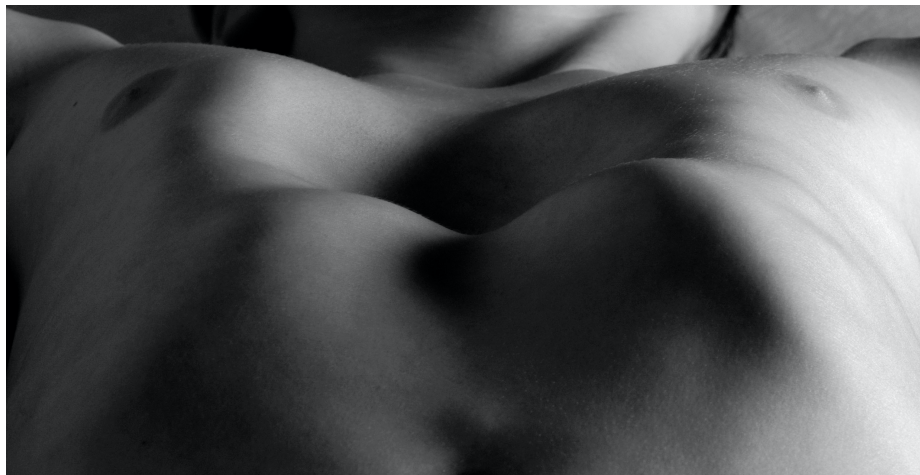


THE PAEDIATRIC & ADOLESCENT  
ANTERIOR CHEST WALL DEFORMITY SERVICE

**Annual Report  
2018/19**



**NHS Greater Glasgow and Clyde**

**“The right option for the right patient”**

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*Please refer to Guidance Notes for completion of the Annual Report prior to submission*

*The completed Annual Report should be sent electronically by 31 May to:*

*Email: [nss.nsd-reports@nhs.net](mailto:nss.nsd-reports@nhs.net)*

## Executive Summary

The paediatric and adolescent anterior chest wall deformity service is based in the Royal Hospital for Children, Glasgow. This is hosted within the Greater Glasgow & Clyde Health Board.

The service provides assessment and treatment of anterior chest wall deformities that include Pectus Excavatum, Pectus Carinatum and other variations. These conditions cause protrusion or depression of the sternum and changes to the shape of the cartilage ribs as they join the sternum.

Non-invasive treatment options include dynamic bracing for Pectus Carinatum and use of a vacuum bell for Pectus Excavatum. Surgical options are reserved for those unsuitable for, or not responding to, these conservative measures. The Modified Ravitch procedure is the surgical treatment for Pectus Carinatum and Arcuatum and the thoracoscopic assisted Nuss procedure is used for Pectus Excavatum.

Patients are referred to the service from a number of different specialities including GPs, consultants and AHPs.

In 2018/19 the service undertook the following activity for patients from across Scotland.

426 Outpatient Appts

27 Surgical Procedures

73 Dynamic Braces

## 1. Service Delivery

The service accepts referral of a child or adolescent with an anterior chest wall deformity up to the age of 16. The prevalence of anterior chest wall deformities in Scotland is unknown but is less than 10 per 1000 across the UK. There is a 4:1 male:female ratio.

The national service receives referrals from General Practitioners and Specialists, the latter usually from Paediatric Medicine, Cardiothoracic Surgery, Orthopaedics and Paediatric Surgeons from other Scottish Units. All referrals are vetted and patients are reviewed in clinic. Some patients have their chest wall deformity from early in life but a significant number develop their chest wall deformity at a later age, typically as they transition from Primary to Secondary education.

There are two main treatment pathways in the service.

- The first is for Pectus Excavatum patients:
  - Younger patients and those older patients not keen on surgery may be suitable for a Vacuum Bell. This development was added to the Service Level Agreement mid-way through this reporting period. There has been a big uptake for this option, especially in the younger cohort of suitable cases.
  - The thoroscopically assisted Nuss operation is the surgical option for Pectus Excavatum. Typically, this is offered to patients in their teens when they are considered fit to give consent for surgery.
- The second pathway is for Pectus Carinatum patients:
  - This is focused on Dynamic Bracing for those suitable (>8 years old, sufficiently compliant chest wall and suitably motivated patient). The brace is worn for 16-20 hours each day in the treatment phase and this is reduced once correction is achieved (the maintenance phase).
  - Those who fail dynamic bracing, or who are not suitable for bracing, or who opt for surgery by choice are considered for surgical correction of their Pectus Carinatum with a modified Ravitch Operation.

