SCOTTISH NATIONAL OBSTETRIC BRACHIAL PLEXUS INJURY SERVICE

ANNUAL REPORT 2017/18

NHS Greater Glasgow & Clyde

CONTENTS

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

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Section A: Service/Programme

A2 Aim / Purpose / Mission Statement / Date of Designation

The Paediatric Brachial Plexus Injury Service is based at the Royal Hospital for Children in Glasgow and became a designated National Service in April 2006.

It provides an integrated multidisciplinary service for obstetric brachial plexus injury, traumatic brachial plexus injury and tumours involving the brachial plexus including:

- **Diagnosis:** Clinical, MRI, Ultrasound, Neurophysiology.
- **Surgery:**
  - Early surgical exploration and nerve repair.
  - Secondary reconstruction for shoulder and other deformities.
- **Physiotherapy**
- **Occupational Therapy**

A3 Description of Patient Pathway

A3 a) Target Group for Service or Programme

Children with obstetric brachial plexus injury are the main group managed by the service. When necessary, children with traumatic brachial plexus injury or tumours involving the brachial plexus are seen.

A3 b) Abbreviated Care Pathway for Service or Programme

This integrated multidisciplinary service receives referrals nationally from maternity units, paediatricians, orthopaedic services and plastic surgery services. Along with their parents children with obstetric brachial plexus injury (OBPI) are assessed in the outpatient clinic by medical staff and therapists to confirm the diagnosis, exclude immediate complications (e.g. shoulder dislocation), counsel parents, ensure optimal parent-child bonding, address parental perceptions of the injury mechanism (and any related blame attribution) and to establish a likely prognosis. Some children are seen prior to this first clinical review by the specialist therapists and receive instruction on therapeutic exercises.

A management plan is formulated that includes parental counselling, physiotherapy (initial passive stretching to mitigate shoulder deformity, later active range exercises, post-operative therapy as required), occupational therapy (safe positioning & optimal handling, age-specific sensorimotor developmental assessments, activity-based interventions, provision of aids, fit-for-schooling assessment, school visits & educational liaison role), investigations when necessary (neurophysiology, imaging studies), and monitoring of progress (developmental milestones, school progression, body-image development, pain, psychosocial welfare, fit-for-life).

Surgical decisions on nerve surgery and prophylactic shoulder interventions are made around 3 months of age and on secondary surgery (shoulder procedures, hand reanimation, functional muscle transfers) as necessary during growth into adulthood.

Interventions are carried out by the surgical team to:

- Optimise recovery from nerve injury: in a small percentage of children (more severe lesions with inadequate motor recovery at 3 to 6 months of age), exploration and microsurgical reconstruction of the brachial plexus nerves may benefit recovery and enable prognostic stratification.

- Optimise growth trajectory: early nerve surgery may reduce growth disturbance in more severe nerve injuries (detailed above). In these, and in other children with early shoulder subluxation/instability, conservative interventions (e.g. casting, Botox injections) can forestall more severe shoulder abnormalities.

- Correct functionally significant secondary deformity/functional impairment: joint releases, tendon transfers, bony procedures and free functional muscle transfers for upper limb deformities resulting from OBPI. These most commonly affect the shoulder.

Children with persisting deficit are followed up in outpatients at least until skeletal maturity.

Section B:

B1 Efficient

B1 a) Report of Actual v Planned activity

Statement of Activity 2017-18

		Total	*Agreed*
***Number of Patients Assessed**			
Total OBPI per database	45		
Minus Adults with OBPI (see Adult report)	[redacted]		
		42	*35*
NHS Board for Referrals			
England	[redacted]		
Fife	[redacted]		
Forth Valley	[redacted]		
GG&Clyde	18		
Grampian	[redacted]		
Highland	[redacted]		
Lanarkshire	8		
Lothian	[redacted]		
Northern Ireland	[redacted]		
Orkney	[redacted]		
Tayside	[redacted]		
		42	
Outpatient Follow-Up Appointments			
Total OBPI clinic visits per database	237		
**Minus Adults with OBPI (See Adult report)	-31		
Minus OBPI New Referrals	-45		
		161	
NHS Board for Follow-Up Outpatient Appointments			
Ayrshire & Arran	[redacted]		
Borders	[redacted]		
Dumfries & Galloway	[redacted]		
England	0		
Fife	8		
Forth Valley	[redacted]		

GG&Clyde	65	
Grampian	7	
Highland	8	
Lothian	18	
Northern Ireland	16	
Orkney	[redacted]	
Shetland	[redacted]	
Tayside	[redacted]	
Wales	[redacted]	
		161
Admissions for Surgery		
Nerve	[redacted]	
Other (Shoulder, Elbow)	[redacted]	
		[redacted]
Ward Bed Days		
HDU/ITU	2	
Nerve Surgery	22	
Other Surgery	[redacted]	
		29
NHS Board for Admissions		
GG&Clyde	[redacted]	
Lanarkshire	[redacted]	
Lothian	[redacted]	
Northern Ireland	[redacted]	
		8

**Based on date first seen.*

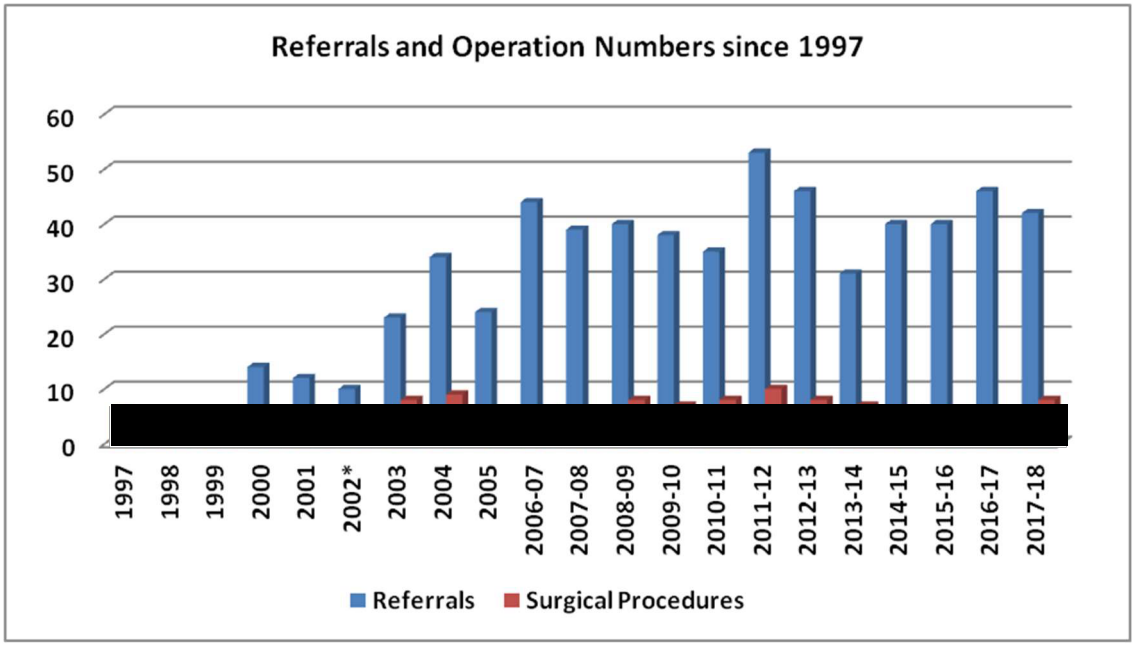
***Adults with OBPI seen at New Victoria clinics and Aberdeen outreach clinics.*

The activity for return appointments should be representative of children who have ongoing problems resulting from OBPI.

