inhalers.

Forth Valley Royal Hospital

30 patients (though one has shared care with Glasgow and one with Dundee teams).

0.4 WTE Band 7 physiotherapist, ring fenced for CF and access to Band 5 hours.

Although timing is restricted for inpatient treatments to the beginning of the morning and afternoon sessions, those admitted and requiring inpatient treatments are seen twice a day weekdays and weekends. Community visits are possible.

Children do not have formal exercise testing done if they attend RHSC and unfortunately finding space for exercise testing locally is very difficult.

Areas of Excellence:

- There is a physiotherapist present at every clinic and they are well supported by the RHSC team with clinic visits and training.
- Frequency of inpatient treatments is good.
- Committed and enthusiastic staff.

Areas for Improvement:

- It is hard to access either inpatient paediatric or adult gym facilities.
- There needs to be equity in the system for annual reviews as to where they are done, ensuring RHSC involvement even if only to discuss the results.
- There needs to be a ring fenced budget for nebuliser provision and cohesive organisation of the service (this problem is being taken on at present by the physiotherapist and community nurse).

Recommendations:

- The physiotherapist should be able to see a patient at the end of a course of home IVs as well as the start.
- There should be equity with RHSC for formal exercise testing and free gym membership locally.
- The establishment of a funding stream for nebuliser equipment, Promixin and dry powder inhalers.

Borders General 4 patients

0.5 WTE physiotherapy time is allocated to complex respiratory, which allows for physio to be present at all respiratory clinics – this equates to approximately 0.1 WTE dedicated to CF physiotherapy.

Patient's annual reviews are done at RHSC. The physiotherapist from RHSC does not come to the Borders clinic visits, only the RHSC doctor and nurse do clinic visits. This means that children only see the Centre physiotherapist once a year.

Education and support from the Centre physiotherapist is available at network meetings.

Lung function tests in clinic are done in the adult respiratory department which is not appropriate for children.

Areas of Excellence:

- The physiotherapist is able to do community visits when necessary including visits whilst children on home IVs.
- Committed and enthusiastic staff.
- Networking with other physiotherapy staff ensuring Continuing Professional Development (CPD).

Areas for Improvement:

- The provision of an extra clinic room would enable individualised physio reviews to be undertaken whilst the consultant is reviewing another patient which isn't possible at present as there is only one room available.
- Establish post clinic discussions and MDT meetings to facilitate greater MDT working.
- There is no budget for nebuliser provision or physiotherapy adjuncts such as Acapellas and PEP masks.

Recommendations:

- Equity with RHSC to free gym membership locally.
- Lung function tests are not done at the beginning and the end of IV treatment. This should be addressed.
- The establishment of a funding stream for physiotherapy adjuncts, nebuliser equipment, Promixin and dry powder inhalers.

Dietetics

There is currently a Band 7 dietitian based at Edinburgh providing 0.7 WTE to 145 patients, 80 full care and 65 shared care. The CF Trust Standards of Care recommend 1.0 WTE for 150 patients. This means there is a deficit of 0.3 WTE. The post holder previously worked 0.4 WTE which was increased to 0.7 WTE after funding from the National Delivery Plan. (2008). However, the substantive post was not backfilled so although there was an improvement in the service it did not benefit from the full additional NDP funding. Nevertheless since 2008, there has been no reduction in CF dietetic staffing despite budget reductions elsewhere in NHS Lothian Dietetic Service and there are no plans to cut in the future. In addition there is funding for 0.5 WTE at Fife and 0.2 WTE at Forth Valley as a result of the NDP. No dedicated funds were awarded to the dietetic service for the Borders. At present there are only four patients who are seen as part of the core dietetic caseload in Borders General.

All Dietitians are members of the Scottish CF Dietetic Group and attend regular Scottish National Educational MDT Meetings. The dietitian in Forth Valley also has membership to the UK CF Dietetic Interest Group. The Specialist Centre dietitian had a poster and oral presentation at the 2013 European conference.

The dietetic service at Edinburgh is provided over four days so there is no cover for Fridays. There is a dietitian available for Network outpatient clinics, except for when on leave. Children from the Network are also seen separately by the local dietitian in either dietetic-led clinics, or at home. The local dietitian also offers school and nursery visits. The Specialist Centre does not provide any community service. MDT meetings are attended across the Network. Ward rounds and teaching sessions are attended at the Specialist Centre when applicable.

Cover for leave is only routinely provided in Forth Valley, where the two dietitians cross-cover. The dietitian in Fife has been on long-term sick leave for six months and cover was limited to emergency cover by the Specialist Centre. Since then the 0.5 WTE allocation is now divided between two dietitians.

The Specialist Centre dietitian does not see all full and shared care patients for annual review and therefore is not meeting the CF Trust Standards of Care. As she is part time she is unable to attend all full care annual review clinics. Instead they are seen either at the previous or following clinic.

There is no input from the specialist dietitian to clinics in Fife or the Borders. They are seen by the Network dietitians for annual review. Children from the Borders are seen in Edinburgh for annual review. Forth hold quarterly joint clinics which the Specialist Centre attends but annual reviews do not take place in these clinics. The Network clinic leads on the annual review process and results are discussed with the Specialist Centre.

The dietitians are all involved with transition. The Specialist Centre attends joint clinics with the Adult Centre and is in contact with the adult dietitian.

Inpatients at Edinburgh are reviewed one or two times a week and discussed at weekly MDT ward round, thereby meeting the CF Trust Standards of Care. Across the Network IP numbers are small and reviews can be difficult if parents have opted for home IVs or on day leave for much of their admission. Forth are addressing difficulties in inpatient (IP) reviews and creating a patient contract which will state that all must been seen by dietitian during admission.

In Edinburgh, hospital meals are provided using a bulk service operation and meals come from a different site. There has been significant development and there are now new Scottish standards for children's catering which they are striving to achieve. There is a Nutritional Care Group where issues can be addressed. The specialist dietitian reported that complaints have been received. Additional food provision such as extra snacks and higher calorie meals are available across the Network.

Areas of good practise:

- Dedicated and experienced team committed to CPD.
- The Specialist Centre has led on many Scottish nutritional guidelines and audits with active contributions from the entire Network.
- The annual review process has been audited and the report indicated a consistent approach across the Network. The findings were presented at the recent UK CF Dietetic Interest Group Meeting.

Areas for improvement:

- No consideration has been given to succession planning and NDP funding was not on the basis of a 52 week service, and so does not include cover for leave. Cover for the specialist dietitian is very limited and provided by dietitians with little CF knowledge or experience. In addition, cover is expected across the Network for other specialities which can be for extended periods of time such as a maternity leave.
- There is no specific Network meeting and therefore no formal opportunity for service development to be addressed.
- Specialist Centre dietitian to continue to work closely with catering via the Nutritional Care Group to minimise complaints.

Recommendations:

- Increased dietetic funding at Edinburgh of a minimum 0.3 WTE would meet the CF Standards of Care. This additional resource would allow for five day's cover a week, availability at all annual reviews and Network clinics and allow for the development of a training role to support succession planning.
- Annual Network Meeting lead by the Specialist Centre dietitian. This could be part of a MDT Annual Network Meeting where service and quality issues could be discussed.

Pharmacy

Staffing

147 patients are seen across six sites: Edinburgh (57 patients), 0.65 WTE CF pharmacist, but less received due to other duties and responsibilities; St John's (20 patients), no designated pharmacist, recently vacated post; not filled, cover is ad hoc; Fife, (32 patients), recently appointed a 0.5WTE Band 8a pharmacist for paediatrics who will cover CF patients; Forth valley (29 patients), 0.5 WTE Band 8a pharmacist for paediatrics, with supporting 0.5 WTE Band 7 pharmacist; Border, (four patients), covered by a 0.66 WTE Band 8a pharmacist who has many other specialties/responsibilities; Dumfries and Galloway, (five patients), pharmacy provision not clarified. The Cystic Fibrosis Trust Standards of Care state that for 150 patients, there should be 1.0 WTE CF pharmacist. As a network sites model of care provision, it is difficult to interpret whether or not the staffing requirements are met. With the exception of Edinburgh, care is provided by general paediatric pharmacists, although with high-quality network communication this need not be a deficit. At Edinburgh, in her absence, the CF patients are seen by another pharmacist. The pharmacist at Edinburgh has recently returned from six months away and is therefore re-establishing contact with her colleagues and she is the main focus of this review.