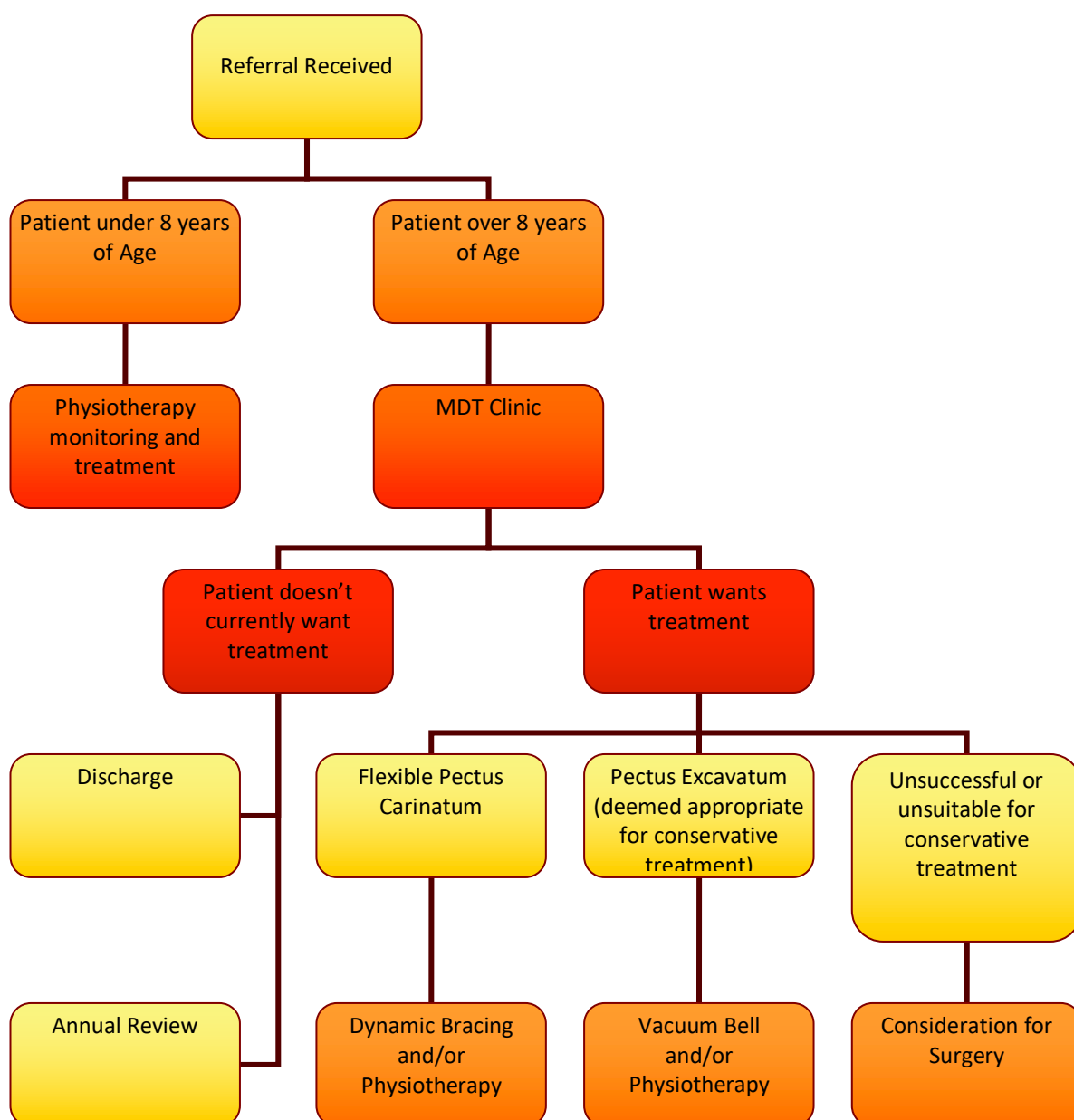
The service is delivered by a number of staff groups. The core group who attend the dedicated multi-disciplinary outpatient clinic consist of:

- 2 Consultant Paediatric Surgeons
- 2 Paediatric Orthotists
- 1 Paediatric Physiotherapist

Other services essential to the success include:

- Paediatric Anaesthetic & Theatre nursing team
- Inpatient Paediatric Nursing
- Paediatric Pain Team
- Paediatric Radiology
- Paediatric Cardiology
- Paediatric Respiratory Physiology Laboratory
- Medical Illustration
- Paediatric Clinical Psychology

## Patient Pathway of Care



## 2. Activity Levels

Service indicator	SLA	2018/19	2017/18	2016/17
New Outpatient Appointments	100-150	165	100	116
Nuss operation	8	12	13	6
Modified Ravitch operation	3	6	1	3
Metal removal at surgery	8	9	5	9
Dynamic Bracing	25	73	45	55
Vacuum Bell	10	9	0*	0*

**Table 1 Activity for 3 years and agreed SLA**

\*Vacuum Bells were not being provided for these report years

Service indicator	2018/19	2017/18	2016/17
Total Outpatient Appointments	426	322	247
Physiotherapy Outpatient Appointments	314	218	8*
Orthotics Outpatient Appointments	272	272	218

**Table 2 Overall Outpatient Activity for last 3 years**

\*Our designated physiotherapist joined the service in May 2017.