Referrals and Operation Numbers since 1997:

Year	Referrals	Surgical Procedures
1997	6	[redacted]
1998	[redacted]	[redacted]
1999	[redacted]	0
2000	14	[redacted]
2001	12	[redacted]
2002*	10	[redacted]
2003	23	8
2004	34	9
2005	24	[redacted]
2006-07	44	6
2007-08	39	[redacted]
2008-09	40	8
2009-10	38	7
2010-11	35	8
2011-12	53	10
2012-13	46	8
2013-14	31	7
2014-15	40	6
2015-16	40	6
2016-17	46	[redacted]
2017-18	42	8
Total:	**625**	**115**

Activity Graph



B1 b) Resource use

Covered in other parts of the report.

B1 c) Finance and Workforce

Twelve Month Report: 17/18

	Full Year Funded Value Of Agreement	Twelve Month Funded Value Of Agreement	Actual Outturn As At 31st March 2018	Variance	Projected Full Year Outturn
	£	£	£	£	£
FIXED					
Nursing/PAM	70,379	70,379	70,379	0	70,379
Medical	10,588	10,588	10,588	0	10,588
Other direct	43,731	43,731	43,731	0	43,731
Indirect	15,865	15,865	16,083	-218	16,083
Capital charges	58	58	58	0	58
Total Fixed	140,621	140,621	140,839	-218	140,839
VARIABLE					
Pharmacy	5,326	5,326	4,352	974	4,352
Travel & Training	2,231	2,231	1,823	408	1,823
Total Variable	7,557	7,557	6,176	1,381	6,176
TOTAL	**148,178**	**148,178**	**147,015**	**1,163**	**147,015**

Summary

Fixed	140,839	140,839
Variable (8 Cases)	6,176	6,176
Total	147,015	147,015
Less		
Variable Non Contract (2 Cases)	1,544	1,544
Fixed Costs	28,168	28,168
Final Total Owed By NSD	**117,303**	**117,303**

B1 d) Key Performance Indicators (KPIs) and HEAT Targets

1. **Time from referral to first physiotherapy assessment/intervention < 2 weeks**.

   All babies referred to physiotherapy at RHC were seen within 2 weeks of referral and all before they were 4 weeks of age.

2. **Time from referral to first clinic appointment being offered < 6 weeks**.

   The mean wait between referral and the first outpatient appointment was **4** weeks and the median was **4** weeks (*Range 0 – 14. See below*).

Time from Referral to Treatment (Monthly Breakdown)			
	Patients Seen	Median Wait (Weeks)	Max Wait (Weeks)
April	[redacted]	4.0	4.3
May	[redacted]	1.3	3.0
June	7	3.7	4.9
July	[redacted]	3.6	8.4
August	[redacted]	4.6	4.6
Sept.	[redacted]	4.8	9.0
Oct.	[redacted]	3.6	*13.6
Nov.	[redacted]	5.4	7.9
Dec.	[redacted]	4.6	5.7
Jan.	[redacted]	4.8	7.0
Feb.	[redacted]	6.6	9.6
March	[redacted]	4.6	6.0
Year:	**42**	**3.9**	**13.6**

[redacted] historic injury previously treated in Leeds. Not urgent. Family moved to Orkney. Family requested to wait until later in the year.

3. **Age at first review: physiotherapy 4 weeks; clinic 8 week**s.

Age at First Review (Years)			
Minimum	Maximum	Average	Median
0.0	13.0	1.3	0.0

   The results above are affected by a few children who are referred for the first time at an older age. Most cases are seen before the age of 8 weeks. (*0 value = less than 6 months of age*).

4. **Assessment and stratification for nerve surgery benefit by 4 months; nerve surgery by 6 months**.

   All nerve surgery cases were carried out by age 6 months during 2017-18.

5. **Clinic letters issued within 2 weeks**.

   All clinic letters and operation notes are typed and checked within a few days.

6. **OT review before commence schooling**.

   Pre-school visits to children in GG&C are carried out by the specialist O.T. who also liaises with nursery/primary schools outwith GG&C prior to the children attending primary school.

7. **Service audit completion, including satisfaction survey, once every 3 years**.

   See section B5c.

8. **Educational talks with referring specialties, care providers and professional groups within and outwith NHS GG&C**.

   During the 2017-18 period brachial plexus injury (adult & obstetric) has been taught to medical students, occupational therapy students, general plastic and orthopaedic surgeons and neurophysiology trainees. (*Also see Appendix*)

9. **Review of surgical outcomes every 3 years, including Mallet shoulder scores**.

   See section B2a

B2 Effective

B2 a) Clinical Audit Programme

OBPP Nerve Exploration / Repair Cases 2004 to 2017

A continuing audit is being carried out to monitor the operations for nerve exploration and repair carried out for obstetric brachial plexus injury in Glasgow.

Since the appointment of Professor Andy Hart in 2008 exploration of the brachial plexus has been included in the interventions offered by the obstetric brachial plexus injury service. A few cases had been carried out before 2008 with the help of Professor Rolfe Birch from the Royal National Orthopaedic Hospital and by Mr Tim Hems.

Nerve exploration is only considered in the most severe cases of OBPI. The main indication is failure of recovery of elbow flexion and shoulder movement by 4 to 6 months of age, which may be associated with complete or partial paralysis of the hand.

Interpretation of results is affected by:

- The small number of cases.
- The variation in the extent and severity of the injuries.
- Follow up is too short to assess the final result in the cases carried out during the last 2 years.

20 cases (13 male, 7 female) have been carried out between 2004 and January 2018.

Timing of Operation

The mean age at operation was **5.6** months (*Median = 5 months, Range 4 to 14 months*). (The child who had operation at 14 months was born 3 months prematurely and was not fit for earlier intervention).

Classification

Cases were classified using the Narakas system:

		Number
Group 1	C5, 6. Biceps and deltoid paralysis.	[redacted]
Group 2	C5, 6, 7. Only the long finger flexors work.	9
Group 3	Whole plexus involved with slight finger flexion only.	[redacted]
Group 4	Whole plexus involved plus Horner's syndrome.	7

Indications for Operation

In 17 cases the aim of the procedure was reconstruction for elbow flexion and shoulder elevation. In [redacted] of these the lesion was found to be recovering and no repair was carried out. Nerve repair was performed for shoulder function in 12 patients and 11 for elbow flexion.

In [redacted] cases the aim of the procedure was reconstruction for shoulder elevation and external rotation only. In [redacted] of these the lesion was found to be recovering and no repair was carried out. Nerve repair was performed in [redacted] patients.

Method of Repair

Elbow flexion: nerve grafting of the upper trunk of the brachial plexus or nerve transfer using ulnar nerve fascicle.

Shoulder elevation: re-innervation of the suprascapular nerve was by transfer of the accessory nerve in 12 of 14 cases, transfer of the dorsal scapular nerve graft in [redacted], and nerve suture in [redacted].

7 children had release of shoulder contracture or MUA & Botox at the same time as nerve reconstruction which will also have affected the result for shoulder recovery.

Results

13 of the 15 cases who had nerve repair have sufficient follow-up.

Elbow flexion:

Mean active elbow flexion = 90° (0 - 120)

[redacted] children have subsequently had free muscle transfers to strengthen elbow flexion.