CF MDT meetings and ward rounds

The specialist centre pharmacist attends the weekly respiratory grand round where all the respiratory patients, including those with CF, are discussed. In time she is due to start attending annual reviews, though requires support from senior colleagues to achieve this.

Clinics
Currently the specialist centre pharmacist is not involved in outpatient clinics, but is available if called to attend. Support from senior pharmacy colleagues is needed to reduce her other workload to allow her to attend clinics at Edinburgh and St John's.

Audit and research
The specialist centre pharmacist has been able to attend one international conference, CF Pharmacy Group study days in 2010–14 (she is also a member of their committee) and other national study days. In addition, she set up the Scottish Paediatric CF Pharmacist group as part of the Scottish Paediatric CF managed clinical network. Through this group she has been involved in producing national guidelines. She has been involved in an audit and has also been involved in the running of national trials at her hospital.

Key life stages
Currently the specialist centre pharmacist involvement in the key life stages is minimal at Edinburgh and St John's. The extent of involvement at other networks sites by local pharmacists has not been possible to clarify.

Three areas of excellence:

- the potential for strong leadership from the Edinburgh pharmacist if given the time to lead the network,
- strong links with the national CF groups, and
- strong clinical knowledge.

Three areas for improvement:

- it was noted that there are some medication availability problems across the network that need to be resolved,
- pharmacy involvement in clinics, annual reviews and key life stages (particularly transition) at Edinburgh (and potentially across the other sites too), and
- more communication required between the network sites.

Three recommendations:

- reorganise staffing and workload at Edinburgh to achieve 0.65 WTE for CF,
- restablish and then strengthen links with pharmacists at network centres, and
- share expertise and innovate on methods to do this.

Psychology

Edinburgh 0.3 WTE (expected 0.6) Fife 0.1 WTE (expected 0.3) Forth Valley (until recently 0.2 no current cover) Borders 0.0 WTE (only 3-4 patients).

Areas of excellence/good practice:

- Flexibility in the provision of psychology provision given time constraints.
- Includes using self-help/MDT-enabled initiatives eg 'Hospital Passports' for each patient and their family in order to reduce and prevent procedural distress.
- Both psychologists feel very integrated in CF teams.
- Annual reviews are attended for all patients at Fife and recommendations for the coming year are made (very commendable given the limited time psychologist has available to work with patients with CF and their families and carers).
- Monthly psychosocial meeting in specialist centre where patients from across the network are discussed.

Areas for improvement:

- Currently there is no service outside of RHSC Edinburgh for children who have CF and their families whilst they are inpatients (unless they are undergoing a current piece of work with the psychologist). Also no dedicated social work at Edinburgh across the network therefore using psychology and nurse specialist time and resources.
- Transition is an area recognised by the psychologist as requiring improvement (that being transition to adult services but also the transition of care (inpatient or outpatient) to the Edinburgh tertiary service). Processes between each centre could be improved.
- More formal service to be offered to newly diagnosed (newborn screening or medically diagnosed) patients and annual review.

Recommendations:

- Increase provision of psychology and social work as above. This to ensure that inpatient work is offered at Fife and more formal contact with patients and their families as per the Cystic Fibrosis Trust's Standards of Care at times of transition eg newborn screening; annual assessments, change of centre care (to another paediatric or adult service).
- Establish greater links between network and tertiary care centre.
- Establish equity of clinical psychology service to all patients in area (especially Forth Valley and Borders service).

Social work

Currently there is no social work provision that meets the Cystic Fibrosis Trust's Standards of Care requirements at Edinburgh or at any of the shared care clinics. 1 WTE qualified and experienced social worker is indicated.

The majority of the shared care clinics report having strong support from and good general communication with the Edinburgh team.

In the Centre and one shared care area there is strong psychological consultation and this supports CNSs in approaching the more pressing social issues.

Social work support through the hospital team has been constantly diminishing, involves no dedicated time and only some consultation re child protection. There is some support for parents from a local specific CF charity. This offers support in relation to welfare rights appeals and a befriending, counselling service. Feedback from staff and parents is that this is patchy over the extensive region, is struggling to meet local demand and by definition cannot offer an integrated service in terms of information-giving to other agencies. In reality this means that there are both gaps and duplication.

Availability of social work to outpatients at the Edinburgh and the shared care clinics would bring improvements for the patients and the team.

Patients would have the opportunity to build up a relationship with a social worker. This would be of value in terms of prevention and normalising support. It would allow for home visits, annual review, support through new diagnosis, parenting issues, education, transition and if necessary transplant and end-of-life. In addition to direct input social workers can signpost and facilitate access to local services. Specialist nurses and psychologists would be freed up from those aspects of the role that they currently cover and would be able to develop their roles within the service.

Availability of social work at shared care clinics would greatly improve the accessibility of the service. This is likely to be particularly the case for adolescents for whom less universal services will be available locally and for whom using centralised services will have an increased cost and time implication.

Recommendations:

- The appointment of 1 WTE social worker employed directly by the NHS Trust. Local authorities are now seldom involved in specialist social work provision and many Trusts employ directly.
- The social worker would be a senior social worker with considerable experience. This is because of the range of areas covered within the role and nature of being a lone professional within the multidisciplinary team.
- The social worker would attend shared care clinics with the rest of the team, contributing to support as outlined above. This would allow equality of service provision to all patients and normalisation of support. Further detail has been provided to the Commissioning Panel member.

5. User feedback

Royal Hospital for Sick Children

	Completed surveys (by age range)			
	0–5	6–10	11–15	16+
Male	6	4	3	0
Female	4	2	2	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	17	5	1	0
From the ward staff	9	4	3	0
From the hospital	11	5	3	0

Areas of excellence:

1 Availability of team.

2 Cross-infection (outpatients).

3 Cleanliness (outpatients).

Areas for improvement:

1 Car parking.

2 Cleanliness (inpatients).

3 Food.

6. Appendices

Appendix 1

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

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

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

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

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

Hospital name

Royal Hospital for Sick Children

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	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	?	Not known	
	% 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%	Red 100% discussed	Red	All CFRD patients are discussed at monthly CF diabetes meeting [minimum is a discussion of all patients between CF specialty doctor – Dr Fall and Diabetes Associate Specialist – Dr Noyes along with dietetic representatives from CF and diabetes teams] but are not reviewed at a joint clinic

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%	Red 50% not part of policy now catching up	Red	Previously liver ultra sound scan was performed when lung function tests and/or coagulation were abnormal. This was changed to performing on all aged >10 years in 2010 approximately. It is now practice to perform liver USS in all >5 years and this will be 100% compliant by the end of the 2016 annual review cycle.