### 3. Performance and Clinical Outcomes

#### 3.1 Equitable

NHS Board	Out Patient Appointments			AHP Appointments			Surgical procedures		
	2018/19	2017/18	2016/17	2018/19	2017/18	2016/17	2018/19	2017/18	2016/17
Ayrshire & Arran	27	29	23	35	30	11	2	1	3
Borders	3	1	1	4	0	0	0	0	0
Dumfries & Galloway	7	3	4	12	1	0	0	1	1
Fife	6	9	5	4	14	8	0	1	0
Forth Valley	17	7	13	18	14	4	1	1	2
Grampian	9	16	11	14	34	17	0	0	0
Glasgow & Clyde	212	166	124	311	241	116	16	9	7
Highland	15	10	5	24	18	7	1	0	0
Lanarkshire	82	42	28	104	72	31	6	4	4
Lothian	14	14	11	15	25	6	1	1	2
Tayside	27	16	13	41	30	12	1	1	0
Other	6	9	10	3	11	14	0	0	0
<b>Total</b>	<b>426</b>	<b>322</b>	<b>247</b>	<b>586</b>	<b>490</b>	<b>226</b>	<b>28</b>	<b>19</b>	<b>19</b>

Table 3 Activity by Health Board for last 3 years

Data for report period only - 2018/19

Figure 1 and 2 show activity by Health Board for the report period.

