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Cystic Fibrosis why we're here

British Thoracic Society

BIPRS

Peer review report

West of Scotland Service

Gartnavel Hospital

5 November 2014

1. Executive summary

Overview of the service

The adult cystic fibrosis service at Gartnavel General Hospital is well established and run by consultants with specialist interest in CF, and supported by an experienced and dedicated multidisciplinary team (MDT). The service does not have a dedicated inpatient unit but is integrated within the respiratory department. The respiratory department is moving to a state-of-the-art new build with single room, en suite accommodation. Over the past five years there has been significant investment in the CF service and the recent appointment of a 0.8 whole time equivalent (WTE) psychologist. The team is actively involved in research and clinical trials.

Good practice examples

- An approachable consultant body with an enthusiastic, dedicated multidisciplinary team.
- A high quality physiotherapy service in which patients have access to wide range of adjuncts to airway clearance and an established non-invasive ventilation service.
- Experienced pharmacists who are providing an excellent service to both inpatients and outpatients.

Key recommendations

- Appropriate MDT accommodation and office space needs to be identified in the new build as a matter of urgency to ensure good MDT communication and the smooth running of the service. The panel was surprised by the lack of forward planning with reference to the accommodation; this is a perfect opportunity to configure the service to an exceptionally high level.
- The service must provide single side room accommodation for all patients during the intervening months. This is an essential part of infection control and will no longer be a problem following the move in 2015.
- Ward staff need to be trained in port management so that they can be accessed out of hours. Only the CF clinical nurse specialist (CNS) can access ports at present.
- The CF service needs to address staffing levels within the multidisciplinary team. There needs to be further investment in 2.0 whole time equivalent (WTE) physiotherapy when a seven-day service is provided following the move.
- The dietetic service has been disrupted over the last year and this was highlighted as a concern. This needs to be addressed as patients have limited access to a specialist dietitian.
- The CF service would benefit from having an experienced social worker/s as recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)'. The lack of a CF team social worker was reported as being due to commissioning issues across Health and Social Care in Scotland despite multiple attempts from the team.
- Communication of annual assessment needs to be formalised, with clear feedback to patients.

Areas for further consideration

- The peer review panel felt that there was an opportunity to improve nursing and MDT communication following the move as long as suitable accommodation was available. The team understands the plan to spread patients across the respiratory bed base, although creating a dedicated unit could provide advantages. Ensure appropriate parking following the move.

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

Models of care

Summary

The adult CF service at Gartnavel General Hospital cares for 242 adult patients with cystic fibrosis. There are daily ward rounds with good out-of-hours senior cover. There is no formal CF unit but patients are distributed on separate respiratory wards according to microbiology status. The majority of patients are admitted to en suite side rooms. The unit is moving to state-of-the-art facilities in 2015 and the service will change significantly. There are great opportunities to deliver an outstanding service.

Multidisciplinary care

Summary

The teams demonstrate a high level of enthusiasm and commitment to the care of patients, with cystic fibrosis. The unit is committed to a multidisciplinary model of care for patients with CF and follows current guidelines and practices, with some areas of excellence. There was an element of disjointed ward-based MDT working due to the lack of certain key disciplines such as dietetics and out-of-hours CF specialist nurse support.

Principles of care

Summary

User feedback surveys and patient interviews confirm a high level of satisfaction with the services. The most negative feedback related to food and parking.

Delivery of care

Summary

There was very positive patient feedback, demonstrating a high level of satisfaction. The service follows the Cystic Fibrosis Trust's Standards of Care and is supported by three enthusiastic and dedicated consultants and an associated specialist. The team was reported as being very accessible. There was a high standard of cross-infection control although this broke down during bed shortages due to the lack of side rooms. The inadequacies of single rooms is being addressed with the move.

Feedback following annual assessment needs to be formalised and key staff shortage of certain disciplines needs to be addressed.

Commissioning

Summary

The adult CF service is commissioned by National Services Scotland for and on behalf of the Scottish Government, and a service agreement is in place for all designated components of the service. There are close relationships between the service and the commissioners who meet up formally twice a year and more frequently when required. There is frequent telephone and email communication between meetings.

The service is currently based at Gartnavel Hospital, Glasgow but will be moving to a new location within the Southern General campus where there will be single rooms for all patients with en suite facilities. In the last 12 months no formal written complaints were received and no clinical incidents reported. The service regularly carries out patient satisfaction reviews including that of transitional care. They actively engage in clinical research and secured funding for a three-year PhD fellowship.

The service is currently caring for a cohort of 242 patients. Following discussions with the service, additional funding was invested in recruiting a clinical psychologist to the team this year. The service had also commenced an extended CF adolescent transition clinic structure with new clinics at Wishaw General Hospital and Crosshouse Hospital in the last year. The service outcomes are consistently good and they receive a high degree of approval from patient satisfaction responses.

3. UK CF Registry data

Data input	Number of complete annual data sets taken from verified data set	206

			Male	Female
FEV_1	Median FEV_1% pred at age 16 years split by sex		(N=2); 40.07%	0
	Number and % of patients with FEV_1 <85% by age range and sex	16–19 years	19; 75.75 (35.64-117.31)	14; 79.65 (13.02-117.03)
		20–23 years	27; 66.85 (22.9-110.84)	22; 65.84 (15.9-109.57)
		24–27 years	14; 54.5 (25.06-100.33)	14; 76.58 (19.56-116.26)
		28–31 years	14; 53.58 (19.45-106.41)	13; 64.42 (34.54-104.13)
		32–35 years	15; 49.95 (20.73-93.98)	7; 67.7 (31.69-106.39)
		36–39 years	8; 73.54 (38.17-109.62)	3; 44.93 (39.75-97.33)
		40–44 years	5; 48.22 (23.37-103.29)	8; 64.86 (33.94-78.3)
		45–49 years	7; 77.05 (33.87-89.02)	3; 53.22 (39.75-66.37)
		50+ years	7; 74.6 (33.87- 89.02)	6; 51.8 (30.38-68.49)

Body mass index (BMI)	Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=116); 65 (72%)	(n=90); 46 (51%)
	Number of patients and % with BMI <19 split by sex	22 (19%)	15 (17%)

***Pseudomonas aeruginosa* (PA) chronic PA is 3+ isolates between two annual data sets**	Number and % of patients with chronic PA infection	100 (49%)
	Number and % of patients with chronic PA infection on inhaled antibiotics	76 (76%)

Macrolides	Number and % of patients on chronic macrolide with chronic PA infection	82 (82%)
	Number and % of patients on chronic macrolide without chronic PA infection	78 (74%)

4. Delivery against professional standards/guidelines not already assessed

Consultants

The adult CF unit is run by an experienced clinical team with a passion for improving and delivering high quality care. There are 1.6 FTE consultants and a highly experienced associate specialist. Staffing seems to be appropriate for patient numbers. The unit is supported out of hours by respiratory consultants who have had some CF training. There are daily ward rounds and patients are seen on the general respiratory round. There is one MDT meeting each week.