Shoulder:

Mean active shoulder elevation (flexion or abduction) = 90° (Range 30 – 160°)
Mean active shoulder external rotation (in adduction) = 28° (Range -30 – 60°)

Mean Mallet score = 14.5 (Range 5 - 21)

Complications

Overall the interventions appear safe.

[redacted] had phrenic nerve dysfunction after operation. However, the phrenic nerve may be injured in association with OBPI. It is therefore likely that the condition had been present before surgery. In subsequent cases phrenic nerve function has been assessed before operation.

Conclusions

These early results appear satisfactory taking into account the severity of injuries being treated. Shoulder function: results are suggestive of an improved outcome in many of the cases treated. The unit will continue to monitor new cases and longer term outcomes.

B2 b) Clinical Outcomes/ complication rates / external benchmarking

Covered in other parts of the report.

B2 c) Service Improvement

Referral Process

The referral process is streamlined with referrals vetted by CFM and then directed centrally to the service administrator who has access to booking all new patient appointments.

The service administrator ensures that referrals are processed within twenty-four hours of receipt where possible. Newborn referrals are copied to the paediatric physiotherapist for early review. Referrals are received by post, email, via the electronic GP Gateway (e-vetting) or by direct referral to the Children's Physiotherapy Service but all are handled now by the SNBPIS which is a more robust system than the previous method of involving the Central Medical Records department.

A standard referral form is available on the service website and has also been circulated to maternity units in Scotland. The generic *brachial.plexus* email address is forwarded to other members of the team in the administrator's absence to ensure constant monitoring of email referrals. Email referral has been highlighted to referrers as the speediest method. All email referrals are acknowledged upon receipt.

Communication

At the NSD meeting in September 2016 it was suggested that we should start to record email/mail correspondence in addition to the new referrals seen at clinic. Each member of the team receives similar correspondence.

Over the past year there has been considerable communication from many regions in the form of letters and emails. The use of the central email address for the Scottish National Brachial Plexus Injury Service ensures that many health professionals (and families) have a means to contact us directly.

An example of effective communication over the past year has been in relation to one particularly challenging case from Grampian where there were concerns about the child's social circumstances and the parents' lack of engagement with health professionals. As a result of involving AHPs, GPs and consultants in their local region we were able to encourage re-attendance to RHC for inpatient assessments and clinic appointments.

Physiotherapy

Heather Farish, Team Lead Paediatric Physiotherapist

The Role of Physiotherapy in the Service

- I continue to be the first point of contact for families in Glasgow who have a baby born with OBPP. I assess, give advice and treat as appropriate and refer into the OBPP clinic if required.

- I liaise regularly with paediatric physiotherapists across Scotland and Northern Ireland regarding children with OBPP who attend the specialist clinic in Glasgow but are seen locally for physiotherapy. This includes telephone conversations, emails and receiving and providing reports before and after clinic appointments. I also receive referrals from local physiotherapists for children they would like seen at the specialist OBPP clinic.

- I work in conjunction with Occupational Therapy to see patients jointly if required which helps to minimise hospital appointments.

- I educate more junior staff and students at RHC on OBPP through in-service training, shadowing patients with OBPP and clinics. I have also had requests from local physiotherapists to observe clinics with me.

- I promote early physiotherapy intervention for OBPP through education with maternity unit staff, information on the Scottish Brachial Plexus website and communication to local areas.

Physiotherapy Patient Numbers for 2017/18:-

At Clinic

New	Return
27	55

In Physiotherapy

New	Return
8	25

I have also been involved with a few patients after their casts were removed in the plaster room and also patients admitted to the ward for assessment and arranged follow up locally as required.

Over the past year I have had contact with paediatric physiotherapists in Ireland and Sweden asking for advice regarding assessments for babies and children with Erb's palsy.

I have had requests from two paediatric physiotherapists in Scotland to shadow me at the clinic to assist them with managing patients with Erb's palsy whom they have on their caseloads.

Developments in Physiotherapy

Therapy-Led OBPI Clinic (TLC)

The therapy-led clinic has now been running for almost one year. This is a joint clinic run by Physiotherapy and Occupational Therapy. Clinics run approximately one afternoon per month.

So far the clinic has offered appointments to 18 patients. We expect this number to increase now the clinic is more established.

The purpose of the clinic is:-

1. To reduce appointments at the consultant-led clinic by carrying out annual reviews at the therapy-led clinic for patients who do not require a medical review at every appointment.

2. To offer joint Physiotherapy/Occupational Therapy appointments for patients who require it and where we can spend more time with the patient and families.

3. To offer additional appointments in between consultant-led clinics if required where Occupational Therapy and Physiotherapy are both present.

Assessments carried out at this clinic are uploaded onto Portal and update letters are sent to GPs and also uploaded to Portal to ensure communication is maintained.

(See Occupational Therapy)

Occupational Therapy

Nicola Hart, Specialist Occupational Therapist

Over the past 12 months Nicola Hart has continued to perform the requirements of the OBPI specialist post as outlined in last year's report. The following occupational therapy data was compiled by Nicola:-

Patients seen at consultant-led clinic for 2017/18:

- Under 5 years of age = 26
- 6 to 10 years of age = 25
- 11 to 16 years of age = 14

Developments in Occupational Therapy

Therapy-Led OBPI Clinic (TLC)

I attended a one day Quality Improvement (QI) Workshop on 27th Sept 2017 focussing on improving the therapy service for OBPI patients. This has resulted in the therapy-led clinic (TLC) which is run jointly with my Physiotherapy colleague Heather Farish.

The first clinic was held on 22nd May 2017. Eight clinics were completed in the year 2017/18. So far seven clinics have been set up for the year 2018/19.

A maximum of four patients are offered therapy outpatient appointments at each clinic session.

This clinic provides individual therapy and advice to patients and their families. The clinic is offered to all patients attending the OBPI service.

Patients seen at TLC for 2017/18:

- Patients appointed = 18
- Patients attended = 14
- Patients DNA = [redacted]

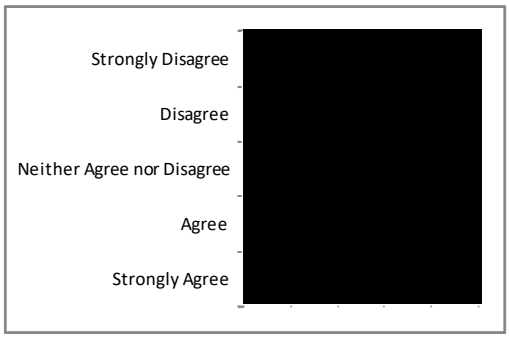
TLC Patient Survey

Following the QI Workshop a patient satisfaction questionnaire was devised for this clinic. This survey is ongoing with results to be updated when available. (*See data on next page*)

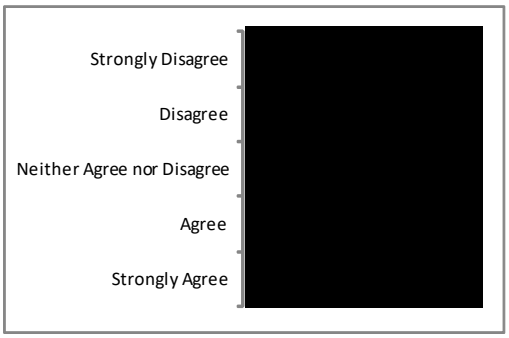
Patient Comments:
"I think more time should be allocated so that the physiotherapist will have enough time to take the child through various activities to establish possible areas of improvement."