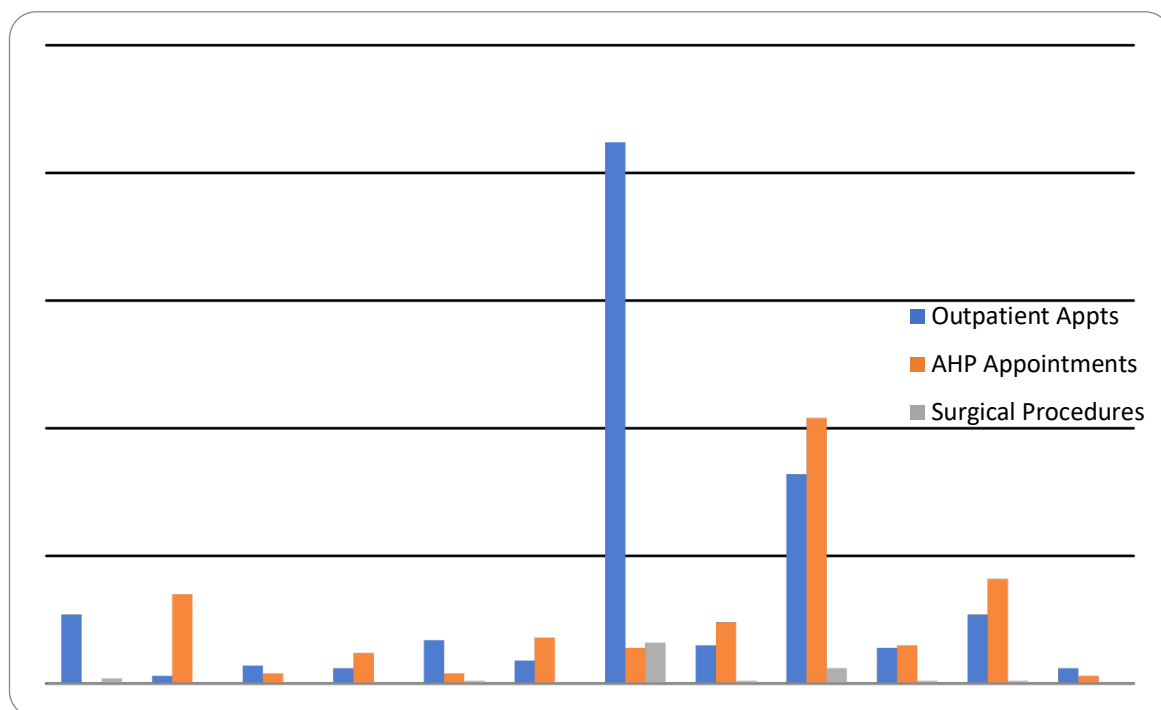


Figure 1 Activity by Health Board 2018/19

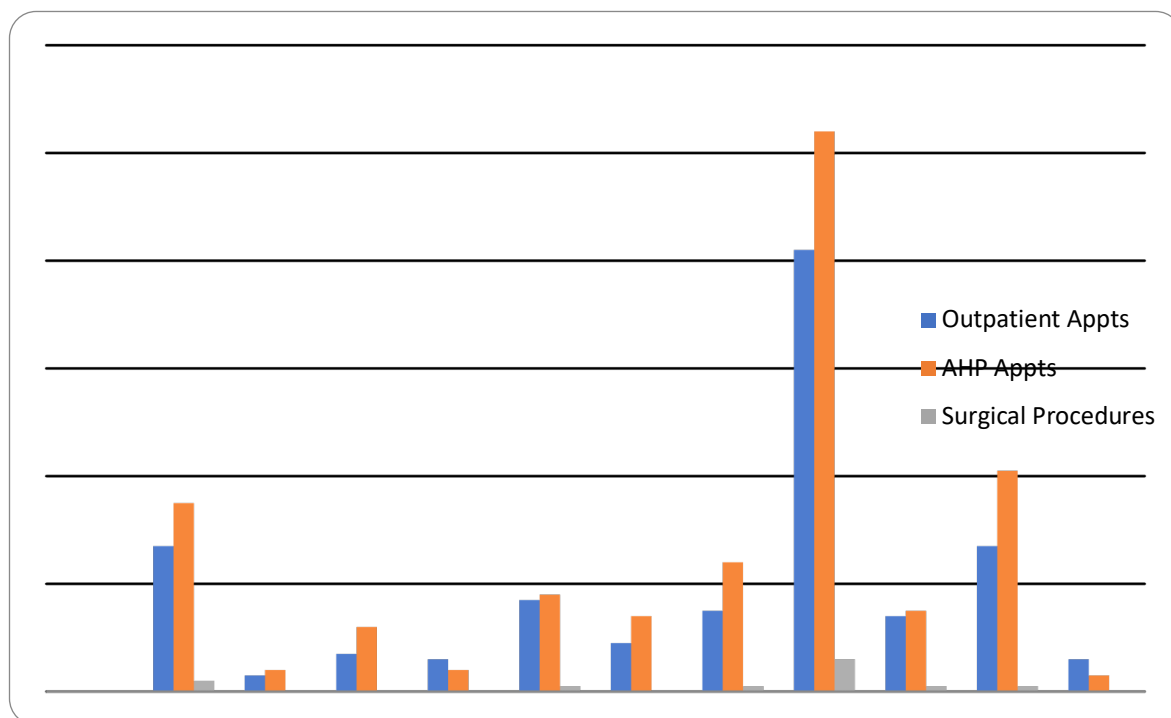


Figure 2 Activity by Health Board excluding GG&C 2018/19



We continue to see a large cohort of patients from Greater Glasgow and Clyde. Our service is well established in the Royal Hospital for Children Glasgow with referrals received from a wide variety of specialities. We continue to work on raising the profile of the service across other Health Boards but tend not to have as varied a pattern of referral sources from other Health Boards.

We promote the service via professional channels and by attending the CWIG conference. Our physiotherapist, Ashley Johnstone, presented 2 posters and won a first mentioned poster award at the conference in Seoul, South Korea in 2018. Appendix 1.

Ashley has also presented at a number of meetings with Community Paediatric Physiotherapy Teams to promote the service in Glasgow 29/05/18, Lanarkshire 11/11/18 and Ayrshire & Arran on 19/02/19.

### **3.2 Efficient**

The Service continues to provide and evaluate efficiency using a number of means:

- We have continued to complete as a minimum the SLA agreed activity as shown in Section 2 of this report.
- Regular service meetings have led to a review of our clinical assessment and non-invasive interventions.
  - This led to a change in the review process for all patients undergoing Dynamic Bracing. They are now followed up by the Orthotists only until treatment has completed or a Consultant opinion is required. This has created more space in the MDT Clinic to facilitate earlier review of new referrals.
  - All Vacuum Bell patients are followed up by our dedicated physiotherapist. This again releases consultant time in the MDT clinic.
  - We also changed the assessment process for patients <8 years of age as they are very unlikely to need surgical intervention due to their age and the non-invasive treatment options and they are now initially monitored and treated by the physiotherapist and directed back into the MDT Clinic or the Orthotists if required.
- We are constantly reviewing our care pathway for surgical patients with the aim of early mobilisation, minimising side effects of analgesia and reducing length of hospital stay. Our average length of stay following Nuss procedure or Modified Ravitch is 6 days as outlined in the SLA. Following bar removal our average length of stay is 0 days, as these patients use 23 hour beds; this is under the requirement of the SLA of 1 day.

### **3.3 Timely**

The surgical case load for the Nuss procedure and the Modified Ravitch procedure is deliberately scheduled to provide surgical input out with the academic year due to the impact this type of surgery would have on education. This is related to both the immediate recovery period and also the level of pain medication required post operatively.

All post-operative patients are followed up in the Outpatient clinic 2-3 weeks post surgery when they have a multidisciplinary review including the Pain Team and have a chest x-ray to assess their repair. The Physiotherapist will see them at 6 weeks post-op (either face to face / phone call / attend anywhere VC). They are then reviewed at the MDT clinic at 3 months and 6 months post-operatively.

Vacuum Bell patients are followed up by our physiotherapist every 3 months.

Dynamic bracing patients are followed up every 3 months either in clinic or by phone.

We do not have patients breaching these standards unless by their own request.

Table 4 shows timing from referral to initial clinic appointment for the MDT clinic.