Specialist nursing

There are currently 4 WTE nurses employed by NHS Greater Glasgow and Clyde.

The nurses look after 242 patients throughout Greater Glasgow and Clyde.

Their experience ranges from 22 years in CF, to five years.

The nurses split their time covering all aspects of inpatient, outpatient and home visits as the patient need dictates.

They do not get any cover for the absent nurse and are covering for each other's holidays, study leave and also to allow nursing team members to attend local and national CFNA meetings.

They commented on how useful they find the twice monthly CFNA Scottish meetings as this gives a friendly forum to raise day-to-day issues regarding CF nursing care. Also this forum allows for larger audits to take place which they are happy to be a part of.

They all try and attend the Scottish biannual CF study days held in Dunblane.

They have attended the European and North American conferences in the past but have found these more tricky to fund lately due to local policy regarding accepting funding from pharmaceutical companies. They remain positive however that this can be overcome.

There is a weekly MDT meeting and members of the nursing team routinely attend this. All inpatient, outpatient and other patient activity is discussed at this time. Planned ward rounds are attended but often ward rounds may be ad hoc, therefore difficult to attend around planned workload.

One of the main improvements during the past five years was the increase in staffing levels overall. A new WTE nurse was appointed five years ago and they now also have a CF-dedicated pharmacist which they feel has had a very positive impact on the service.

The CF nurses are all happy in their roles and have no issues they wish to raise.

Areas of good practice:

- Great communication between nurses and all members of the MDT.
- Flexibility of nursing staff to adapt care needs to suit patients' requirements.
- Unit planned to move to purpose built building sometime next year with single room, en suite accommodation.
- Ward nurses have an excellent teaching programme in place for cystic fibrosis care.

Areas for improvement:

- More time for audit and research.
- Only CF CNS can access ports at present.

Recommendations:

- Obtain more information about the new unit and be involved in discussions about CF patients' requirements in the new unit.
- Clarify the paperless notes system which may be in place in the new unit to enable CF nurses to begin to get used to this new system in advance, to facilitate a smooth transition to paperless notes.
- Teach some ward staff how to access ports to facilitate seamless weekend and evening care.

Physiotherapy

Overview of staffing:

- CF inpatient and outpatient care is provided by two Band 7 (0.8 & 1.0 WTE) and two Band 6 (0.67 & 1.0 WTE) static posts. These posts are entirely CF-funded, with the exception of the Team Lead post, of which the majority is CF-funded. A rotational Band 5 Therapies-funded post also provides some input into inpatient care. Currently 3.8 WTE physiotherapists for 242 patients but the team also provides non-CF respiratory care, which is around 40% of caseload (although this fluctuates), reducing actual WTE to approximately 2.4. Recommended staffing is 5.9 WTE.
- A future seven-day service has been proposed, to coincide with the planned move to the new hospital. The therapies lead has submitted a business case for additional staffing of 1.5 to 2.0 WTE as recommended by the Team Lead. This would support a true seven-day service where weekday 'rest days' would be backfilled by CF physiotherapists rather than by non-specialist staff (so ensuring no loss of quality of input during weekdays) and would bring CF physiotherapy staffing levels closer in line with the Cystic Fibrosis Trust's recommendations.

Areas of good practice:

- Committed physiotherapy team with highly experienced team lead who is internationally/nationally involved with guideline development/systematic reviews, regularly presents at conferences and leads audit/research activities. All static physiotherapists are members of the Association of Chartered Physiotherapists in Cystic Fibrosis (ACPCF) and attendance at annual study days is rotated to ensure equal access. The team attends the weekly MDT meeting, ward rounds as appropriate and is involved at all key stages of life.
- A high quality physiotherapy service in which patients have access to a wide range of adjuncts to airway clearance and an established non-invasive ventilation service which is run in conjunction with Respiratory Physiology.
- Provision of patient-individualised pre- and post-transplant rehabilitation programme.

Areas for improvement:

- The team is considering introducing a homecare service, to improve access to physiotherapy input eg during home IV therapy, at end of life and when general reviews, eg of participation in exercise or airway clearance technique, are required for patients who are unable to attend clinic.
- Implementing use of a more formal postural screening tool, as identified by the team.
- Not all patients are reviewed twice daily during weekends, unless this is required to prevent acute deterioration, as input is provided as part of emergency on-call physiotherapy service. The proposed move to a seven-day service, staffed by CF physiotherapists, would therefore be a positive step as it would increase the number of weekend sessions provided but also the quality of the input.

Recommendations:

- The current team skill-mix - consider re-grading team lead to a Band 8a and recruiting a physiotherapy assistant to release qualified physiotherapists to perform more specialist activities and improve access for CF inpatients to gym sessions.
- Ensure that posts which are entirely CF-funded are being fully utilised for the benefit of the CF service, as at present, physiotherapists in these posts are being required to provide non-CF respiratory care.
- Ensure that additional staffing of 1.5 to 2.0 WTE is obtained to support future CF physiotherapy seven-day staffed service and service development as described above.
- Ensure that the facilities for exercise in the new hospital site are readily accessible to CF inpatients. A designated area for exercise for CF adults would be ideal.

Dietetics

The dietetic service to the cystic fibrosis patients has been disrupted over the last year and this review has highlighted issues of concern.

It is believed there is funding for 1.5 Band 7 dietitians. On initial telephone review the permanent Band 6 post holder was on maternity leave. The rotational Band 5 position had not been filled once that person had been upgraded to cover the full time maternity leave as a Band 6. The Band 6 was very keen and enthusiastic.

There is concern that the cystic fibrosis patients have no access to a specialist dietitian when there is sickness (as on the day of review), holidays, and study leave. They do have access to a dietitian once a referral has been triggered and after it has gone through the dated referral process. It also became clear that the specialist cystic fibrosis dietitian had also been providing a dietetic service to non-CF patients- The understanding is that this will also be addressed as now people are fully aware of what dietetic cover is provided There would appear to be a delay in cystic fibrosis patients being seen by a specialist dietitian and this would also impact on not achieving the Cystic Fibrosis Trust's 'Standards of Care (2011)' requirements: "inpatients should have specialist CF dietetic input at least twice a week and more frequently if appropriate".