3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Red 50% High did not attend (DNA) and long waiting list	Red	

4 Delivery of care

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

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	Green	Green	
	% availability of a clinical psychologist for inpatients	100%	Green	Green	
	% availability of a social worker at clinic	100%	Red	Red	
	% availability of a social worker for inpatients	100%	Red	Red	
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0%	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	N/A	N/A	

Appendix 2

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Royal Hospital for Sick Children 147 patients
Consultant 1	0.5	1	1	1.8 PA (0.2 WTE)
Consultant 2	0.3	0.5	1	1.5 PA (0.15 WTE)
Consultant 3			0.5	0.8 PA (0.1WTE)
Consultant 4				1.2 PA (0.1 WTE)
Staff grade/fellow (Assoc Specialist)	0.5	1	1	0.8 WTE
Specialist registrar	0.3	0.5	1	0
Clinical Nurse Specialist	2	3	4	2 WTE
Physiotherapist	2	3	4	0.5 WTE
Physio (Acute and Community)				0.5 WTE
Rotating physio				0.5 WTE
Dietitian	0.5	1	1.5	0.7
Clinical psychologist	0.5	1	1.5	0.3
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.6 WTE
Secretary	0.5	1	2	0.7 WTE
Database coordinator	0.4	0.8	1	0

Appendix 3

UK CF Registry data

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

UK CF Registry data 2013	
Demographics of centre – Royal Hospital for Sick Children	
Number of active patients registered (active being patients within the last two years)	118
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	117 for total centre; 95 Edinburgh; Forth Valley 22
Median age in years of active patients	8
Number of deaths in reporting year	0
Median age at death in reporting year	n/a

Age distribution (ref: 1.6 'Annual Data Report 2013')		
Number and % in age categories	0–3 years	16 (17%)
	4–7 years	27 (28%)
	8–11 years	22 (23%)
	12–15 years	18 (19%)
	16+ years	12 (13%)

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

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2013')	
Patients with a BMI percentile <10th centile on supplementary feeding	(n=4); 3 on supp feeding

FEV_1 (ref: 1.14 'Annual Data Report 2013')			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	2 (14%)	2 (28%)
	8–11 years	4 (29%)	0
	12–15 years	5 (35%)	3 (44%)
	16+ years	3 (21%)	2 (28%)

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	16
	4–7 years	27
	8–11 years	22
	12–15 years	18
	16+ years	12
Number of patients with chronic PA by age group	0–3 years	3
	4–7 years	1
	8–11 years	1
	12–15 years	4
	16+ years	0

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	2 (2%)
Number and % of *cenocepacia*	1 (1%)
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	2 (2%)
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	1 (1%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	3 (3%)
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	with PH 3 (3%) without PH 1 (1%)

Transplantation (ref: 1.18 'Annual Data Report 2013')	
Number of patients referred for transplantion assessment in reporting year	1
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	0–3 years	56
	4–7 years	110
	8–11 years	70
	12–15 years	221
	16+ years	116
Number of days of home IV therapy in reporting year split by age group	0–3 years	121
	4–7 years	51
	8–11 years	102
	12–15 years	260
	16+ years	116
Total number of IV days split by age group	0–3 years	177
	4–7 years	161
	8–11 years	172
	12–15 years	481
	16+ years	232

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=63); 29 (46%)
If not on DNase, % on hypertonic saline	2 (3%)

Chronic antibiotic therapy (ref: 1.22 'Annual Data Report 2013')	
Number and % of patients with chronic PA infection	9 (10%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	9 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	5 (56%) with chronic PA 11 (13%) without chronic PA

Appendix 4

Patient survey

Royal Hospital for Sick Children

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	6	4	3	0
Female	4	2	2	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	14	9	0	0
Communication	12	9	2	0
Out-of-hours access	8	4	3	2
Homecare/community support	10	5	2	1

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	15	6	2	0
Waiting times	13	6	2	0
Cross-infection/segregation	13	5	3	1
Cleanliness	15	6	1	0
Annual review process	12	9	1	0
Transition	3	0	0	0

How would you rate your inpatient care (ward)?

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

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	8	4	0	0
Availability of equipment	10	4	1	0
Car parking	2	1	7	9

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	17	5	1	0
Of the ward staff	9	4	3	0
Of the hospital	11	5	3	0

Comments about CF team/hospital

"I think we have a great team at Edinburgh Sick Kids. Specialist nurses are excellent!"

"Have never had any reason to complain about our team. They are being great with my non-compliant nine-year-old."

"Inpatient care is dependent on parents to a great extent. This includes issuing reminders about the administration of medicines. IV doses have been missed altogether when parents were present during one day of our child's stay."

"The CF team are amazing and without them we would be lost. Nothing is ever a problem. The hospital is ok but look forward to the new one."

"Nothing is a problem for them. Quick to respond back to us with any queries we have had. Friendly. Treat us well."

"I have no issues at all with the CF team, I can approach them about anything. The hospital is great; all departments we have dealt with. The issue with the food is not the hospital's fault as it comes from outside the hospital."

"Luckily my son has not been admitted this year so have indicated."

"My son's CF team are all lovely people, always happy! The hospital is great, all the nurses on my son's ward have always been really helpful. When we are at the Sick Kids I know my son is in very good hands."

"No faults. Helpful and very attentive."

"Very pleased with all aspects of staff/hospital."

"CF nurses and doctors at Sick Kids Hospital Edinburgh are top class. We only have one child with CF and three other kids without so they've been so helpful for us bringing him up. Had our ups and downs but they're always there to help us."

Appendix 5

Parent/patient interviews

Parent/carer telephone interviews

Outpatient clinic

Parent A felt that segregation measures at clinic are very good. Height and weight are measured before being sent straight to a side room for consultation, so that her child doesn't come across other children with cystic fibrosis. She felt that there is good use of hand gel and wiping down of equipment by staff. Her child sees the full multidisciplinary team (MDT) at clinic appointments. They have seen a clinical psychologist at Dumfries and she does know that she can contact the social worker at Edinburgh if need be. Parent A mentioned that she and her child have to wait in an open waiting area in Dumfries clinic, but added that they stagger the appointment times to reduce the risk of patients with CF meeting and thereby minimise cross-infection risk. Parent A felt that decisions made by the CF MDT are very much joint decisions made with her involvement too.

Inpatient care

Not applicable to this child.

Annual review

Parent A's child is offered annual review each year at Edinburgh and they have had this year's review. Her daughter is seen at Dumfries on a quarterly basis and is seen by the Edinburgh team twice a year (March and September).

At annual review the child has a chest x-ray, lung function and a review in clinic. The outcome of the annual review is reported back three months after the review appointment.

Parent A felt that communication from the CF team is usually very good, whereby the CF team gets back to her straight away or as soon as possible.

Home care

DNase and prophylactic nebulised antibiotics are ordered through the GP. Her daughter has had more recent home visits from the physiotherapist – every Monday for a month – to provide additional physio support and explain the significance of physiotherapy to parent A's daughter. Her last home IVs were two years ago, from Dumfries.

Good practice:

- "It's a very good CF service."
- "The specialist CF team keep us well informed and are nice to my daughter."

Area for improvement:

- "They cannot improve on their current service."

Parent B

Outpatient clinic

Parent B's child has full care from the Edinburgh Hospital for Sick Children. The Edinburgh team comes out to Livingston to hold a satellite clinic on a monthly basis and his son is seen in Edinburgh for annual review.

At Livingston they are directed straight to a consultancy room, on arrival at clinic. He felt that the clinic and staff are scrupulously hygienic and the CF multidisciplinary team (MDT) is really good at involving them in decisions on changes to treatments and specifically at directing conversation towards his son. They see the full CF MDT at 90% of clinic appointments and have been offered psychosocial support, if needed.

Inpatient care

Not applicable to this parent's child.

Annual review

Their annual review is offered each year and they described it as 'thorough'. All the assessments take place at Edinburgh over a two day period. On the second day they are seen in the department of physiology and lung function. A summary outcome of the annual review is provided at next clinic appointment and a letter detailing outcomes is sent home.

Home care

Parent B's child has no scheduled home care. If he has a cold, then the clinical nurse specialist will visit to take a cough swab.

Transition

Parent B's son has started the transition process, with transition clinics at the last two outpatient appointments helping them to draw up how transition would be managed and including presence of familiar paediatric team faces. His feeling was that transition would be handled gradually and was being properly arranged.

Good practice:

- "A caring CF team who are professional and providing a seamless service."
- "They have made effective choices in the use of treatments for my son so far."
- "Improvements to the service continual to be gradual."