Sample Group = [redacted] patients.

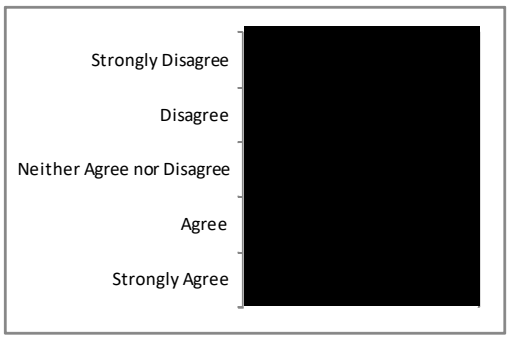
Q1. I understand the reasons for attending the Therapy-Led Clinic:



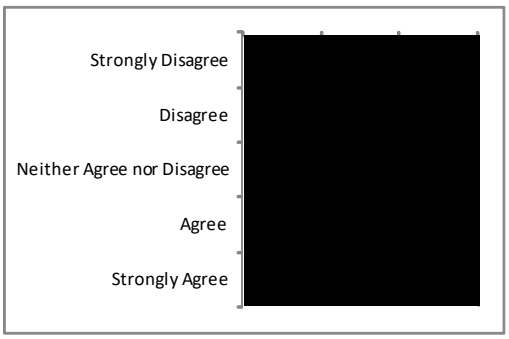
Q2. I understand the role of the Occupational Therapist for children with a Brachial Plexus Injury:



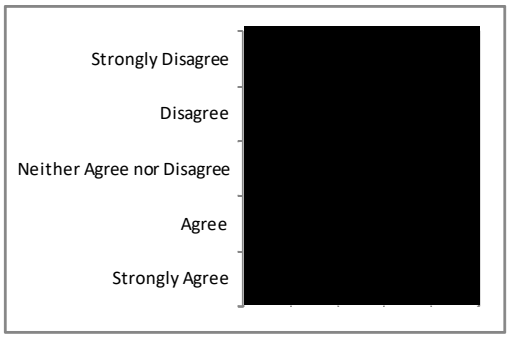
Q3. I understand the role of the Physiotherapist for children with a Brachial Plexus Injury:



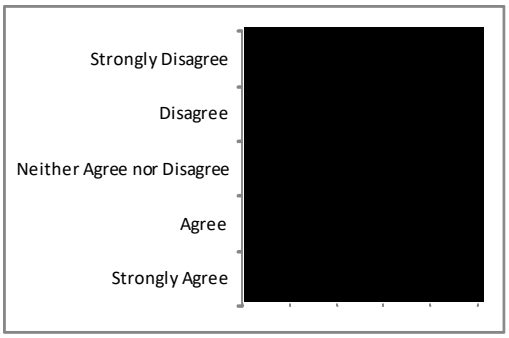
Q4. The aims of the session were clear:



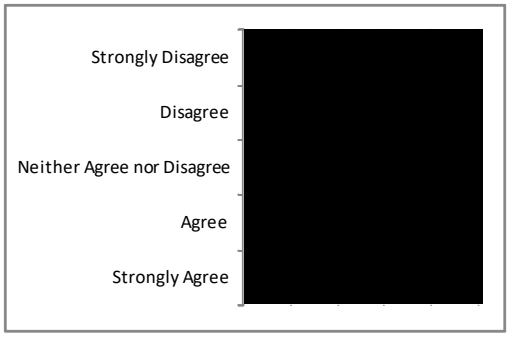
Q5. I learned about new strategies that I will try out at home with my child:



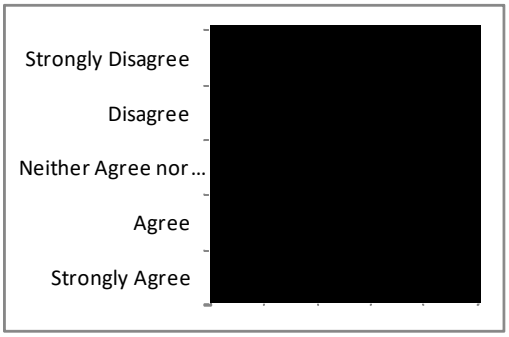
Q6. The Therapy-Led Clinic has increased my confidence to help my child's participation in everyday activities:



Q7. The clinic session length of 30 minutes was just right:



Q8. The therapy session accommodation was comfortable and clean:



Birmingham Meeting

A Brachial Plexus Injury Collaboration Meeting, held in Birmingham, was attended by myself and my occupational therapy and physiotherapy colleagues from the Adult BPI service last year. This has provided us with direct networking contacts with therapists working with this patient group. The group plans to meet on an annual basis and aims to look at uniform outcome measures, standardising assessments and sharing of research. The next meeting is in September this year in London.

Family Study Day 3rd June 2017

A Family & Patients day was organised in collaboration with the Erb's Palsy Group and the University of Glasgow. The aim of the day was to allow families and patients to meet and network, to receive feedback on the service, to educate about the pathophysiology of the condition and on management principles, to discuss research needs, and to explain the roles of the different individuals in the team.

The event was held in the Science Centre in Glasgow. Short talks were given by team members and by a scientist from the university who each then staffed separate tables for a prolonged period to allow families and children to discuss their own issues. Play support was provided by RHC staff, interactive play and drawing (2-D and 3-D) was used to help understanding and anatomical body painting used to help explain the brachial plexus and nature of the injury.

Overall feedback was very positive from those who attended, and from the Erb's Palsy Group itself. Particularly strong praise was voiced for the service administrator, Mr John McCrum.

(See appendix for full report)

Links with Other Departments at RHC, Glasgow

Neurology

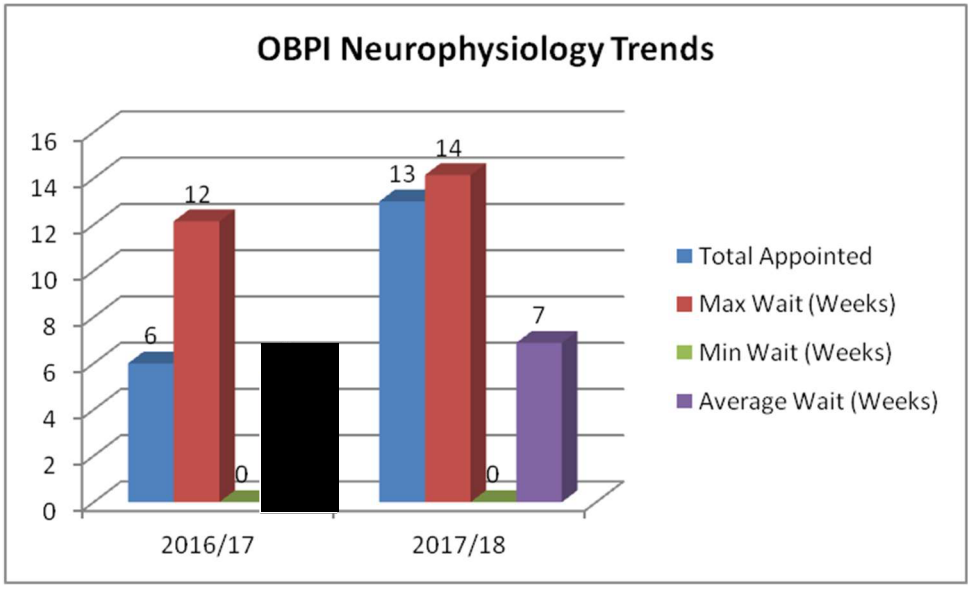
Dr Iain Horrocks (Consultant Neurologist) provides clinical assessment of some of our patients along with neurophysiology investigations, which is particularly useful in those who may require surgical intervention.