Standards of Care would also indicate that there should be two specialist dietitians to provide a service to the cystic fibrosis patients, especially as current patient numbers are near 250 with the potential for this figure to continue to increase (as is occurring in every other UK centre). The increasing complexity of this patient group as well as increasing longevity means a highly specialist dietitian is needed to support patients through these challenges.

Catering:

From the patient feedback and discussions with the dietitians and catering staff there could be a good food service. There appears to be unclear pathways for ordering meals, having extra portions and meeting the individual needs of the cystic fibrosis patient. The catering manager appeared to be very accommodating to meet the needs of the CF patient. In order to help meet this need, having a person responsible ie a dietitian to facilitate/action these pathways would appear to be advantageous. Nutritional needs are best served by a specialist dietitian who has the expertise to encourage and support appropriately.

Diet and nutrition is a fundamental part of CF care, with BMI being an indicator, and with good nutrition and support this can be achieved with food and expert nutritional modification.

Pharmacy

The pharmacy team comprises two experienced specialist CF pharmacists, each working 0.5 WTE – Band 8A and Band 7. The staffing is compliant with Cystic Fibrosis Trust's 'Standards of Care (2011)'. They overlap hours on Wednesday so they can both attend the MDT meeting. They also attend all other team meetings. They do have support from a pharmacy technician (0.5 WTE) who covers the satellite pharmacy. Cover is provided by an experienced Band 8a respiratory pharmacist. This cover is limited to a prescription screening service only.

The pharmacists are both members of the UK Cystic Fibrosis Pharmacy Group (CFPG) and regularly attend regional and national meetings. They have also attended the European and North American CF conferences. They are both non-medical prescribers.

All inpatients receive a level 2 medicines reconciliation review and the team is available to review all patients in the outpatient clinics. However, it was noted that during busy clinics and at peak times during clinic it was not possible to see all patients.

They also see the majority of the patients when they have their annual review.

The pharmacists are also involved in writing and/or reviewing guidelines. They have fed into their local CF protocol document, and have also been involved in conducting audits. They are also hoping to do some work with the recently appointed psychologist around patient compliance/ motivational interviewing. In addition, the pharmacists would be keen to work with neighbouring specialist CF centres and pharmacists to develop joint guidelines and protocols.

All treatments are commissioned by the National Services Division with GPs doing the majority of the long term maintenance prescribing (except Kalydeco®) and there are no plans to repatriate medications to secondary care. There is currently no provision of low-tech or high-tech homecare within Scotland but we have been informed that this is being considered. The pharmacist team could make a valuable contribution to this process.

Areas of good practice:

Experienced team providing excellent service to inpatients and outpatients.

Recommendations:

Focused targeting of patients for review in clinic by the pharmacist team.

Consideration of low-tech and high–tech homecare models to support service delivery.

Psychology

Clinical psychologist (CP) has been in post approx one month at time of review, therefore the new service is in the early stages of development. Post is 0.8 WTE, recommended provision for this size service is1.8 WTE so current shortfall of 1.0 WTE. As the post is newly funded, increased staffing may be not likely at present. Development of the service will allow any potential gaps in provision to be identified and will aid further development in future as required.

Summary:

CP is a member of the UK Psychosocial Professions in Cystic Fibrosis (UKPPCF) and already using the list serve facility and accessing conference presentations etc.

CP regularly attends MDT meetings that do take place for inpatients/outpatients (no regular CF 'team/staff meeting' in place)

CP will arrange workload to manage any expected absences eg non-working days/leave. For longer/unexpected absences it is not clear if cover would be available.

No opportunity to attend conferences etc as yet, as it's a new post. A potential psychosocial research project is already being planned. Future input in key service development areas will depend on joint priorities of CP and CF team, and time available with current staffing.

Areas of good practice:

- Post holder has settled quickly into the CF team, been made to feel very welcome, and has many plans for service development for this new post. The team is very enthusiastic and motivated re optimising psychological care in the CF service. Plan in place to meet all appropriate Standards of Care, (within constraints of current staffing level).
- Commitment to research and service development alongside more direct work with service users.
- Commitment to (and significant experience in) developing wider roles of CF CP, in addition to direct therapy work, ie offering consultation as required, supporting psychological care by CF team etc.

Areas for improvement:

Initial priorities–

- Establish specialised psychological therapy service for CF patients according to need.
- Ensure MDT is informed re other potential roles of CF clinical psychologist and decide further priorities for the service.
- Develop clinical psychology annual assessment format and process.

Recommendations:

- Establish new CF clinical psychology service as already planned, through close working with rest of CF MDT.
- Address plans for accommodation in the new hospital (2015) to ensure there is appropriate space and to provide confidential therapy sessions, confidential telephone sessions and all tasks requiring frequent access to a computer.
- Consider the implications of the absence of a CF social worker in this service eg help MDT plan to meet relevant needs of patients (that allows delivery of most effective psychology service for the more complex areas of psychological need).

Social work

There are no social workers employed in the Gartnavel adult CF centre. Although a psychology post has recently been created and filled, there appears to be no future plans for a social work post. This was reported as being due to commissioning issues across Health and Social Care in Scotland.

It was also reported that social work input can be provided by community social care teams; however this provision is unlikely to be as effective or consistent as having an experienced CF social worker based in the hospital, a member of the core team who could see patients on the wards and in outpatients and feedback and liaise with the MDT/welfare rights assistant/community teams as appropriate. If the service is unable to secure a social work post, they feel a designated CF welfare rights assistant would be beneficial.

At present the social and welfare needs of patients are currently met by other members of the CF MDT and supported by a general welfare rights program that has been devised by Glasgow City Council (The Long Term Conditions/ MacMillan Financial Inclusion Partnership) which is also financially supported by the Cystic Fibrosis Trust. Patients have access to an experienced welfare rights advisor who has been trained in CF by Gartnavel consultants and specialist nurses and who is able to signpost to other services when patients live outside the Glasgow area. Patients also have the Butterfly Trust which is a charitable trust for Scottish people with CF and can offer

mentorship and financial support for patients. Although input from the above is highly regarded, it is unknown as to whether it fully meets the complex and often challenging social needs of such a large group of patients.