Area for improvement:

- No suggestions provided by Parent B.

Parent C

Outpatient clinic

Carer C's child receives shared care between Edinburgh specialist centre and Queen Margaret and Queen Victoria hospitals, Dunfermline. He described the outpatient clinic experience as excellent in term of its segregation measures – they are directed straight to a consultation room on arrival at clinic. He mentioned that the dietitian at Queen Margaret Hospital has been off for a while, with cover provided which he felt was fine. They also see the rest of the CF multidisciplinary team at each clinic appointment and have met the clinical psychologist at Queen Margaret Hospital, but cannot remember seeing or being offered access to a social worker. They felt very much involved in the decision making process regarding changes to treatments for their child.

Inpatient care (on ward)

Their child was admitted last summer for a gastrostomy insertion – an elective admission. There was a good level of knowledge and understanding of CF amongst the ward staff nurses, but mainly seen by doctors on the respiratory ward, according to this child's carer. They explained that physiotherapy was provided four times a day and they thought it was the same at the weekends, though not sure of this. They felt that everything necessary was provided for their child to eat, although he struggles with eating anyway.

Annual review

Annual review is offered each year and has taken place this year at Queen Margaret Hospital. All tests take place at this same hospital and a letter is sent home with the outcome of the annual review.

Home care

The clinical nurse specialist recently made a home visit. Abbott nutrition company provides the extension/giving sets for the home gastrostomy feeds and this child's carer felt their service was fine. The liquid feeds are ordered and delivered from the high street chemist and they've experienced just one issue with this service since gastrostomy feeds have started last summer.

Good practice:

- "Queen Margaret Hospital and Edinburgh Hospital for Sick Children's respective CF services are excellent."
- "At the Queen Victoria Hospital we have to wait in a communal waiting area and we could do with being put in isolation (ie being segregated)."

Area for improvement:

- "More information required on new drug treatments coming out."

Parent D

Outpatient clinic

Parent D's child attends outpatient clinics at St John's Hospital, Livingston and the Edinburgh specialist centre team travels to Livingston to provide a satellite clinic. They see the full multidisciplinary team, although they have never seen or had to see a clinical psychologist. In terms of segregation measures, appointments are staggered, so although parent and child wait in an open waiting area, they feel safe. They also feel that hand hygiene and wiping down of equipment is good and once in the consultancy room, they stay there for the duration of clinic. Mother felt that decisions made about her child's treatments are made with her full involvement. She was happy about hospital pharmacy arrangements in terms of waiting time and level of cross-infection risk whilst waiting at pharmacy.

Inpatient care (on ward)

Not applicable to this child

Annual review

Parent D's child is offered annual review each year and has had their annual review in the last 12 months. All the child's assessments took place at the same site at Edinburgh Royal Hospital for Sick Children. They receive feedback on the outcome of the annual review at their clinic appointment and by letter which they receive four to five weeks after the annual review.

Homecare

Their only homecare required is home delivery of parental feeds, by Nutricia Homeward. Mother described their service as "really good and they telephone for stock checks every month".

Good practice:

- "Caring, genuine CF staff. They will do anything to help."
- "The team is approachable and make multiple calls to check how my son is."

Area for improvement:

- "Lack of awareness of CF at the GP surgery. I feel the GP needs educating more about CF."
- "Correspondence seems unreliable between Edinburgh CF centre and GP" – ie parent doesn't feel confident that the GP has all the latest information from the CF team.

Parent E

Outpatient clinic

Parent explained that once directed to a consultancy room at outpatient clinic it is fine. However, on arrival at clinic, on three occasions she and her child have had to wait with other children in the open clinic area. Parent has raised this with CF team, adding 'if you don't ask, you don't get', but felt that receptionists are not educated about the risks of cross infection and significance of segregation – there are three receptionists.

Parent always tries to book first appointment to minimise risk of cross infection, adding that she doesn't see use of hand gel and wiping down of equipment between patients, but assumes it is done.

At outpatient clinic appointments, mother and child see the consultant and a physiotherapist, sometimes a dietitian too. Her child has a good record of weight gain and no current issues with intestinal blockages so is not concerned about not seeing the dietitian at every appointment; rather on a needs basis. They see the clinical nurse specialist on home visits or at next appointment. They have seen a clinical psychologist in the past but don't require psychosocial support currently.

Mother pointed out that there is variable level of encouragement from the physiologist staff when doing her son's spirometry at clinic. She felt that there should be more encouragement and more consistency in techniques to encourage her son during spirometry. She added that sometimes her son's blows could be better if encouraged properly during the test.

Inpatient care (on ward)

Parent felt the CF team is very good with safety in care, but feels that other staff are less reliable. She has had to ask staff to change gloves on the ward on numerous occasions, and experienced the same concerns at A&E in the past. Parent felt the experience was variable according to which member of staff was treating her son, but generally felt it was a risk going into hospital.

Parent felt that physiotherapy coverage is definitely better during the week than at the weekend, adding that 'the physiotherapy support is variable, but not a risk to her son.' She explained that they sometimes felt left to their own devices in terms of inpatient physio, either her son frequently doing his own or with mother's help, but mother added that 'the physios will pop in if need be – support is there'. The physiotherapy department has a gym and mother explained that the physios have taken her son to the gym on occasions for exercise.

Mother voiced concern about the number of staff coming into her son's cubicle on the ward and felt that this could be managed better to reduce the risk of infection, whilst understanding that the hospital was a teaching hospital. As examples, she mentioned a large team at ward round and visits from stoma nurses, ITU nurses. On the theme of reducing infection risk, mother also made the comparison with Yorkhill Hospital where medical equipment from other departments (scanning etc) is brought to her son's room, rather than her son being taken to various other departments whilst an inpatient, adding that "at Edinburgh the child has to go to other departments for various tests".

Annual review

Parent E felt that annual review has vastly improved since doctor AF joined the team. She felt that AF acted as both a doctor and nurse as the service has lost 1.5 WTE of a clinical nurse specialist (it used to have 2.5 WTE clinical nurse specialist coverage, but the full time replacement went on maternity leave without replacement, according to parent).

Parent felt there is more consistency in approach in the annual review process now, along with a written report, which she described as "great, and a brilliant document for taking abroad with us, including his medical history, current treatments and notes on risks."

All parent E's son's annual review assessments take place at the Royal Edinburgh for Sick Children Hospital, where they always see the doctor and physiotherapist at least and other MDT staff where available (around summer holiday time). Mother felt the annual review was not much different to the routine outpatient clinic appointments, except for bloods tests and ideas drawn up on how to treat ready for the coming winter, with parents involved. This information is then included in the annual review report.

Mother felt that generally the CF team are 'run off their feet' and suspected that work load is too high in the service, which she explained covers Fife and Forth Valley, adding that she suspected "more patients were doing home IVs too, requiring greater level of investment in community nursing support."

Home care

Parent E's child has port flush at clinic if it coincides with routine outpatient appointment, or the clinical nurse specialist makes a home visit on her way to/from work.

Mother described the local pharmacist as 'brilliant' in speaking with the doctor to help ensure same day receipt of prescribed medications. She added that the GP was also very good.

Her son has received home deliveries of nasogastric feed and ancillaries from Nutricia Homeward and has had a good home oxygen service, but not needed in the last 12 months.

Good practice:

- "I can't speak more highly of the clinical nurse specialist, for example she texted me whilst she was on holiday (on a CF matter)."
- "Specialist doctor (AF) has made a massive difference to the team in terms of continuity in care, quickly advising on how to treat infection based on swab results and providing consistency in terms of parent contact in the team."

Area for improvement:

- "We have to go through A&E out of hours (eg to be seen for CF-related abdominal pain – son has history of DIOS). We go through various departments. Can't there be a fast-track system? Can't there be a rota for a specialist to be on in the CF service out of hours, rather than a general respiratory doctor, so that the best person available can see my son?"