The Neurology clinics are held in the outpatient department of the Royal Hospital for Children in Glasgow on a Monday, which coincides with the Children's Brachial Plexus Clinic.

I Horrocks, Consultant Neurologist, RHC; Updated May 2018.

Outpatient Neurophysiology (seen within NHS GG&C)					
Total Appointed	**Total Seen**	**DNA / CANCELLED**	**Max Wait (Weeks)**	**Min Wait (Weeks)**	**Average Wait (Weeks)**
13	12		14	0	7

Children's Neurophysiology arranged outwith GG&C = 0



Radiology

In addition to radiographs, CTs and MRIs obtained at the children's hospital we also have access to the hospital's ultrasound machines in order to facilitate CFM to perform imaging of shoulders in young patients under the age of 1 year. CFM can perform this study when the child attends the outpatient clinic in a "One-Stop-Shop" setting, rather than having to re-appoint them to an imaging slot.

Plaster team

Our specialist plaster technicians and nurses provide an invaluable role by providing pre-treatment information for the family by meeting them when they attend clinic. They are able to show photographs of various types of upper limb plasters used and the families have the opportunity to handle dolls with plaster spicae applied in order to understand the challenges they may face once their child is in plaster. The plaster team attends theatre for safe application of casts and splints and liaises with the family and their local plaster team/hospital about ongoing plaster care and potential problems.

Website

The SNPBIS website (*www.brachialplexus.scot.nhs.uk*) is hosted by NHS Services and was designed in-house as an easy to access and informative resource for both clinicians and patients. Forms are available on the website for quick referral to the service, along with detailed pages on all aspects of obstetric brachial plexus injury. The website can also be accessed by NHS GG&C staff via the StaffNet intranet site.

In light of upgrades in web browser software the website is frequently reviewed, and in some areas simplified in order to be readable on as many platforms as possible. This represents a continuing challenge to the administration team with the website currently functioning on most web browsers satisfactorily. The intention is it to upgrade the website in the future to preserve functionality in line with future browser upgrades.

Administration

Administration is overseen by the service administrator at the New Victoria Hospital with access to offices and clinics at the Royal Hospital for Children when required. Outreach clinics in Aberdeen encompassing both the adult and children's services are organised by the administrator, normally twice per year.

The administrator is the main point of contact for referrals to children's service ensuring that referrals are processed and vetted within twenty-four hours of receipt where possible. The service database is maintained by both the administrator and the lead consultant and is under constant revision to facilitate reporting and service developments.

Data from all clinics is gathered and recorded in the EPR and on the service database for future clinical and reporting purposes. The administrator endeavours to gather this data within seventy-two hours of the clinic in order to keep clinical information as current as possible.

The administrator takes responsibility for all other administrative requirements of the service including typing and mailing of clinical notes and correspondence, setting up future clinics on the TrakCare system, liaising with other departments and hospitals as required, appointing new and return patients, speaking to patients by telephone or email when necessary and organising

service study days such as the last one held at the New Victoria Hospital on 21st April 2017. Another study day is planned for autumn 2018

New Children's Hospital

The service moved to the new Royal Hospital for Children (co-located with the Queen Elizabeth University Hospital) in June 2015.

The team has adapted well to the changes and the outpatient clinic facilities represent an improvement on those in the old hospital. Co-location with the adult service administration has helped with organisation.

The New Royal Hospital for Children has been designed specifically with patients and families in mind.

Play

Play is an important element of a child's time in hospital. An outdoor play area at the side of the hospital has disabled-accessible installations. Play specialists are based in the indoor play zone area to work with children ahead of treatment or to keep them entertained. To entertain children whilst they wait for their outpatient appointment the atrium of the hospital has been fitted out with an array of interactive activities provided by the Glasgow Science Centre and funded by the Glasgow Children's Hospital Charity. These innovative "distraction therapy" installations provide a range of approaches that delight young patients or their siblings and while they engage in play in these areas the patients can be observed by healthcare professionals to see how they are functioning. Such observations of play can alleviate more stressful situations in clinic rooms where patients may not show their best abilities due to fear.

Management

Currently, we maintain management links with Mr Jamie Redfern, General Manager, Women and Children, who has attended the last two annual reviews. We understand that further changes in structure of the management team may occur in the near future.

Young Adult Clinic

Patients who were previously seen in the Children's Brachial Plexus Clinic often require ongoing review upon reaching the age of 16. It was felt inappropriate to continue to see these patients in the children's clinics, therefore a new clinic for young adults was created, the first being held in April 2011.

The Young Adult Clinic is held twice-yearly at the New Victoria Hospital, Glasgow, which is the same location as the Adult Brachial Plexus Clinic. The clinical nurse specialist, occupational therapist and physiotherapist who work with the adult service are contributing.

Adults who have ongoing problems resulting from an OBPI are also occasionally referred to the service and are usually seen first at the Young Adult Clinic.

B2 d) Research

Tim Hems

Tim Hems with Terence Savaridas (Specialist Registrar in Orthopaedics) have completed a project to quantify elbow flexion strength in children who have had obstetric brachial plexus injury (OBPI). Although it is known that elbow flexion usually recovers to a functionally useful level after OBPI this has not be formally quantified.

The study involved measuring elbow flexion strength in children over the age of 5 attending the outpatient clinic using a hand held dynamometer. Ethical approval was obtained.

Thirty-nine patients were recruited with a mean age of 12.6 years. Results show that the mean isometric force of elbow flexion was 63% of the unaffected side at the first measurement. A mean force of 8.7kg suggests that patients have a sufficient strength of elbow flexion for most activities.

Analysis of the results has been completed, including correlation of elbow flexion strength with the severity of the OBPI. The results have been presented at national and international meetings and a paper published.

It is hoped to continue analysis of the measurements which are routinely recorded on patients with OBPI, particularly in respect of fixed flexion of the elbow and limitations in forearm rotation.

Presentations:

The Natural History of Elbow Flexion Strength Following Obstetric Brachial Plexus Injury. British Society for Surgery of the Hand meeting, Bath, April 2017.

The Natural History of Elbow Flexion Strength Following Obstetric Brachial Plexus Injury. Federation of European Societies for Surgery of the Hand. Budapest, June 2017.

Publications:

Hems TEJ, Sherlock D, Savaridas T. The natural history of recovery of elbow flexion after obstetric brachial plexus injury managed without nerve repair. Journal of Hand Surgery, European Volume. 2017, 42(7): 706-709.

Andy Hart

During the year 2017-18 Professor Hart has continued to be engaged in laboratory-based research work relevant to brachial plexus and peripheral nerve injury. Details have been included in the report on the Adult Brachial Plexus Injury Service.

B3 Safe

B3 a) Risk Register

All healthcare professionals funded within the structure of the Obstetric Brachial Plexus Injury Service meet Greater Glasgow & Clyde Trust requirements for vetting by Disclosure Scotland and registration with the Information Commissioner's Office.

Miss Claire Murnaghan has certified Level 3 Child Protection training.

B3 b) Clinical Governance

Patients reviewed or treated at the RHC site fall under the hospital's own governance system, reinforced by internal audit within the Orthopaedic and the Plastic Surgery services. No significant governance issues have been identified through these mechanisms during 2017-2018.