Social work professionals have a body of knowledge and range of skills that generally include safeguarding and protection, counselling, assessment, advocacy, group work, community development and family therapy, as well as the ability to empower others to obtain the appropriate services and resources in the community. These skills could be of great benefit to a service, and would possibly give other members of the MDT more time to work with the increasing number of adult patients attending the centre.

Recommendations:

This CF service would benefit from having an experienced social worker/s as recommended in the Cystic Fibrosis Trust's 'Standards of Care (2011)'.

5. User feedback

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	61+
Male	4	2	4	5	11	2	0
Female	0	1	6	4	4	1	1

	Overall care			
	Excellent	Good	Fair	Poor
From your CF team	31	12	1	1
From the ward staff	17	15	2	0
From the hospital	12	25	4	0

Areas of excellence:

1 Accessibility of CF team

2 Outpatients – Cross-infection

3 Outpatients – Cleanliness of the room

Areas for improvement:

1 Car parking

2 Food

3 Admission waiting times

6. Appendices

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

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

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

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

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

Hospital name

St James Hospital, Leeds

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%	Amber	Amber	
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	Amber	Annual review is not always discussed with patients.

2 Multidisciplinary care

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

2.1 Multi-disciplinary care	Are there local operational guidelines/ policies for CF care?	100%	Green	Green	
	Respiratory samples analysed by a microbiology laboratory fulfilling the Cystic Fibrosis Trust's 'Standards of Care (2011)'	100%	Green	Green	
	% of patients reviewed on 50% of clinic visits by a CF medical consultant	95%	Green	Green	
	% of patients with cystic fibrosis related diabetes (CFRD) reviewed at a joint CF diabetes clinic	100%	Amber	Amber	100% is surprising as most units get a few DNAs

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%	Amber	Red	This will change but open wards were not appropriate in 2014.
	% of patients cohorted to outpatient clinics according to microbiological status	100%	Green	Green	
3.2 Monitoring of disease	% attempted eradication of first isolates *Pseudomonas aeruginosa* (PA) in the previous 12 months	100%	Green	Green	
	% of patients admitted within seven days of the decision to admit and treat	100%	Green	Green	

3.3 Complica-tions	% aminoglycoside levels available within 24 hours	60%	Green	Green	
3.4 Cystic fibrosis-related diabetes (CFRD)	% of patients aged >12 years screened annually for CFRD	100%	Amber	Amber	
3.5 Liver disease	% of patients aged >5 years with a recorded abdominal ultrasound in the last three years	100%	Amber	Amber	
3.6 Male infertility	% of male patients with a recorded discussion regarding fertility by transfer to adult services	100%	Green	Green	
3.7 Reduced bone mineral density	% of patients aged >10 years with a recorded bone mineral density (DEXA) scan in the last three years	100%	Green	Green	

4 Delivery of care

Standard	Audit question	Expected compliance	Reported compliance	Actual compliance	Panel comments
4.1 Consulta-tions	% of patients seen by a CF consultant a minimum of twice a week while inpatient	100%	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	Amber	Lack of experience out of hours. Unable to access ports
	% 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%	Amber	Amber	
	% 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%	Amber	Red	See report.
	% availability of a clinical psychologist at clinic	100%	Red Psychologist will start 01/10/14.	Red	However a 0.8 FTE has been appointed and service is being developed.

4.2 Inpatients/ outpatients	% availability of a clinical psychologist for inpatients	100%	Red Psychologist will start 01/10/14.	Red	As above.
	% availability of a social worker at clinic	100%	Red Long term partnership with GCC and Cystic Fibrosis Trust	Red	See report.
	% availability of a social worker for inpatients	100%	Red Long term partnership with GCC and Cystic Fibrosis Trust.	Red	See report - Cystic Fibrosis Trust needs to review if this section should be removed in Scotland.
	% availability of pharmacist at clinic	100%	Green	Green	
	% 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%	0	Green	
5.2	Number of clinical incidents reported within the past 12 months	<1%	0	Green	
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		

Appendix 2

Staffing levels (adult)

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

	75 patients	150 patients	250 patients	Gartnavel General Hospital
Consultant 1	0.5	1	1	0.60 WTE
Consultant 2	0.3	0.5	1	0.50 WTE
Consultant 3			0.5	0.50 WTE
Staff grade/fellow	0.5	1	1	1 WTE Associate specialist
Specialist registrar	0.4	0.8	1	1 WTE
Specialist nurse	2	3	5	4 WTE
Physiotherapist	2	4	6	3.5 WTE
Dietitian	0.5	1	2	1.5 WTE
Clinical psychologist	0.5	1	2	0.8 WTE
Social worker	0.5	1	2	
Pharmacist	0.5	1	1	1 WTE
Secretary	0.5	1	2	1 WTE
Database coordinator	0.4	0.8	1	1 WTE
Diabetic nurse specialist				0.10 WTE
Respiratory technician				0.25 WTE
Pharmacy technician				0.50 WTE

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 – Gartnavel General Hospital	
Number of active patients registered (active being patients within the last two years)	221
Number of complete annual data sets taken from verified data set (used for production of Annual Data Report 2013)	206
Median age in years of active patients	26
Number of deaths in reporting year	2
Median age at death in reporting year	21

Age distribution (ref: 1.6 Annual Data Report 2013)		
Number and % in age categories	16–19 years	33 (17%)
	20–23 years	49 (24%)
	24–27 years	28 (14%)
	28–31 years	27 (13%)
	32–35 years	22 (11%)
	36–39 years	11 (5.5%)
	40–44 years	13 (6%)
	45–49 years	10 (5%)
	50+ years	13 (6.5%)

Genetics	
Number of patients and % of unknown genetics	11 (5%)

Body mass index (BMI) (ref: 1.13 Annual Data Report 2013)		
	Male	Female
Number of patients and % attaining target BMI of 22 for females and 23 for males	(n=116):65 (72%)	(n=90); 46 (51%)
Number of patients and % with BMI <19 split by sex	22 (19%)	15 (17%)
Number of patients and % with BMI <19 split by sex on supplementary feeding	6 (27%)	7 (47%)