Patient interview on peer review day

Patient A

Patient A is a 14-year-old female who lives in Ratho Station, a suburb of Edinburgh which is about a 20-30 minute drive away from the hospital.

Patient A wasn't diagnosed with having cystic fibrosis until the age of 10 years. Throughout her life she had suffered from persistent shortness of breath and coughing but cystic fibrosis wasn't identified as a possible cause until a locum general practitioner identified it at their local GP surgery.

Following diagnosis, she required regular intravenous antibiotic treatment which she came into hospital for, approximately, every three months. She now comes in for a two-week course of intravenous antibiotics twice a year when she feels ill or her lung function drops significantly.

The MDT were extremely supportive of Patient A and her mum following diagnosis; they found the home visits from the CF nurses and the information leaflets particularly helpful.

Patient A's mum said that she often finds it difficult to find car parking at the hospital – it is also very expensive. A parking permit with a reduced daily tariff is issued, but only after seven consecutive days in hospital.

Patient A described the food offered on the ward as terrible. On one of her stays in hospital, the dietitian planned a menu with her and the food from it was supplied by the hospital's canteen and was much better.

Patient A's mum said that sometimes bed availability is a problem and that on occasions she has been admitted to St John's Hospital as there were no beds available at Edinburgh Sick Children's Hospital.

She has sometimes been allocated a room which is not en suite and there is a degree of concern that when walking down the ward to use the bathroom facilities that there may be a potential risk of cross-infection.

Patient A has recently been referred to see the service's psychologist but has been advised by letter that there may be a three to four month wait until an appointment is available, which seems like a long time when she and her family need support now.

Patient A's mum feels that the nursing team are extremely busy. There have been a couple of occasions where appointments with the nurses have been cancelled due to them being too busy. The appointments have been cancelled on the day they were due to take place so this has meant that booked annual leave is potentially wasted.

Patient A and her mum have a good relationship with the majority of the MDT and feel that they are always accessible.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic – RHSC Edinburgh

	Hospital Name	Royal Hospital for Sick children
	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	Three to five rooms available for clinics. Patients given strict appointment times. Moved quickly into and stay in rooms until visit completed then home.
Do patients spend any time in waiting room?	No	Minimal while awaiting weighing – large area – CF patients colour-coded and wait in different areas.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	In weighing room in clinic, or side room with scales for babies.
Where are the lung function tests done for each visit?		In individual clinic rooms. Spirometer and Sats monitor on trolley – data downloaded to central computer after clinic
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Seen in programmed investigation unit – play lady and toys/games/books available
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Seen in main outpatient department (OPD) diabetic clinic and CF clinic separately both in the same outpatient (OP) facilities
Transition patients – can they get tour of outpatients' facilities?	Yes	Different hospital so visit arranged pre-transition
Transition/new patients – do they get information pack?		Adult team has booklet – process discussed at each of three joint clinics – and in advance of transition year. New patients get Cystic Fibrosis Trust info leaflets and local info with contact numbers etc. GPs get basic CF care info leaflet too.

Environmental walkthrough: ward

Ward name: Edinburgh Paediatrics

Microbiology status: All

		Hospital name	Royal Hospital for Sick Children
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Main respiratory ward of hospital – not just cystic fibrosis. Some acute general paediatric patients also admitted if longer stay. All CF patients in cubicles – mostly en suite.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Two en suite side rooms. One room without WC. Smaller cubicles for babies/mothers if inpatients stay required Some patients care for on other ward B. cepacia in ward 6 – en suite room. Other wards cubicle only.
Number of side rooms?		Three	Two en suite in main respiratory ward. Smaller cubicles available for babies.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		Yes	If patient not in en suite room – then may have to share with other non-CF patients. Mostly CF patient in en suite rooms.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Bedside locker with lockable medicines compartment in the top for all bed spaces.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	Free TV and Wi-Fi. Games and other entertainments supplied by play ladies.
Are there facilities to allow parents/ carers/partners to stay overnight?		Yes	Side rooms big enough for camp beds. Other rooms in parents unit in other part of the hospital.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Unlimited visiting – within reason.

	Yes/no number N/A	Notes/comments
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?	No	No access to kitchen in the ward. Some kitchen facilities in parents accommodation.
What facilities are provided for teenagers?		Single rooms with en suite. Wi-Fi. Some money available for carry outs. Drop in centre.
Is there access to a gym or exercise equipment in the rooms?	Yes	Exercise equipment can be brought to the rooms – daily visits to gym with physios is offered.
What facilities are there to help with school and further studies?		Schooling offered only to those from the Edinburgh city catchment area. Teachers may help out those from outside Edinburgh if work supplied.
Is there a relatives' room?	Yes	
What internet access is there?		Free Wi-Fi
What facilities are there to enable students to continue to work and study?		Nothing specific if not from Edinburgh city.
Are there facilities to allow patients to clean and sterilise nebuliser parts?		Wash and clean but not sterilised.
What facilities are provided for those with MRSA?		All MRSA patients in cubicles.
What facilities are provided for those with *B. cepacia*?		Admitted to cubicle in separate ward – seen at separate clinic.
What facilities are provided for those with other complex microbiology?		Nursed in cubicles – segregated by time and space in clinic.
Are patient information leaflets readily available on ward?		CF leaflets available from CF nurses.
Transition patients – can they get a tour of ward facilities?		Adult hospital on the other side of town, so visit arranged during 6 month transition process.

Environmental walkthrough: Other

	Hospital name	Royal Hospital for Sick Children
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	On-street, metered parking. Some free parking by day (limited) and in staff parking overnight. For inpatients staying longer than one week there is free parking in metered spaces.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	No dedicated CF or respiratory ward. Most patients looked after in ward 1 or day cases in PIU – programmed investigations unit – clearly signed.
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	Open waiting area at x-ray. Smaller open area at pharmacy. DEXA at adult hospital.
Do patients have to wait at pharmacy for prescriptions?	No	Prescription usually sent by compressed air pod in advance – while patient seeing rest of team – so often ready when patient ready or collected by CF nurses.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Some leaflets and posters	
Are there patient comment/ feedback boxes?	Yes and no	Yes – suggestion box in OPD. No suggestion box in the ward any more.

Borders General Hospital

No patient surveys were returned

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

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	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Red Regional centre	Red	

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 patients	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 No IP 2014 however all en suite	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 No new isolates 2014	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	N/A	N/A	
3.3 Complications	% aminoglycoside levels available within 24 hours	100%	N/A	N/A	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	N/A	N/A	
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%	N/A No transition patients	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 Patients not old enough yet	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%	N/A No IP episodes	N/A	
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%	N/A	N/A	
	% 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%	N/A	N/A	
	% 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%	N/A	N/A	
	% 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%	N/A	N/A	

4.2 Inpatients/ outpatients	% availability of a clinical psychologist at clinic	100%	N/A Ad hoc input as required	N/A	
	% availability of a clinical psychologist for inpatients	100%	N/A Ad hoc input as required	N/A	
	% availability of a social worker at clinic	100%	Red	Red	
	% availability of a social worker for inpatients	100%	Red	Red	
	% availability of pharmacist at clinic	100%	Red	Red	
	% availability of a pharmacist for inpatients	100%	Green	Green	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Red	Red	
5.4	Service level agreements in place for all	100%	Red	Red	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Borders General Hospital 4 patients
Consultant 1	0.5	1	1	1 WTE/1 PA per week
Consultant 2	0.3	0.5	1	RHSC
Consultant 3			0.5	0
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	Outreach from RHSC
Physiotherapist	2	3	4	0.1 WTE
Dietitian	0.5	1	1.5	0.05 WTE
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0.05 WTE
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	0

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Borders General Hospital, Melrose
	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	No two CF patients are scheduled to be in waiting area at same time.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	See notes	In OPD, appropriate facility.
Where are the lung function tests done for each visit?	See notes	Adult physiological measurement department.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	See notes	Annual review performed in regional centre.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	See notes	No current patients with CF-related diabetes (CFRD). Paediatric diabetes clinic delivered in same OPD area.
Transition patients – can they get tour of outpatients' facilities?	See notes	Transition clinic run by regional centre with transition to adult regional care
Transition/new patients – do they get information pack?	See notes	Transition clinic run by regional centre with transition to adult regional care

Additional comments

Currently only four patients with CF under the care of our team – all respiratory clinics are booked by CF lead clinician with no overlap between CF patients attending. Rooms cleaned between each patient. Any patients with known transmissible pathogens are reviewed in separate area away from other CF patients (ambulatory care unit on paediatric ward).