Measure	2018/2019	2017/2018	2016/2017
<b>Average wait time (days)</b>	50.5	64.2	58.1
<b>Max wait time (days)</b>	84	140	155
<b>% seen within 6 weeks</b>	34.2%	21.1%	19.4%

**Table 4 Time from Referral to 1st Clinic assessment for the last 3 years**

### 3.4 Effectiveness

Clinical Outcomes	Measure	2018/2019
<b>Effectiveness:</b> Providing services based on scientific knowledge	Mortality of less than 1%	0%
	Number of complications:	3*
	- Bleeding following removal of Nuss bars	0
	- Infected prosthesis	1
	- Pneumothorax requiring treatment	0

**Table 5 Agreed Clinical Outcome Measures**

\*The remaining 2 surgical complications were Nuss bars displacing early post-op. These were successfully surgically repositioned.

### **3.5 Safe**

We have had no significant adverse events and no HAI outbreaks / notification of surveillance concerns.

#### **Scottish Patient Safety Programme (SPSP)**

The Royal Hospital for Children (RHC) is at the forefront of patient safety. The chest wall surgical team aims is to ensure delivery of safe, high quality peri-operative care for all patients with pectus deformities. In line with SPSP recommendations, RHC theatres use a standardised approach to patient safety ensuring surgical team briefing and surgical safety checklists are carried out prior to commencing and following all surgical procedure. These processes ensure that key equipment, personnel and resources are available prior to commencement of surgery (e.g. Sternal saw in theatre and on-site Cardiac Surgery Service support). As part of the team debrief, each case is reviewed and any perceived improvements or risks are addressed. Improvements in ward staffing and training have allowed us to manage these patients in a ward setting immediately post-operatively.

### **3.6 Person centred**

Our dedicated Physiotherapist is assessing the impact of treatment (surgical, bracing and vacuum bell) by utilising the PedsQL™ Paediatric Quality of Life Inventory. Appendix 2 & 3 show the ones we use; one for the teenagers and one for the parents.

Our physiotherapist also completed a satisfaction survey for the surgical patients for the report period. The results of this including patient feedback is attached as appendix 4.

## **4. Quality and service Improvement**

This year we have introduced the provision of Vacuum Bell treatment. This allows a conservative treatment option for patients with flexible Pectus Excavatum. We are seeing good results from the initial patient cohort provided with these devices. There are a number of publications supporting the effectiveness of this treatment option.

Our most common intervention conservatively at the moment is dynamic bracing. Provision of the Vacuum Bell is in its infancy and we expect the numbers of these to grow going forward. Surgically the most common procedure is the Nuss procedure. Last year we implemented Peri-operative, respiratory and post-surgery protocols to enhance recovery. We also implemented the Physiotherapy In-Patient Pathway for Pectus Surgery and have a Pectus Surgery Recovery Protocol.

We are running two 'Chest Wall School' sessions for the year's surgical patient group following last year's feedback. This allows us to provide pre-operative information to patients and families so they have the information they require for the post operative phase. Feedback from these has been very positive and will be included in the report for 2019/2020.

## **5. Governance and Regulation**

### **5.1 Clinical Governance**

The Service and professionals involved adhere to the robust clinical governance structures of NHS Greater Glasgow and Clyde.

The Service organises Multidisciplinary meetings every 3 months.

### **5.2 Risks and Issues**

Last year we reported that the main risk going forward was being able to cope with the outpatient work load. We have taken steps this year to address this by reducing the return of patients who have opted for conservative treatment to the outpatient clinic. Also all patients under the age of 8 are being seen in the physiotherapy clinic. This has reduced the waiting time for the outpatient clinic and therefore, reduced this risk.

### **5.3 Adverse Events**

We have had no adverse events.

### **5.4 Complaints and Compliments**

We have had no complaints to date. Compliments were documented as part of the post surgery patient satisfaction survey and are available in appendix 4.

### **5.5 Equality**

All staff receive equality and diversity training. We have not undertaken any specific projects in this field.

## 6. Financial reporting and workforce

**NHS Greater Glasgow & Clyde**  
**Women & Children's Directorate**  
**Chest Wall Service**  
**Twelve Month Report: 2018/19**

Actual Activity 25  
 Projected Activity 25  
 Contract Activity 10  
 Contract Type Block