FEV_1 (ref: 1.14 Annual Data Report 2013)			
		Male	Female
Medium FEV1% predicted at age 16 year split by sex		N=2); 40.07%	0
Number and medium (range) FEV1 %n predicted by age range and sex	16–19 years	19; 75.75 (35.64-117.31)	14; 79.65 (13.02-117.03)
	20–23 years	27; 66.85 (22.9-110.84)	22; 65.84 (15.9-109.57)
	24–27 years	14; 54.5 (25.06-100.33)	14; 76.58 (19.56-116.26)
	28–31 years	14; 53.58 (19.45-106.41)	13; 64.42 (34.54-104.13)
	32–35 years	15; 49.95 (20.73-93.98)	7; 67.7 (31.69-106.39)
	36–39 years	8; 73.54 (38.17-109.62)	3; 44.93 (39.75-97.33)
	40–44 years	5; 48.22 (23.37-103.29)	8; 64.86 (33.94-78.3)
	45–49 years	7; 77.05 (33.87-89.02)	3; 53.22 (39.75-66.37)
	50+ years	7; 74.6 (33.87- 89.02)	6; 51.8 (30.38-68.49)

Lung infection (ref: 1.15 Annual Data Report 2013)		
Chronic *Pseudomonas aeruginosa* (PA)		
Number of patients in each age group	16–19 years	33
	20–23 years	49
	24–27 years	28
	28–31 years	27
	32–35 years	22
	36–39 years	11
	40–44 years	13
	45–49 years	10
	50+ years	13
Number of patients with chronic PA by age group	16–19 years	15
	20–23 years	26
	24–27 years	14
	28–31 years	11
	32–35 years	11
	36–39 years	4
	40–44 years	9
	45–49 years	3
	50+ years	7

***Burkholderia cepacia* (BC)**	
Number and % of total cohort with chronic infection with BC complex	18 (9%)
Number and % of *cenocepacia*	7 (3%)
Meticillin-resistant *staphylococcus aureus* (MRSA)	
Number and % of total cohort with chronic infection with MRSA	5 (2%)
Non-tuberculous mycobacterium (NTM)	
Number and % of total cohort with chronic infection with NTM	1 (0.5%)

Complication (ref: 1.16 Annual Data Report 2013)	
Allergic bronchopulmonary aspergillosis (ABPA)	
Number and % of total cohort identified in reporting year with ABPA	38 (18%)
Cystic fibrosis related diabetes (CFRD)	
Number and % of total cohort requiring chronic insulin therapy	67 (33%)
Osteoporosis	
Number and % of total cohort identified with osteoporosis	22 (11%)
CF liver disease	
Number and % of total cohort identified with cirrhosis with portal hypertension (PH) and cirrhosis without PH	3 (1.5%) with PH 2 (1%) without PH

Transplantation (ref: 1.18 Annual Data Report 2013)	
Number of patients referred for transplantion assessment in reporting year	9
Number of patients referred for transplantion assessment in previous three years	17
Number of patients receiving lung, liver, kidney transplants in previous three years	6

IV therapy (ref: 1.21 Annual Data Report 2013)		
Number of days of hospital IV therapy in reporting year split by age group	16–19 years	157
	20–23 years	292
	24–27 years	155
	28–31 years	134
	32–35 years	28
	36–39 years	10
	40–44 years	52
	45–49 years	17
	50+ years	19
Number of days of home IV therapy in reporting year split by age group	16–19 years	113
	20–23 years	133
	24–27 years	207
	28–31 years	181
	32–35 years	77
	36–39 years	46
	40–44 years	164
	45–49 years	13
	50+ years	47
Total number of IV days split by age group	16–19 years	270
	20–23 years	425
	24–27 years	362
	28–31 years	315
	32–35 years	105
	36–39 years	56
	40–44 years	216
	45–49 years	30
	50+ years	60

Chronic DNase therapy (ref: 1.22 Annual Data Report 2013)	
DNase (Pulmozyme)	
% of patients aged >16 years with FEV1, % predicted <85% (ie below normal) on DNase	n=153; 76 (50%)
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	100 (49%)
Number and % of patients in that cohort on anti-pseudomonal antibiotics: Tobramycin solution, Colistin	76 (76%)
Number and % of patients on chronic macrolide with chronic PA infection and without chronic PA infection	82 (82%) with chronic PA 78 (74%) without chronic PA

Appendix 4

Patient survey

Gartnavel General Hospital

	Completed surveys (by age range)						
	16–18	19–20	21–30	31–40	41–50	51–60	60+
Male	4	2	4	5	11	2	0
Female	0	1	6	4	4	1	1

How would you rate your CF team?

	Excellent	Good	Fair	Poor
Accessibility	31	12	2	0
Communication	20	18	4	2
Out-of-hours access	14	11	7	2
Homecare/community support	14	11	1	3

How would you rate your outpatient experience?

	Excellent	Good	Fair	Poor
Availability of team members	23	17	4	0
Waiting times	13	18	9	0
Cross-infection/segregation	25	10	6	2
Cleanliness	24	15	4	2
Annual review process	18	14	6	3
Transition	11	7	4	2

How would you rate your inpatient care (ward)?

	Excellent	Good	Fair	Poor
Admission waiting times	12	6	9	1
Cleanliness	15	5	6	3
Cross-infection/segregation	14	10	3	2
Food	7	3	12	7
Physiotherapy availability to assist/ assess airway clearance and exercise during weekdays	15	12	4	0
Physiotherapy availability to assist/ assess airway clearance and exercise during weekends	10	10	6	0

How would you rate the following?

	Excellent	Good	Fair	Poor
Home IV antibiotic service	15	6	3	0
Availability of equipment	19	9	5	2
Car parking	2	2	10	25

How would you rate the overall care?

	Excellent	Good	Fair	Poor
Of your CF team	31	12	1	1
Of the ward staff	17	15	2	0
Of the hospital	12	25	4	0

Comments about CF team/hospital

"Perhaps need more CF nurses as they are so busy - a CF nurse at weekends would be excellent. CF trained physios are needed too."

"I am very happy with all my visits to the hospital and all the CF team are all easy to talk to as well."

"CF team and staff are very professional and helpful. No complaints. Waiting times can be long but understandable. Not sure how they could be improved. Don't personally spend much time as an inpatient and haven't had IVs for many years therefore it's difficult to judge. Stopped driving to hospital and started taking train due to difficulty finding parking space."

"Automated appointment reminder often gives the wrong information, very confusing and usually results in additional phoning!"

"I have not been an inpatient on the CF ward for over 10 years. Nor have I had home IVs in that time hence not able to answer."

"Very friendly, accessible and resourceful. I feel taken good care of and also okay to talk to them about anything."