B3 c) Healthcare Associated Infection (HAI) and Scottish Patient Safety Programme (SPSP)

The outpatient clinic has fully adopted recommendations on hand hygiene, dress code, and cleaning of equipment as recommended nationally. These measures are also in full implementation within the inpatient ward and theatre complex used. Regular monitoring of compliance within the hospital is performed by assessors independent to the SNBPIS. No peri-operative bacterial infections occurred during the period 2017-18.

B 3 d) Adverse Events

The service uses existing Greater Glasgow & Clyde thresholds for instigation of adverse event reporting and investigation, plus online reporting systems. No adverse events have been reported to occur during the period 2017-2018.

B 3 e) Complaints/Compliments

Complaints are handled by the Complaints Liaison Officer, per the NHS Complaints Procedure. Information leaflets regarding the complaints policy are available from any member of staff at RHC.

There have been no complaints received about the Children's Brachial Plexus Service per se.

B4 Timely (Access)

B4 a) Waiting / Response Times

The mean time between referral and first clinic consultation offered was **4** weeks (*Range 1 to 14 weeks*). (*See also section B1 d)*

Referrals are sent in several ways such as by letter to Miss Murnaghan at RHC, by post to the administrator and physiotherapist using the pro forma available on the website, by email via the same pro forma, or via the electronic vetting system for those who are not directly referred by the maternity units but instead via their general practitioner.

Neonatal referrals from the maternity units are duplicated and sent to Heather Farish (Physiotherapist). Therefore during periods of staff leave there is a system in place to ensure that new babies do not wait a longer time for their first appointment with a member of the team.

The urgency of the referral is graded when it is received. The response times have been appropriate to the condition of the patients.

B4 b) Review of Clinical Pathway

(i) Review and Changes to Clinical Pathway

Formal in-house discussions have been held around the indications for nerve exploration, and for nerve reconstruction, in light of discussions with international colleagues. Further pathway review will follow completion of the iPluto project that seeks to harmonise pathways in major centres across Europe and Northern America. In addition, as instigated by the Scottish service (AH), care pathways for OBPI will be presented at the 2017 UK-Scandinavian workshop by all services in order to further facilitate pathway optimisation by the Scottish service and harmonisation of standards across Northern Europe.

(ii) Improvements to Local Delivery of Care

Early in 2014 the referral guidelines were revised so that these are consistent for cases occurring throughout Scotland. Over recent years earlier referral to the service has been encouraged in the belief that earlier intervention with physiotherapy, provision of information to parents and selection of cases requiring surgery is beneficial.

The new guidelines are on the service website and appear to have been functioning well. In the future it is hoped that an on-line referral system can be developed.

B5 Person-Centred

B5 a) Patient Carer/Public Involvement

New and return patients are actively informed about the UK-based Erb's Palsy Group, a parent-run charity which provides a source of support and practical information for families dealing with Neonatal Brachial Plexus Injury.

B5 b) Better Together Programme Involvement

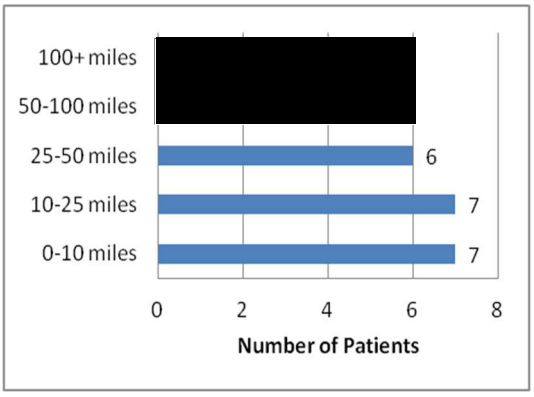
Patients and their families benefit from early review by a multidisciplinary team at the paediatric brachial plexus clinic and are given contact details for our named therapists in order to maintain a close relationship during their treatment. They are given the opportunity to ask questions and find out more information about their diagnosis and are actively involved in the care of the child, particularly through sharing of information and responsibility for exercises and therapy.

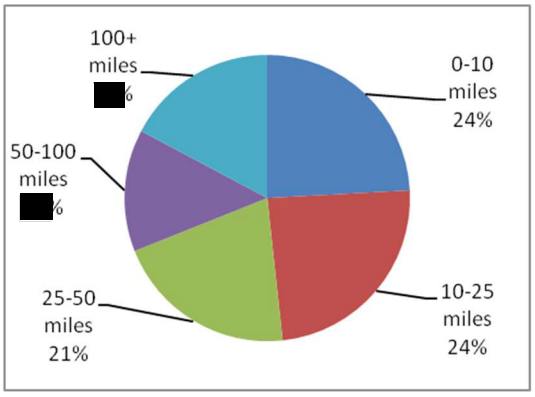
B5 c) User Surveys

Survey of patients attending the OBPI clinic at Royal Hospital for Children 2018

(*Survey Group = 30 patients*)

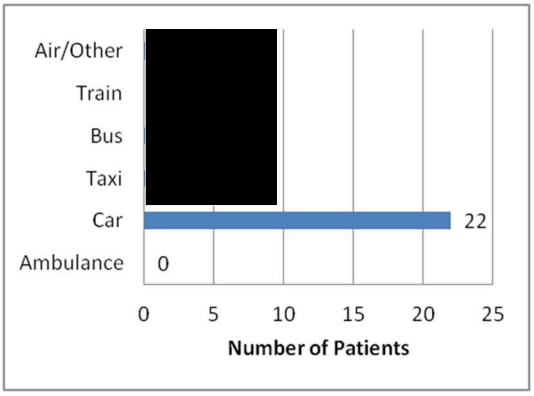
Q1: How far did you travel to the clinic (one way journey in miles)?

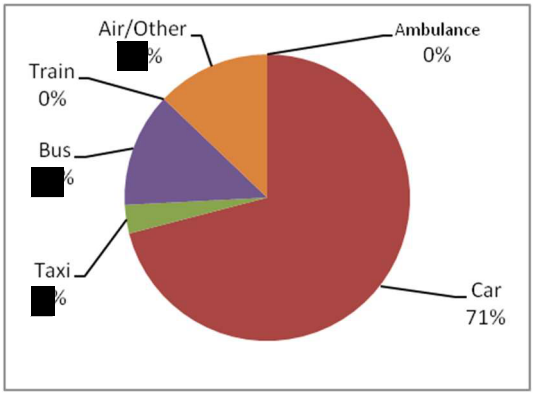




Comments:
[redacted]

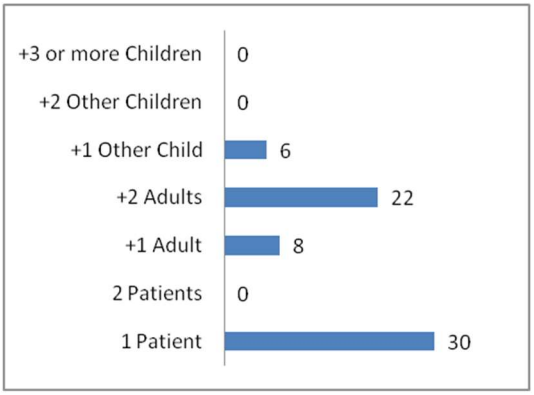
Q2: What mode of transport did you use?