Environmental walkthrough: ward

Ward name: Ward 15

Microbiology status: All

		Hospital name	Borders General Hospital, Melrose
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	General paediatric ward with ambulatory care unit.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Five	Two en suite rooms.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	
Do CF patients have to share any bathroom facilities?		No	If admission required, then normally admitted to en suite room.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		N/A	No adult inpatients; all medication stored in drug cupboard.
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
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?		Yes	Open access to ward at all times for families.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Parents' kitchen
What facilities are provided for teenagers?		See notes	Free Wi-Fi for all paediatric inpatients Later "lights out" for TV etc. No specific adolescent unit.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	Able to attend physiotherapy department gym if required.
What facilities are there to help with school and further studies?	See notes	No specific classroom or visiting teacher.
Is there a relatives' room?	Yes	
What internet access is there?	Free Wi-Fi	
What facilities are there to enable students to continue to work and study?	See notes	Normal practice is to deliver home IVs. If inpatient care necessary, then treatment coordinated to allow attendance at own local school.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	See notes	Patients use own equipment.
What facilities are provided for those with MRSA?	See notes	Isolated in own cubicle.
What facilities are provided for those with *B. cepacia*?	See notes	No current patients with *B. cepacia.* If occurs in future would be isolated in own cubicle and risk assessed in conjunction with regional centre if two patients needed inpatient care at same time.
What facilities are provided for those with other complex microbiology?	See notes	No current patients with complex microbiology – if occurred in future would be risk assessed in conjunction with regional centre.
Are patient information leaflets readily available on ward?	No	No specific CF information on ward.
Transition patients – can they get a tour of ward facilities?	Yes	Transition clinic run by regional centre with transition to adult regional care.

Additional comments

Currently only four patients with CF under the care of our team, so need for inpatient management is limited. All patients who require regular IVs have been trained to deliver these at home, with first doses supervised on our ambulatory care unit. Ongoing monitoring coordinated by outreach CF nurse from regional CF centre.

	Hospital name	Borders General Hospital, Melrose
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	See notes	Four hours free parking for all patients. If extended parking needed then concession available from ward.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	See below
Do patients have to wait at pharmacy for prescriptions?	Yes	See below
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	At hospital entrance
Are there patient comment/ feedback boxes?	Yes	

Additional comments

Currently only four patients with CF under the care of our team – all respiratory clinics are booked by CF lead clinician with no overlap between CF patients attending. Rooms cleaned between each patient. Any patients with known transmissible pathogens are reviewed in separate area away from other CF patients (ambulatory care unit on paediatric ward). Similar arrangements to avoid overlap of patients if need to attend for additional investigations or prescriptions.

Forth Valley Royal Hospital

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

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	Yes	Yes	
	% of MDT who receive an annual appraisal	100%	Green	Green	
	% of MDT who achieved their professional development profile (PDP) in the previous 12 months	100%	Green	Green	
	% of MDT who have attended a cystic fibrosis educational meeting in the previous 12 months (local meeting, conference, specialist interest group)	100%	Green	Green	
	Does the specialist centre have documented pathways for referrals to other specialist medical/surgical or other disciplines?	100%	Refer to Lothian CF team	RHSC	

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%	Red	Red	

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 Dictated on day typed and sent via EDMS	Green	
	% of dictated discharge summaries completed within 10 days of discharge	100%	Green	Green	
	% of patients reviewed by a CF clinical nurse specialist (CNS) at each clinic visit	100%	Green	Green	
	% of patients with access to a CF CNS during admission (excluding weekends)	100%	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	

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

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	<1%	<1%	
5.2	Number of clinical incidents reported within the past 12 months	<1%	<1%	<1%	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Evidence requested from service manager	Not known	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Forth Valley Royal Hospital 26 patients
Consultant 1	0.5	1	1	0.1 WTE
Consultant 2	0.3	0.5	1	0
Consultant 3			0.5	0
Staff grade/fellow	0.5	1	1	0
Specialist registrar	0.3	0.5	1	0
Specialist nurse	2	3	4	0.6 WTE
Physiotherapist	2	3	4	0.4
Dietitian	0.5	1	1.5	0.2
Clinical psychologist	0.5	1	1.5	0
Social worker	0.5	1	1	0
Pharmacist	0.5	1	1	0
Secretary	0.5	1	2	0
Database coordinator	0.4	0.8	1	0

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 – Forth Valley Royal Hospital	
Number of active patients registered (active being patients within the last two years)	(No number submitted)
Number of complete annual data sets taken from verified data set (used for production of 'Annual Data Report 2013')	22
Median age in years of active patients	7.5
Number of deaths in reporting year	0
Median age at death in reporting year	N/A

Age distribution (ref: 1.6 'Annual Data Report 2013')		
Number and % in age categories	0–3 years	5 (23%)
	4–7 years	6 (27%)
	8–11 years	7 (32%)
	12–15 years	2 (9%)
	16+ years	2 (9%)

Genetics	
Number of patients and % of unknown genetics	0

Body mass index (BMI) (ref: 1.13 'Annual Data Report 2013')	
Patients with a BMI percentile <10th centile on supplementary feeding	(n=2); 1 (50%) on supplementary feeding

FEV_1 (ref: 1.14 'Annual Data Report 2013')			
		Male	Female
Number and medium (range) FEV_1 %n predicted by age range and sex	0–3 years	0	0
	4–7 years	2 (14%)	0
	8–11 years	4 (29%)	0
	12–15 years	5 (35%)	2 (18%)
	16+ years	3 (21%)	0

Lung infection (ref: 1.15 'Annual Data Report 2013')		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	0–3 years	5
	4–7 years	6
	8–11 years	7
	12–15 years	2
	16+ years	2
Number of patients with chronic PA by age group	0–3 years	0
	4–7 years	0
	8–11 years	0
	12–15 years	0
	16+ years	1

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	1 (5%)
Number and % of *cenocepacia*	0
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	1 (5%)
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 (5%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	1 (5%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	1 (5%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	1 (5%) 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	0–3 years	0
	4–7 years	15
	8–11 years	21
	12–15 years	32
	16+ years	28
Number of days of home IV therapy in reporting year split by age group	0–3 years	0
	4–7 years	0
	8–11 years	49
	12–15 years	10
	16+ years	0
Total number of IV days split by age group	0–3 years	0
	4–7 years	15
	8–11 years	70
	12–15 years	42
	16+ years	28

Chronic DNase therapy (ref: 1.22 'Annual Data Report 2013')	
DNase (Pulmozyme)	
% of patients aged 5–15 years on DNase	(n=14); 5 36%)
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	1 (5%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	1 (100%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	1 (100%) with PA 3 (14%) without PA

Patient survey

Forth Valley Royal Hospital (2 surveys returned)

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	0	1	0	0
Female	0	1	0	0

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"CF team are very good and quick to deal with any health issues. Hospital is quite far to keep trekking to and from frequently, and parking there is horrendous! Ward staff are excellent there; always very caring and helpful and make us feel at home during our stays. Sadly our equipment isn't regularly serviced and we don't get spare parts."