"I am very happy with all the care that I receive from the CF team."

"In ward 7c as I have cepacia - do not feel this is a proper CF ward as although staff are very good, I often have to wait for staff from CF ward 6 for IVs and care, eg waited days for an appropriate nurse to look at sore arm with line that turned out to be clotted."

"Without doubt the best team ever from the docs to the ward personnel. They all contributed to keep myself as healthy as possible."

"CF team at Gartnavel are superb, nothing is a burden to them and they are always just a phone call away and you never wait long for them to see you."

"The team are wonderful – kind caring and very helpful."

"One doctor (junior) hasn't got a good manner. I have complained and now no longer see this doctor."

"Some nursing staff need to learn how to talk to young people. They should learn to talk to them and not down to them. Better facilities for young adults would make the inpatient process a lot easier/comfortable. Home IVs distance from hospital means all IV care done by self or parent."

"From my own experiences/point of view, they do an amazing job and deliver a constant high standard of care and expertise."

"I feel as if the CF team have always been there when needed."

"The annual review appointment time is always around lunchtime. Do I eat lunch and throw it up during the test or miss lunch and therefore lack the energy to perform the tests properly?"

"Only downfall is I requested over four yearsago to do home IVs, I am still waiting to be trained!"

"If admitted on evening or weekends/public holidays, there is nobody trained to access ports, which can be very distressing when your venous access is poor and you have to resort to canulas. Otherwise excellent care."

"We receive an excellent service – help is always just a phone call away the team are friendly, caring and sensitive to our needs. That goes from nurses, physio and docs. Car parking can be frustrating but I always manage to get a space."

"CF team are first class, nothing bad to say. Only bad thing about the hospital is the parking it's a nightmare but most hospitals are to be fair."

Appendix 5

Patient/parent interviews

Patient A was happy with the segregation measures at the outpatient department to reduce the risk of cross-infection. He felt the team are always exceptionally courteous. For the most part he sees the whole multidisciplinary CF team (MDT) at clinic, though not a psychologist or social worker. Patient A felt whereas in the past decisions on treatments were dictated to him, nowadays he feels fully involved in decisions made on his care and treatments. He classed himself as a well-informed CF adult.

Patient A described the hospital pharmacy as a small waiting area, but not busy or crowded and so did not feel it was a risk area for cross-infection.

Annual review: Patient A's last annual review was towards the end of last year. He is offered annual review each year, as well as attending three-monthly outpatient clinic appointments. He mentioned that there is no written report of the outcome of his annual review. His DEXA scan takes place at Western General Infirmary; his CT scan at his transplant centre.

Inpatient care: Patient A has not had inpatient care for his CF for 8½ years, since transplant.

Homecare: He has a 'courtesy' home visit, but does not require other home visits from any of the CF team.

Good practice:

- "I'm always kept well informed by the CF team, from doctors down."
- The service itself.
- Courteous staff.

Area for improvement:

- "Could improve ward nursing staffing levels."

Patient B explained the outpatient arrival as follows: "Usually straight into a side room or waiting on different corridors. No person with CF is waiting on the same corridor." Spirometry takes place in a separate room from the consultation room.

Patient B usually sees the whole MDT at clinic, although she wasn't sure if there is a psychologist attached to the service. She didn't think there is a social worker, so she turns to the clinical nurse specialist for advice regarding benefits/support etc.

Patient B has a wait of about half an hour on average at pharmacy, although she said she usually sends her father down to collect the medications.

Annual Review: Patient B is offered annual review each year; her last review was very recent. Her DEXA scan takes place at Western Infirmary whilst all her remaining tests are at Gartnavel. She does not receive a written report of her annual review outcome.

Inpatient care: Patient B referred to 'easy, quick admission (same day)' to an en suite side room on the ward. She described nursing staff on Ward 7c as 'lovely and helpful'. She has to wait for Ward 60 nurses to come up to Ward 7c in the evening. She feel s that the nurses are knowledgeable about CF up to a point and that medications are given on time, although she added, "occasionally they're delayed at night… waiting for nurses from downstairs."

Patient B felt that the ward food has got a lot better, but portions are too small, adding, "I quite often have two dinners and lunches." Patient B said she'd never been offered use of exercise equipment in her room, but that the physiotherapists have offered and taken her to the gym a couple of times.

Home care: Patient B makes up her own IVs. She does not have a portacath.

Good practice:

- "CF team's knowledge of CF and me"
- "Always easy to get hold of the CF team; they're always there… If I leave a telephone message they'll get back to me, or the ward staff will get someone."

Areas for improvement:

- Stop the smoking outside the hospital entrance which floats into the foyer.
- Increase the size of ward's food portions.
- Further training of ward nurses.

Patient C felt that safe segregation measures at outpatient clinic were "a good idea" and he likes the way segregation is planned. He's led to a room for spirometry, then transferred to a consultancy room for the rest of the clinic, with the CF MDT rotating between rooms. He sees the doctor, nurse, physiotherapist and dietitian at each clinic appointment and believes he has access to a psychologist and social worker, if needed.

Patient C described the care he receives as "brilliant… no complaints" adding that all the clinic team use hand gels appropriately and all decisions made about his treatments are made with his views in mind, adding "decisions are made with me." Patient C experienced no problems collecting medications from hospital pharmacy, with just a short 10-minute wait in a seated area.

Annual review: Patient C is offered an annual review each year; the last one being early 2014. He sees all of the CF team at annual review and he added that "all assessments take place at Gartnavel."

He explained that he did not receive a written report of the outcomes of his annual review, but added, "if anything's wrong, they phone me".

Inpatient care: Patient C is post-transplant and so has not had inpatient care for two years. His last experience on the ward was positive – en suite side room, first class knowledge of ward nurses and he felt that it was "like being part of a family" with the ward team. He added that "the food was excellent."

Homecare: Not applicable currently.

Good practice:

- "They (the CF team) keep an eye on you."
- "Friendly staff who know me and are helpful… It makes it easier for me."

Area for improvement:

- "Install a coffee/tea machine on the ward and in clinic, so we can help ourselves when we need a drink."

Patient D felt that segregation measures are good at outpatient clinic – "nurses shuffle us away well." She explained that the MDT rotates between patient consultation rooms and that spirometry takes place in the nurses' room, one patient at a time. Patient D felt that the clinic team makes very good use of hand gels, and always changes aprons between seeing patients. She added that "patients have a good understanding of the significance of cross-infection."