	Full Year Funded Value	Twelve Month Funded Value	Actual Outturn As At 31st March 2019	Variance	Projected Full Year Outturn
	Of Agreement £	Of Agreement £	£	£	£
<b><u>FIXED</u></b>					
Medical	40,166	40,166	40,166	0	40,166
Nursing	38,760	38,760	38,760	0	38,760
AHP's	167,745	167,745	167,745	0	167,745
Facilities	80	80	80	0	80
A&C	6,043	6,043	6,043	0	6,043
<u>Total Fixed</u>	<u>252,794</u>	<u>252,794</u>	<u>252,794</u>	<u>0</u>	<u>252,794</u>
<b><u>VARIABLE</u></b>					
Drugs	4,672	4,672	11,680	-7,008	11,680
CSSD /					
Diagnostics	610	610	1,525	-915	1,525
Surgical					
Sundries	31,952	31,952	79,880	-47,928	79,880
Other	16,432	16,432	41,080	-24,648	41,080
<u>Total Variable</u>	<u>53,666</u>	<u>53,666</u>	<u>134,165</u>	<u>-80,499</u>	<u>134,165</u>
<b><u>Indirect</u></b>					
Imaging	4,335	4,335	4,335	0	4,335
Labs	284	284	284	0	284
<u>Total Indirect</u>	<u>4,619</u>	<u>4,619</u>	<u>4,619</u>	<u>0</u>	<u>4,619</u>
<b><u>Overheads</u></b>					
	46,000	46,000	46,000	0	46,000
<u>Total</u>					
<u>Overheads</u>	<u>46,000</u>	<u>46,000</u>	<u>46,000</u>	<u>0</u>	<u>46,000</u>
<b>TOTAL</b>	<b>357,079</b>	<b>357,079</b>	<b>437,578</b>	<b>-80,499</b>	<b>437,578</b>

## **7. Audit & Clinical Research / publications**

We use PedsQL™ Paediatric Quality of Life Inventory to audit the success of our interventions. We are currently collecting data regarding wear time for the dynamic bracing patient group with a view to proceeding to audit the required brace wear time against treatment outcomes. Outcomes are measured using clinical photography for qualitative and 3D surface scanning for quantitative measures of treatment outcome.

Both of the posters produced for CWIG in South Korea are attached in appendix 1.

## **8. Looking ahead**

Going forward we hope to develop in the following areas

- Expand and refine our Chest Wall School Programme.
- Refine our peri-operative protocols to optimise patient experience and reduce in-hospital stay.
- Further develop our non-invasive assessment and treatment of Pectus Excavatum, especially in younger children.
- Further develop website and appropriate information literature and social media platforms.
- Define the role of Clinical Psychology.
- Develop or purchase a pressure measurement device for use to establish pressure to correct.
- Develop a pressure measurement device to monitor in brace pressure.
- Producing a modular dynamic brace to reduce decision to treat to bracing wait times.
- Generate research projects based on data collected.
- The Children's Hospital Charity are presently fundraising for a miller that, when introduced, will reduce turnover time between initial; assessment and starting Dynamic Bracing for Pectus Carinatum patients.



# Incentive Spirometry as a Measure of Recovery Following Chest Wall Surgery

Ashley Johnstone, Highly Specialist Paediatric Respiratory Physiotherapist  
Dr Kathryn Sharp, Paediatric Respiratory Physiotherapy Advanced Practitioner  
Royal Hospital for Children Glasgow, on behalf of the Scottish National Chest Wall Service

## Purpose

To monitor the Inspiratory Capacity of patients following chest wall surgery using an Incentive Spirometer (COACH 2 Device) (Figure 1) as part of their Physiotherapy post-operative management, to help prevent post-operative pulmonary complications.

## Method

The Inspiratory Capacity is the volume of gas that can be taken into the lungs in a full inhalation, starting from the resting inspiratory position.

The predicted Inspiratory Capacity was calculated using the Global Lung Function Initiative Scale. A record of the Inspiratory Capacity was recorded before surgery and then daily whilst in hospital then followed up at 3 weeks and 3 months after surgery of 8 patients undergoing a NUSS Procedure.

No patient had any respiratory symptoms or underlying respiratory condition. All patients were seen for daily Physiotherapy for breathing exercises, incentive spirometry and mobility.



Figure 1: The COACH 2 Incentive Spirometer

## Results

It was identified that each of the patients demonstrated a drop in their inspiratory capacity following surgery with most improving by 3 weeks and also increasing to above their initial values by 3 months following their surgery (Figure 2).

It was identified that 2 patients had a decline in their inspiratory capacity at 3 weeks post-surgery which were patients both with wound infection.

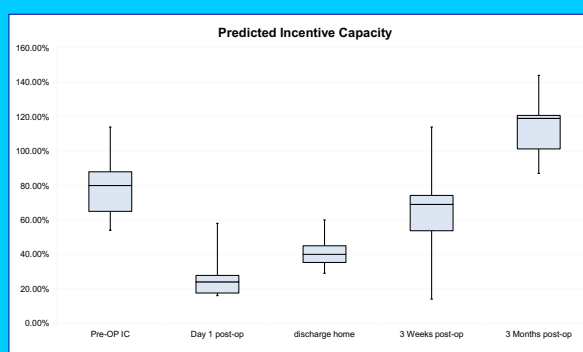


Figure 2: Box-plot of change in Predicted Incentive Capacity Following Chest wall Surgery

## Conclusion

The results from using the COACH 2 Device suggests it is an effective tool in improving inspiratory capacity following chest wall surgery and provides a useful guide in monitoring progress. It may also be a useful tool in helping to identify post-operative complications.