"My daughter is very welcome and is at ease with all staff. I feel as if they know her and take a personal interest in her care and wellbeing."

	Hospital Name	Forth Valley Royal Hospital
	Yes/no/ number/ N/A	**Notes/comments**
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	No	There are occasions when there is no vacant room when a patient arrives for their appointment and have to wait in the waiting area – risk is identified by reception staff and measures are taken to avoid cross-infection.
Do patients spend any time in waiting room?		Communal waiting area may pose risk if clinic room has not been cleaned in time to have patient wait in the room.
Is there easy access to toilets?	Yes	Adjacent to clinic rooms and a second toilet in waiting area, both are wheelchair accessible.
Where do height and weight measurements take place? Is this appropriate?	No	In separate general purpose room in clinic.
Where are the lung function tests done for each visit?		In each clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Provided by hospital play leaders and Starlight Foundation, XBox, DVDs and hospital passport.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	Same facilities as for CF clinic at both FVRH and SCH sites.
Transition patients – can they get tour of outpatients' facilities?	Yes	Invited to have visit to their preferred adult centre before their first clinic review or before they decide which regional adult centre they wish to be referred to.
Transition/new patients – do they get information pack?	Yes	Provided by adult centre when they have their first visit.

Additional comments

Transition clinics are held in Edinburgh for those young people with CF who accept referral to the Western General Hospital (WGH).

Environmental walkthrough: ward

Ward name: Children's Ward

Microbiology status:

		Hospital name	Forth Valley Royal Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	General ward with single rooms with en suite and cubicles, two rooms planned as isolation facilities.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Very rarely other infectious disease cases preclude their use temporarily eg in respiratory syncytial virus (RSV) epidemic season.
Number of side rooms?		12	
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)		N/A	No adult patients are admitted to children's ward.
Can you use mobiles?		Yes	Requires Wi-Fi dongle for some networks
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?			
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?		Yes	This applies to all patients – there is open visiting for parents and immediate family.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	In parents' kitchen
What facilities are provided for teenagers?		Single rooms	Option of adult menu

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	
What facilities are there to help with school and further studies?		Teacher for all inpatients every morning with links to the child/YP's school and internet access.
Is there a relatives' room?	Yes	There is a bedroom and communal parents' kitchen.
What internet access is there?		Via teacher for school work. For patients via Wi-Fi permit issued via the ward.
What facilities are there to enable students to continue to work and study?		Monday to Friday teacher is on the ward mornings with an assistant working with individual patients.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Nurses facilitate this.
What facilities are provided for those with MRSA?		Use of isolation cubicle and standard hospital MRSA protocols.
What facilities are provided for those with *B. cepacia*?		Isolation cubicle and application of control of infection protocols with input from control of Infection advisors if needed.
What facilities are provided for those with other complex microbiology?		Access to control of Infection team including consultant microbiologist
Are patient information leaflets readily available on ward?	Yes	General information leaflets are displayed and specific leaflets can be printed or links provided for internet access if preferred.
Transition patients – can they get a tour of ward facilities?	Yes	Visit to the adult CF centre of the young person's choice is arranged before their first clinic review.

Environmental walkthrough: Other

	Hospital name	Forth Valley Royal Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	Car park permit issued on ward request for inpatients. Free parking for up to four hours for all.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To Women and Children's Unit and ward and outpatient area in FVRH, limited signage in Stirling Community Hospital where alternate local CF clinics are held.
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	Patients attend there individually. There is a hospital-wide infection control policy for hand hygiene.
Do patients have to wait at pharmacy for prescriptions?	No	Inpatient prescriptions are delivered to the ward, most outpatient prescriptions are sent to GPs, occasionally hospital-dispensed prescriptions for outpatients will involve waiting at pharmacy.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	No	Not advertised for children or parents or on children's ward.
Are there patient comment/ feedback boxes?	Yes	Scottish Patient Safety Programme initiative has three questions at discharge for feedback for inpatients, currently no outpatient comment/feedback is invited but generic feedback for the hospital is promoted via the Forth Valley Health Board (FVHB) website.

Fife CF clinic
Queen Margaret Hospital Dunfermline and Victoria Hospital Kirkcaldy

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

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%	Amber	Amber	

2 Multidisciplinary care

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

2.1 Multi- disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care'	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%	Red Discussed jointly, however separate clinics.	Red	

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%	Amber Dependent on transport to lab	Unknown	
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%	Red Current policy to scan at >10yrs	Red	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

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

4.2 Inpatients/ outpatients	% 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 Use SW department as required.	Red	
	% availability of a social worker for inpatients	100%	Red Use SW department as required.	Red	
	% availability of pharmacist at clinic	100%	Red Recruitment in progress.	Red	
	% availability of a pharmacist for inpatients	100%	Red Recruitment in progress.	Red	
4.3 Homecare	% of patients administering home IV antibiotics who have undergone competency assessment	100%	Green	Green	
4.4 End-of-life care	% of patients receiving advice from the palliative care team at end-of-life	75%	N/A	N/A	

5 Commissioning

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
5.1	Number of formal written complaints received within the past 12 months	<1%	0	0	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	0	
5.3	User survey undertaken a minimum of every three years	100%	Green	Green	
5.4	Service level agreements in place for all	100%	Green	Green	

Staffing levels (paediatric)

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

	75 patients	150 patients	250 patients	Fife Clinic 30 patients
Consultant 1	0.5	1	1	1 PA
Consultant 2	0.3	0.5	1	
Consultant 3			0.5	
Staff grade/fellow	0.5	1	1	
Specialist registrar	0.3	0.5	1	
Specialist nurse	2	3	4	0.6
Physiotherapist	2	3	4	0.5
Dietitian	0.5	1	1.5	0.5
Clinical psychologist	0.5	1	1.5	0.1
Social worker	0.5	1	1	
Pharmacist	0.5	1	1	
Secretary	0.5	1	2	
Database coordinator	0.4	0.8	1	

Patient survey

Queens and Victoria Hospital (Fife Clinic) 1 survey returned

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	1	0	0	0
Female	0	0	0	0

How would you rate your CF team?

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

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"CF team are brilliant; could not fault them."

Environmental walkthrough:

Outpatients/CF clinic

	Hospital Name	Queens and Victoria 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?	Under very exceptional circumstances	Normal policy is for children to be put straight in to their pre-allocated rooms. When the waiting room is used, only one CF child is ever allowed to be in the common waiting room.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	In a designated measurement room, yes	
Where are the lung function tests done for each visit?	In the child's own room	
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	Yes	Large supply of age appropriate toys, electronics and magazines available.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	Yes	
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	New patient information pack available	

Environmental walkthrough:

Ward name: Children's Ward

Microbiology status: General ward with mix of cubicles and bays

		Hospital name	NHS FIFE Queen Margaret Hospital Dunfermline (Outpatient) and Victoria Hospital Kirkcaldy (Inpatient)
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Suitable for CF care	
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		12	
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Showers	
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)		N/A	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
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?		Flexible	
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	
What facilities are provided for teenagers?			TV and DVD players, tablets, free patient Wi-Fi, teenagers room with magazines, outdoor play area and equipment.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	No	
What facilities are there to help with school and further studies?	No	
Is there a relatives' room?	Yes	
What internet access is there?	Yes	
What facilities are there to enable students to continue to work and study?	Internet, quiet rooms	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?	Single rooms	
What facilities are provided for those with *B. cepacia*?	Single rooms	
What facilities are provided for those with other complex microbiology?	Single rooms	
Are patient information leaflets readily available on ward?	Yes	
Transition patients – can they get a tour of ward facilities?	N/A	

Environmental walkthrough: Other

	Hospital name	Queen Margaret and Victoria Hospitals
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	N/A	All car parking is free.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	Children's unit is clearly signposted with separate entrance from the main hospital.
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?	Occasionally	In general, prescriptions are sent to pharmacy by pod and collected by a member of staff.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	Yes	
Are there patient comment/ feedback boxes?	Yes	

St John's Livingston Hospital

Patient survey

St John's, Livingston - three surveys returned

	Completed surveys (by age range)			
	0-5	6-10	11-15	16+
Male	1	1	0	0
Female	2	0	0	0

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	3	0	0	0
Communication	3	0	0	0
Out-of-hours access	3	0	0	0
Homecare/community support	3	0	0	0

How would you rate your outpatient experience?