Patient D said that overall she sees the whole MDT at clinic, though she has never seen a psychologist or social worker. She added that there has been less pharmacist input recently due to what she thought was maternity leave/job share, so she relies on the Clinical Nurse Specialist (CNS) to get her the information she needs.

Patient D felt that the CF team is open to contact via email and telephone, a very approachable team and one involves Patient D very much in decision making on her treatments. She added, 'my views are always put forward.'

Patient D mentioned that on the last two occasions the CNS or another member of staff went to pharmacy to collect her medications to take home. She described the waiting area at pharmacy as "small and can be busy."

Annual review: Patient D is offered annual review each year around her birthday; late autumn last year being her last annual review. Her DEXA scan takes place at Western Infirmary on a different date; the CF scan at Gartnavel, on another separate date from annual review (AR) appointment. Patient D did not know if there is ever a report back following AR, although she thought that the GP is informed of the AR outcome, by letter.

Inpatient care: Patient D does not have, nor feels the need for homecare. She said she grew pseudomonas recently and that the nurse had offered to make a home visit to take a sputum sample (40-mile trip).

Good practice:

- Clinic operation – segregation by time slots.
- Support from CF Sisters at clinic.
- Communication system with the CF team is very good and reliable.

Area for improvement:

- 'Need for more formal reporting back of annual review outcome, even if I am well (ie helpful for evidence when claiming benefits etc.).'

Patient E felt segregation measures at clinic are as good as can be, despite "the physical restrictions". She waits in a different clinic to the one assigned as she is concerned that she'd be sitting too close to other CF adults in the corridor waiting, before transfer to a consultancy room.

At clinic Patient E explained that the CF MDT rotates between patients, allowing patients to stay in same individual side rooms. She brings along her own spirometer as she explained she is not satisfied with her personal safety in using equipment shared with other patients.

Patient E sees all of the CF MDT at clinic, although the psychologist only once in 10 years and she is not aware that psychologist support is offered now. She is happy that the CF team involves her in all decision making about her care and treatments – "I feel well involved". Patient E has no issues around collecting medications from pharmacy.

Annual review: Patient E is offered annual review each year and has had annual review already this year. She sees the full MDT at annual review. She explained that annual review outcome is reported back to her at the next clinic, unless there is something untoward beforehand. She receives an x-ray report on the day and her DEXA scan is conducted at Western Infirmary.

Inpatient care: Patient E explained that she can usually be admitted on the day and always into an en suite side room. However, she added that she believed "some other CF patients are treated in a four-bed bay". She was very happy about the level of knowledge and understanding of ward nurses in CF terms. She described the administering of medications as "not always on time" explaining that there can be seven or eight patients on IVs quite often and so knew of the difficulties the nurses face. She had no complaints about the ward food and did not know about the exercise opportunities to inpatients on the ward, adding, "I tend to walk around the grounds for my exercise."

Homecare: Patient E mixes her own IV antibiotics, on IVs twice a year. She has a portacath in place and either receives a home visit from the CNS to flush the port or goes to Gartnavel for this purpose. She finds the CNS very flexible. Patient E lives close to the hospital and has no complaints about communication with the CF team and vice versa.

Good practice:

- Availability of patient care – quick admission to the ward.
- CF Sisters' knowledge and expertise, so that she does not have to see a doctor.

Area to improve:

- Do away with the four-bedded bays for any CF patient care.

Patient interviews on peer review day

Patient One

Male, aged 27 years, diagnosed pre-birth and has one elder brother with cystic fibrosis and one sister who does not have cystic fibrosis. He lives at home with his mother and enjoys cooking for himself. At the age of nine years he moved from Paisley to York Hill, he then transitioned to Gartnavel at 15 years old. He has been admitted for one week and has B. Cepacia.

Areas of excellence:

- En suite facility, it is good to have privacy.
- The rooms are clean and there is room for relatives to stay.
- He likes having the facility of his own fridge in his room.
- Freeview channel and wall-mounted TV.
- Staff constantly asks if he needs anything.
- The twice-daily physiotherapy is really good.
- If he asks he can have a double portion of food.
- He recently met with the new psychologist for a consultation; however he has never met with a social/welfare worker.
- Open visiting time except for protected meal times can be inconvenient.

Areas for improvement:

- Parking – He lives a 35-minute drive from the hospital and it takes just as long to find a parking space.
- He has been admitted to a four-bed bay. The risk of cross-infection made him very anxious. He would delay admission rather than going into a bay again.
- He has not seen the dietitian this admission and would like to have some time with her.
- The consultants seem rushed; he feels that he needs to prompt them and ask questions regarding his wellbeing; he would like more time to talk with them. He would like them to have a conversation rather than feeling it is he who always has to ask for information.

He likes the idea that the new hospital will have all single rooms with en suite as he was previously admitted to a four-bed bay and could not wait to leave; he left early when well enough to go home due to the fact he could not stay any longer in the bay. He does feel lectured to by the nurses as he does not want to be admitted and leaves it until the last minute when he should have come in earlier, however staff do encourage him to take his drugs. When asked about how he felt about ready-made-up IVs, he said that he is happy to make up his own; however he would also be happy to try them.

Patient Two

Male, aged 35 years old, diagnosed age five after experiencing stomach problems. Attended York Hill Hospital, spent two years attending Western General and then moved to Gartnavel. The patient is two years post-transplant after having his operation at Newcastle. He was assessed for the transplant list in July 2012 and was called for his transplant in September 2012. He has taken a retirement package after working as a consultant. He and his wife have plans to have a baby and he will be a stay-at-home dad, while his wife works as a teacher.

Areas of excellence:

- He is happy with the care.
- He was always allocated a side room and never had to wait for a bed.
- Staff are always at the end of the phone when needed.
- There can be flexibility with the menu.

Areas for improvement:

- Lifts break down.
- Smoking at the front main entrance near large 'No Smoking' sign, no enforcement to move them on.
- Parking: it takes a while to find a space.
- Food generally.