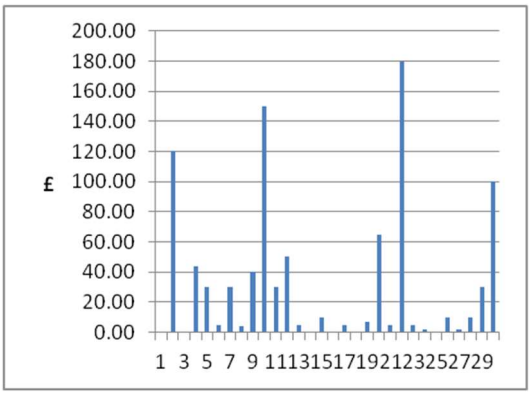


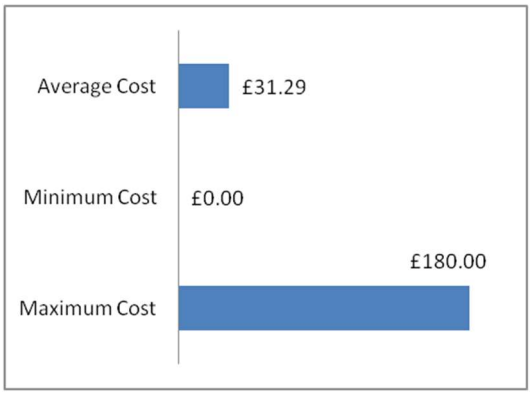
Comments:
[redacted]
[redacted] *patients] "Boat or Plane".*

Q3: How many came to the clinic?



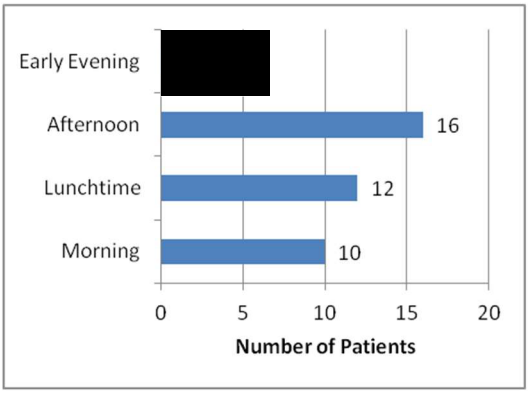
Q4: What would you estimate was the cost of attending the clinic?

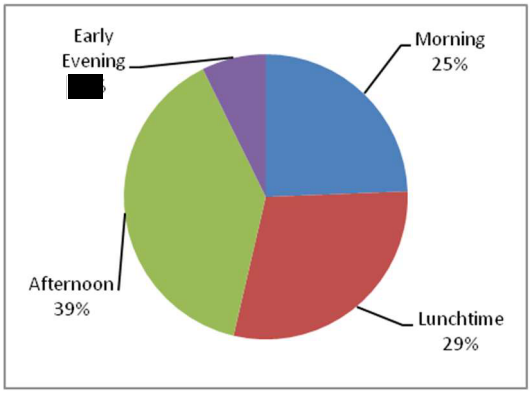




Comments:
[£150.00] "NHS Belfast pay flights & hotel".
[£50.00] "Travel costs reimbursed + some food allowance by local Trust."
[£0.00] "Paid by NHS Belfast."
[£7.00] "£5 to £7 in petrol."

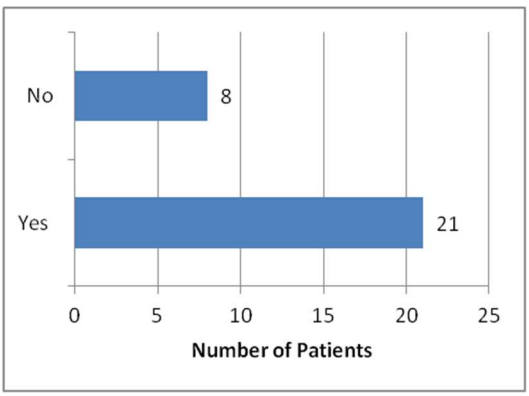
Q5: What time of day suits you best for the clinic?

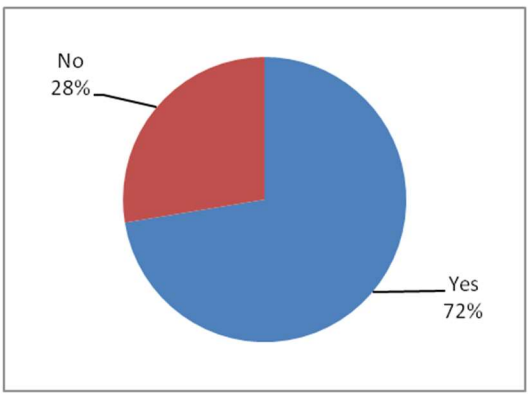




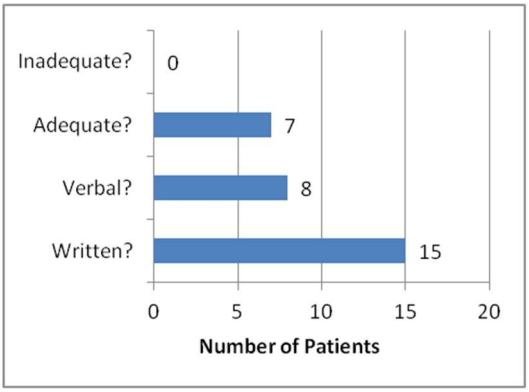
Comments:
"[Afternoon]...as flights are always delayed."
"An earlier in the afternoon appointment suits us to allow for return journey."
"Any"

Q6: Before you attended your appointment were you provided with any information on what would happen during the clinic?





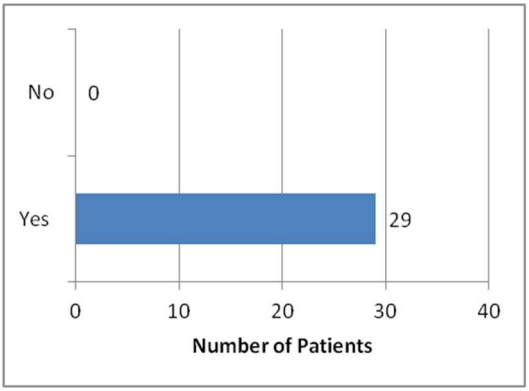
Q6A: If Yes was this information:

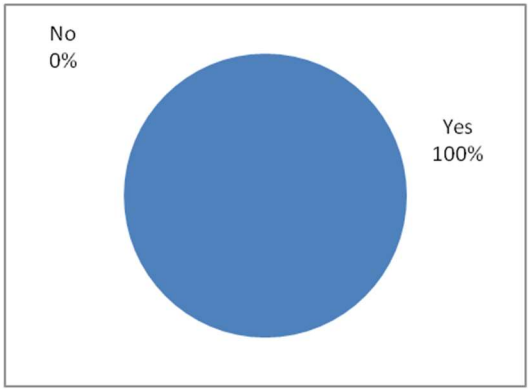


(Only 15 patients responded to this question.)

Comments:
"Letter."

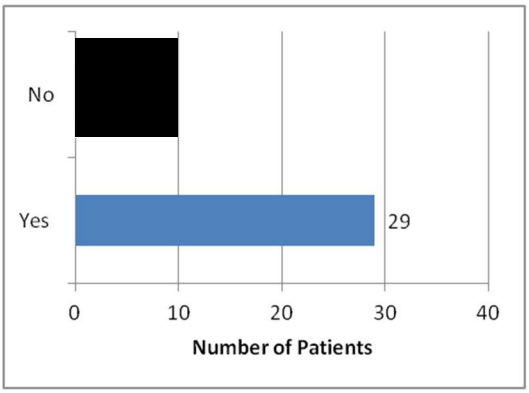
Q7: Do you feel that the Waiting Room was a suitable setting?