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

How would you rate your inpatient care (ward)?

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

How would you rate the following?

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

How would you rate the overall care?

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

Comments about CF team/hospital

"They are professionals."

"An amazing, caring CF team. Can't fault them on anything."

Environmental walkthrough:

Outpatients/CF clinic – OPD1

	Hospital Name	St John's 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?	Occasionally	We try to ensure that appointments are timed so that patients do not need to wait for a room to be available.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	No	Weighing and measuring takes place in a room that doubles as the team base. This is suitable for older children but there is no weighing / measuring equipment for babies in OPD1. Babies have to go to ward for weighing and measuring prior to appointment.
Where are the lung function tests done for each visit?		In individual patient clinic rooms.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	N/A	Annual review performed at Royal Hospital for Sick Children (RHSC).
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?	N/A	
Transition patients – can they get tour of outpatients' facilities?	N/A	
Transition/new patients – do they get information pack?	N/A	

Environmental walkthrough:

Ward name: Children's Ward

Microbiology status: All

		Hospital name	St John's Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		No	Not a dedicated CF ward but CF patients are always admitted to cubicles.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	
Number of side rooms?		Six	
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)		N/A	
Can you use mobiles?		Yes	
If there is a television, is the service free?		Yes	
If no, are there any concessions for CF patients?		N/A	
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?		Yes	Visiting is very flexible; there are no strict visiting hours for parents.
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Parents can use fridge / microwave in ward kitchen.
What facilities are provided for teenagers?			IPads, age-appropriate games, no separate teenage area.

	Yes/no number N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Access to physio gym and hydrotherapy pool on site. Physio can provide exercise equipment eg trampoline in room if required.
What facilities are there to help with school and further studies?		There is no on-site teacher but the local authority provide a teacher for admissions greater than two weeks (very rarely required).
Is there a relatives' room?	No	
What internet access is there?		Kids net available on one PC. No general Wi-Fi.
What facilities are there to enable students to continue to work and study?	None specific	
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	
What facilities are provided for those with MRSA?		Separate cubicles
What facilities are provided for those with *B. cepacia*?		Separate cubicles
What facilities are provided for those with other complex microbiology?		Separate cubicles
Are patient information leaflets readily available on ward?	No	Generally provided by RHSC CF team or downloaded if required.
Transition patients – can they get a tour of ward facilities?	N/A	

Additional comments

The number of children admitted to the children's ward is small, currently less than five admissions per year. It would be extremely rare for more than one CF patient to be on the ward at the same time.

Environmental walkthrough: Other

	Hospital name	St John's Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	N/A	Car parking free but spaces can be difficult to find.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	
Is there sufficient space in other areas of the hospital where patients need to wait to ensure optimal cross-infection control, eg radiology, pharmacy, bone mineral density (DEXA) scan?	Yes	
Do patients have to wait at pharmacy for prescriptions?	Occasionally	Would be very rare for two CF patients to be waiting at the same time.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	No	Provided by RHSC.
Are there patient comment/ feedback boxes?	Yes	Not specific to CF.

7. Panel members

Kevin Southern*	**Consultant**	**Alder Hey Children's Hospital**
Claire Mott	**CF Specialist Dietitian**	**University Hospital of Wales**
Katrina Cox	**CF Specialist Pharmacist**	**University Hospital South Manchester**
Rosemary Ball	CF Specialist Physiotherapist	Leeds Royal Infirmary
Michele Puckey	CF Specialist Clinical Psychologist	Royal Brompton Hospital
Sarah Elworthy	**CF Specialist Nurse**	**Royal Devon and Exeter Hospital**
Sally Egan	**CF Specialist Commissioner**	**Child Health Commissioner**
Angela Mills	**CF Specialist Social worker**	**Nottingham University Hospital**
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	**Quality Assurance and Control Manager**	**Cystic Fibrosis Trust**
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust

*Clinical lead for Peer Review

Bold: attended on the day of peer review

8. Other information

Additional information relating to the cystic fibrosis service in Forth Valley for children and young people.

Una MacFadyen, Consultant Paediatrician and lead for CF care, Forth Valley.

As no paediatrician based in Forth Valley was interviewed prior to the peer review visit, there may have been a lack of context in relation to the service for children and young people in that health board area.

This addition is hoped to offer information that may explain some of the differences in service delivery among the Lothian network.

Until 2009 cystic fibrosis care in Forth Valley was provided at a local level with referral to the RHSC Yorkhill in Glasgow by the responsible consultant on an individual patient basis when complications arose that could not be managed locally. There had been plans for the development of shared care across the West of Scotland based on the Alder Hey model for 12 years before that time, but with the advent of the National Delivery Plan for specialist services for children and young people, resources were identified as described by the Scottish Government:

“The National Delivery Plan meets a key milestone in the commitments set out in Better Health, Better Care. It establishes a national infrastructure for the sustainability of specialist children's services in Scotland, not just in the specialist hospitals but also in District General Hospitals and in the community: it identifies work that needs to take place at a national and regional level to sustain and develop services, drawing down the additional £32 million committed over the financial year”.

A key element of the NDP was the development of Managed Clinical Networks for the care of specific conditions including cystic fibrosis, which was provided with a national MCN administered through the National Services Division. The Scottish Cystic Fibrosis Interest Group recognised that to comply with the Cystic Fibrosis Trust’s Standards of Care a redistribution of caseload among the CF centres could most efficiently be achieved by establishing three regional clinical networks with Forth Valley linked with the Lothian CF centre. From that time the care of children and young people resident in Forth Valley has benefitted from direct involvement of the Lothian specialist CF team and has aimed to achieve the Standards of Care while also offering patient centred care in line with our organisation and clinicians’ vision of best practice.

While cystic fibrosis may be a child’s primary diagnosis in the neonatal period their specialist care may be linked to the West of Scotland neonatal MCN for intensive care, surgery and clinical genetics. The early experience of care by the local, paediatric nursing and medical teams builds strong local bonds that lead to an expectation of care close to home delivered from a local base. This and socio-demographic and cultural norms can lead to families finding attendance at clinics in Lothian stressful or inappropriate as evidenced by the limited engagement for some young people in the Lothian model for transition to adult care. When discussing transition most young people consider where they plan to live after leaving school when they are offered referral to the closest

adult CF centre. This in turn results in occasional deviation from the expected Lothian pathways of care.

All CF patients have direct access to paediatrics for CF-related problems and are routinely seen by a medical or nursing member of the CF team. Cystic fibrosis annual review is completed on every patient in accordance with the Cystic Fibrosis Trust's Standards of Care and national MCN protocol. The scheduling of investigations is managed by the Community Children's Nurses to accommodate the families' availability, radiology and ambulatory unit access. Communication with Primary Care and reporting the conclusion of annual review has until now been included in the child's attendance at an outpatient clinic when both CF nurse and senior paediatrician are present to explain the findings and prepare for further discussion after the family have had time to consider the information. There is no facility for shared office accommodation but the Forth Valley CF team uses a generic team mail mailbox and meets weekly to discuss every patient in its care as otherwise informal conversations may not be recorded and information missed. The geography of Forth Valley has led to the community nursing team adapting their review of children with CF and planned procedures or teaching to a home and school based environment when preferred by the family and so the different nursing practice models highlighted in the peer review report are variations for the same purpose based on local need. Administrative support for the CF service has not been specifically identified with resulting pressure on time allocated to timely report writing and data management.

cysticfibrosis.org.uk