## Acknowledgements

Special thanks to the Physiotherapy and Chest Wall Teams at the Royal Hospital for Children, Glasgow in addition to our patients and their families for enabling this data collection.

Follow the Physiotherapy Service at the Royal Hospital for Children, Glasgow @nhsggrchphysio



*The Physiotherapy Service at the Royal Hospital for Children, Glasgow will listen to what matters to you. We will work with you and your family to help you achieve your goals and join together with local services to support your health and wellbeing.*



ID#	_____
Date:	_____

# PedsQL™

## Paediatric Quality of Life Inventory

Version 4.0 - English (United Kingdom)

### TEENAGER REPORT (ages 13-18)

#### INSTRUCTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you over the **PAST MONTH** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.  
If you do not understand a question, please ask for help.

Over the **PAST MONTH**, how much of a **problem** has this been for you...

<b>ABOUT MY HEALTH AND ACTIVITIES (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard for me to walk more than a couple of streets (about 100 metres)	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activities or exercise	0	1	2	3	4
4. It is hard for me to lift heavy things	0	1	2	3	4
5. It is hard for me to have a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I have aches and pains	0	1	2	3	4
8. I feel tired	0	1	2	3	4

<b>ABOUT MY FEELINGS (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

<b>HOW I GET ON WITH OTHERS (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting on with other teenagers	0	1	2	3	4
2. Other teenagers do not want to be my friend	0	1	2	3	4
3. Other teenagers tease me	0	1	2	3	4
4. I cannot do things that other teenagers my age can do	0	1	2	3	4
5. It is hard to keep up with other teenagers my age	0	1	2	3	4

<b>ABOUT SCHOOL / COLLEGE (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my school / college work	0	1	2	3	4
4. I miss school / college because of not feeling well	0	1	2	3	4
5. I miss school / college to go to the doctor or hospital	0	1	2	3	4

ID# \_\_\_\_\_

Date: \_\_\_\_\_

# PedsQL™

## Paediatric Quality of Life Inventory

Version 4.0 – English (United Kingdom)

### PARENT REPORT for TEENAGERS (ages 13-18)

#### DIRECTIONS

On the following page is a list of things that might be a problem for **your teenager**.

Please tell us **how much of a problem** each one has been for **your teenager** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your teenager had with ...

<b>PHYSICAL FUNCTIONING (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. Walking 100 metres	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activities or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having aches or pains	0	1	2	3	4
8. Feeling tired	0	1	2	3	4