Appendix 6

Environmental walkthrough: Outpatients department

Outpatients/CF clinic

	Hospital Name	Gartnavel General Hospital
	Yes/no/ number/ N/A	Notes/comments
Is there sufficient space in the clinic area to ensure optimal cross-infection control? (Reception, waiting room, etc)	Yes	There are two clinics, both have well-equipped clinic rooms without windows.
Do patients spend any time in waiting room?	No	Patients are taken directly to clinic room on arrival.
Is there easy access to toilets?	Yes	
Where do height and weight measurements take place? Is this appropriate?	Yes	Scales are taken into the clinic room. Height measured at one point in clinic. This may be considered to be done in individual clinic rooms in the new hospital.
Where are the lung function tests done for each visit?		Clinic room.
Are clinic rooms appropriately sized?	Yes	
For annual review patients, are any distractions provided?	No	Patients arrive AM and leave PM. There are some gaps in their appointments, and they could bring in their own electronic device/ distraction.
If diabetics are seen outside of CF clinic, are area and facilities appropriate for CF care?		Patients are seen in the joint clinic, six-weekly.
Transition patients – can they get tour of outpatients' facilities?	Yes	It includes a home visit and visits to alternate sites during transition.
Transition/new patients – do they get information pack?	Yes	The pack is jointly from adults and paediatrics services.

Additional comments:

- Outpatients is located on the ground floor of the hospital. It is tired and drab, in need of refurbishment. However, the move to the new hospital means this clinic will only be utilised until April 2015.

		Hospital name	Gartnavel General Hospital
		Yes/no/ number/ N/A	Notes/comments
Is the ward a dedicated CF ward or a ward suitable for CF care?		Yes	Suitable.
Are there side rooms available for CF care? (If overflow facilities are required)		Yes	Patients are occasionally admitted to four-bed bays with other respiratory patients, however no other CF patients. The new hospital will be all single en suite rooms.
Number of side rooms?		10	Five in both 6C and 7C. CF patient accommodation takes priority over other respiratory conditions.
Do the en suites have:	**Toilets?**	Yes	
	Wash basins?	Yes	
	Bath or shower?	Yes	Shower/wet rooms
Do CF patients have to share any bathroom facilities?		No	Unless in a bay when they would possibly share with non CF or bronchiectesis patients.
Is there a secure place to store medications by the bedside for adults? (Include in notes policy of ward)		Yes	Bedside cabinet
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	Z beds available to put in rooms, if required.
Visiting hours – are there allowances for CF patients/families out of normal hours?		Yes	Open hours
Is there access to a fridge/ microwave either in the side rooms or in the parents' kitchen?		Yes	Fridges in rooms. No microwave in room, there is a staff microwave which could be accessed.
What facilities are provided for teenagers?			PlayStation, Wii. Most patients bring in their own.

Environmental walkthrough: ward

Ward name: 6C and 7C General respiratory

Microbiology status: 6C (Non B. Cepacia) 7C (B. Cepacia & Mycobacterium

	Yes/no/ number/ N/A	Notes/comments
Is there access to a gym or exercise equipment in the rooms?	Yes	Equipment can be brought into rooms and there is a gym available.
What facilities are there to help with school and further studies?		Can liaise with schools/college via teachers in paediatrics. Students usually arrange their own work.
Is there a relatives' room?	Yes	Basic, TV and seating.
What internet access is there?		Wi-Fi
What facilities are there to enable students to continue to work and study?		Patients bring in their own equipment and work.
Are there facilities to allow patients to clean and sterilise nebuliser parts?	Yes	Can use sink in room.
What facilities are provided for those with MRSA?		Always segregated in own room and barrier nursed.
What facilities are provided for those with *B. cepacia*?		Always segregated in their own room.
What facilities are provided for those with other complex microbiology?		*Mycobacterium abscessus* patients are barrier nursed and always segregated in their own room.
Are patient information leaflets readily available on ward?	Yes	General leaflets available on wall mounted racks.
Transition patients – can they get a tour of ward facilities?	Yes	Patients attend the one-year transition clinic, with alternate appointments in both adults and paeds clinic with a standard ward visit offered.

Additional comments

- The wards are located on the sixth and seventh floors, accessed by six lifts which can be extremely busy, especially during visiting times. The seventh floor refurbishment is bright and clean. Ward 6C is in need of refurbishment. The move to the new hospital is due in April, therefore this will not be undertaken prior to moving. Patients will never wait long for a bed to be admitted. 7A - day ward on the seventh floor has two en suite rooms for CF use which are bright, clean and well equipped for use.
- Team room – this large room at the end of the ward accommodates most of the team and is sometimes used for team meetings. The nurses' office is near Ward 7C along with the consultant's secretary/administration office at the other end of the corridor.

	Hospital name	Gartnavel General Hospital
	Yes/no/ number/ N/A	Notes/comments
Car parking		
Any concessions for patients and families?	Yes	First four hours' parking free. If admitted to hospital, patients can be issued a free permit for the duration of their stay. A free permit is issued if appointments over run.
Other hospital areas		
Clear signage to CF unit and/or ward.	Yes	To wards. No CF centre signs as there are no CF-specific wards
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	All arrangements are carefully policed by team members and patients are educated about cross-infection and will try not to attend together.
Do patients have to wait at pharmacy for prescriptions?	Yes	Patients may have to wait, however this is limited by keeping oral prescriptions at clinic for issue.
Patient information		
Is patient advice and liaison service (PALS) well-advertised – leaflets, posters?	No	There is a complaints procedure; these are usually dealt with internally by staff. The centre is looking into a 'Family and Friends' scheme.
Are there patient comment/ feedback boxes?	Yes	On both wards.

Additional comments

- Outside the main entrance is a very large 'No Smoking' sign; however there were quite a few patients and visitors smoking near the entrance door. This was unacceptable. This should be considered urgently.

Appendix 7

Panel members

Dr Daniel Peckham*	Consultant	St James' University Hospital, Leeds
Baljit Ahitan	CF Specialist Pharmacist	Birmingham Heartlands Hospital
Helen Oxley	CF Specialist Psychologist	Wythenshawe Hospital, Manchester
Sandra Steele	CF Clinical Nurse Specialist	Aberdeen Royal Infirmary
Ingrid Small	CF Specialist Dietitian	University Hospital South Manchester
Sarah Cameron	CF Specialist Physiotherapist	Birmingham Heartlands Hospital
Vivian Edwards	Social Worker	Llandough Hospital, Wales
Lyn Hutchison	Commissioning NSD	Scotland
Lynne O'Grady	Head of Clinical Programmes	Cystic Fibrosis Trust
Sophie Lewis	Clinical Care Adviser	Cystic Fibrosis Trust
Dominic Kavanagh	Clinical Care Adviser	Cystic Fibrosis Trust
Andrew Sinclair	Quality Assurance and Control Manager	Cystic Fibrosis Trust

*Clinical lead

cysticfibrosis.org.uk