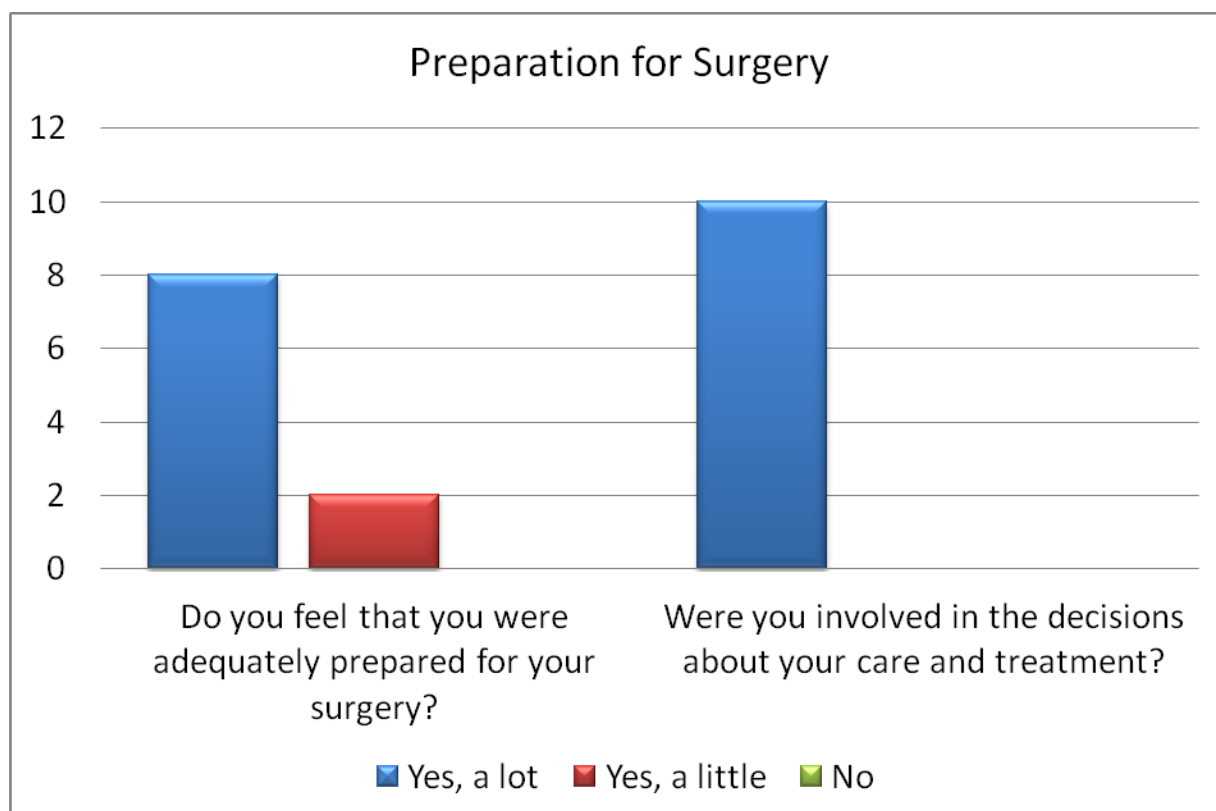
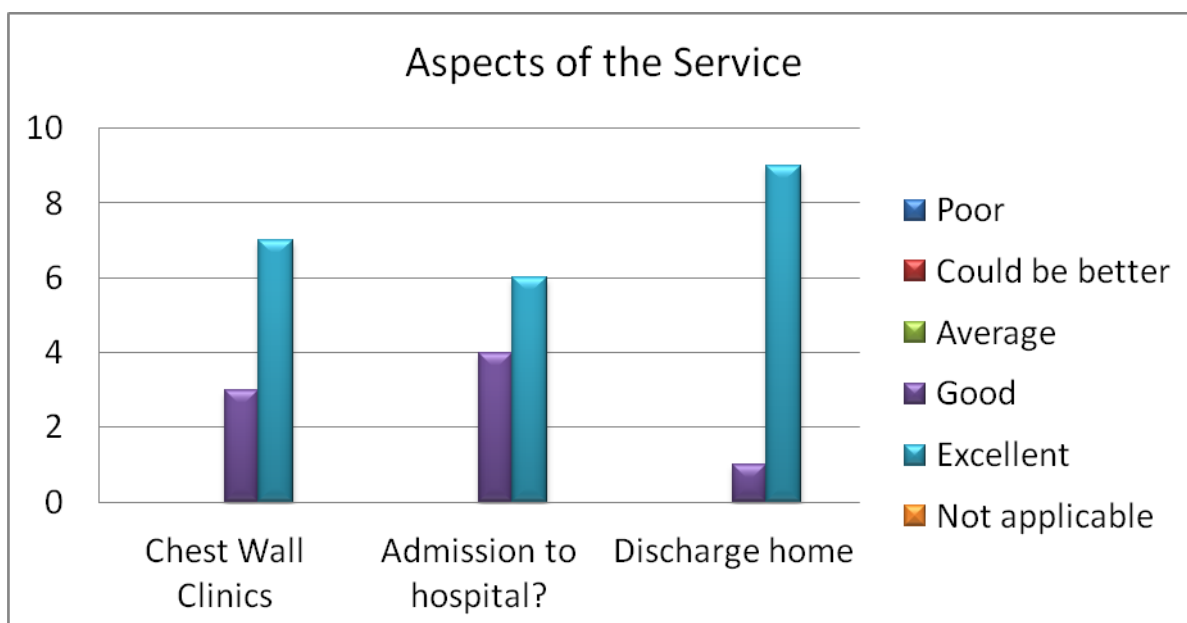
<b>EMOTIONAL FUNCTIONING (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

<b>SOCIAL FUNCTIONING (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. Getting on with other teenagers	0	1	2	3	4
2. Other teenagers not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other teenagers	0	1	2	3	4
4. Not being able to do things that other teenagers his or her age can do	0	1	2	3	4
5. Keeping up with other teenagers	0	1	2	3	4

<b>SCHOOL FUNCTIONING (problems with...)</b>	Never	Almost Never	Some- times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

## Appendix 4

### Chest Wall Surgery 2018 Patient Satisfaction



Can you tell me about the things you like about the service?	All the staff were really good at their job and helped me a lot to recover
	How friendly Ashley was, that made me feel more comfortable to do my exercises
	Amazing nurses and very good service
	Almost everything was explained well. All the nurses, physios and doctors were very nice
	Good communication, very thorough
	I was well looked after before and after surgery
	Nurses treated me well
	That I got my chest fixed
	The nurses and doctors were very nice
	Very caring staff that put me at ease
Can you tell us something about the service that you feel we could improve on?	Make sure the patient is fully aware of the amount of medicine they will need to take. Also make sure the patient is aware of the amount of physio and how much they won't be able to do.
	Post surgery care from doctors when in hospital - re hydration, nausea etc
	TV not working sometimes. Better food
If there is anything else that you would like to tell us about the service?	The time spent with (patient's name) and family was very good. The care before, during and after was top class
	It's made a really big difference in my life and gave me confidence.
	It was very efficient
	So pleased with end result. NHS service excellent. I would like to thank the whole team for the fantastic care I received. I am delighted with the results. My experience with the chest wall team was first class. I couldn't of (sic) asked for better care. I will be forever grateful to you all.