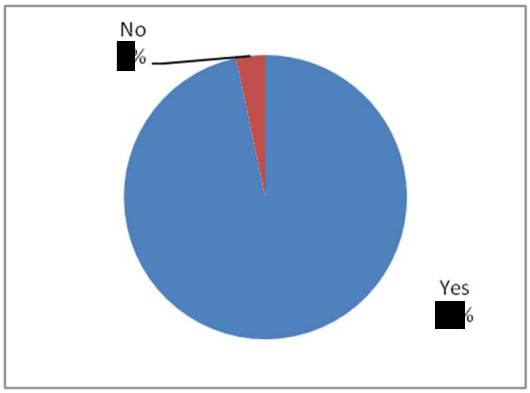




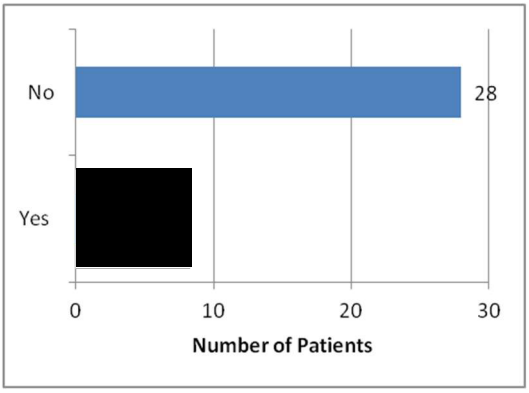
Comments:
"Excellent setting to entertain child while waiting. She never wants to leave!"

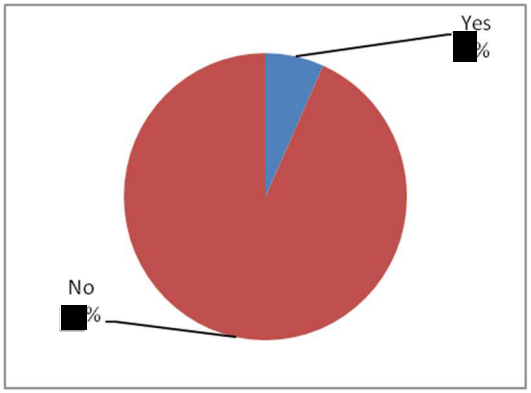
Q8: Were you introduced to the staff in your Clinic Room?





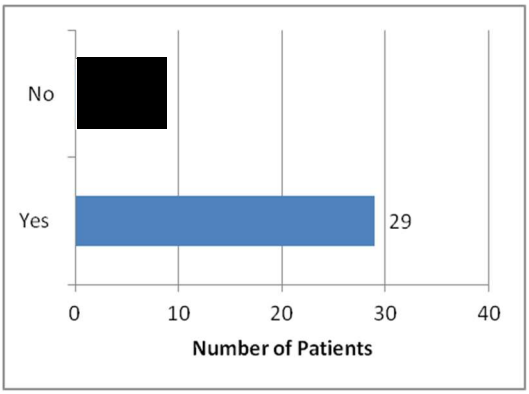
Q9: Were there too many individuals there at one time?

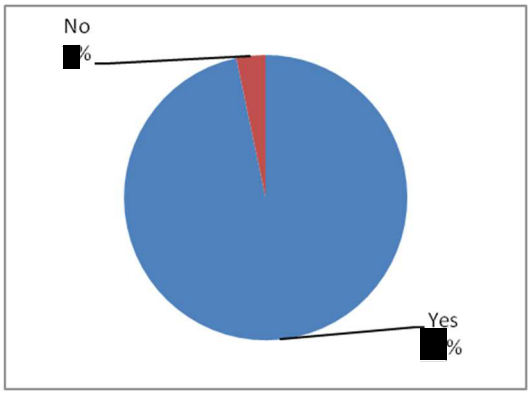




Comments:
[No] "Great approach by having doctor there then bringing in O.T./Physio as required. Child does not get overwhelmed."
[No] "But child goes shy on entry to room."
[Yes] "My son has autism"

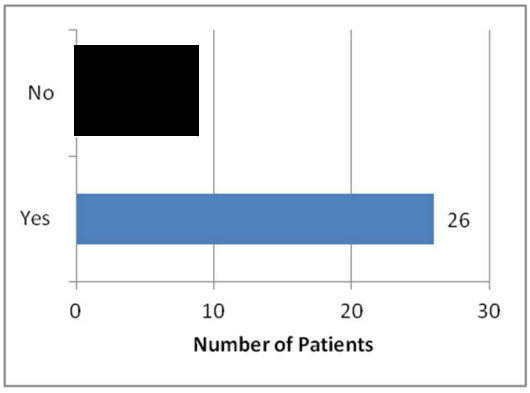
Q10: Do you feel that the Clinic Room was a suitable setting for the consultation and assessment of your child's function?

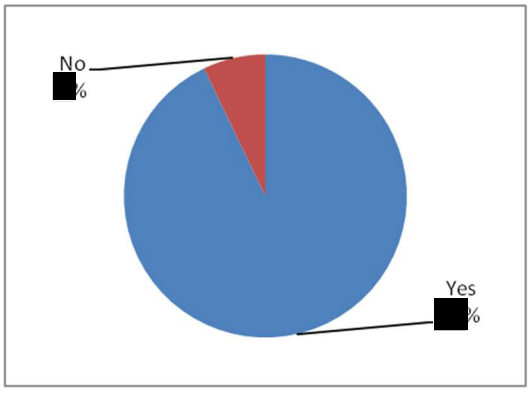




Comments:
[Yes] "Clinic room adequate size for all individuals and assessment."

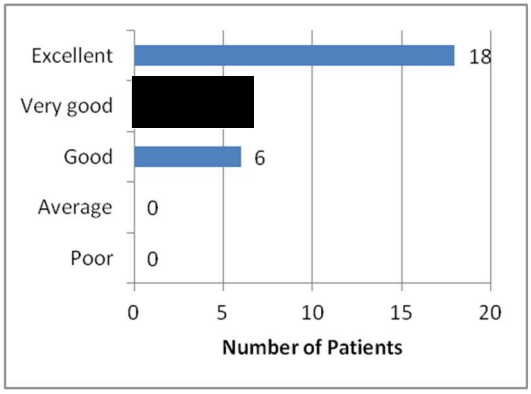
Q11: Did you have enough time to discuss your child's condition with the team members?

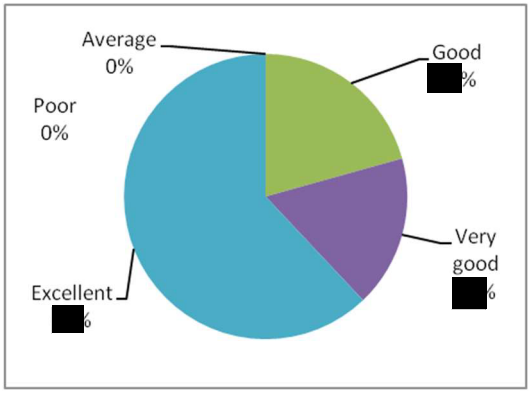




Comments:
[No] "Not really."
[Yes] "Never feel rushed at the clinic. Good amount of time given. This is important to us especially due to lengthy travel. Appointment feels worthwhile."

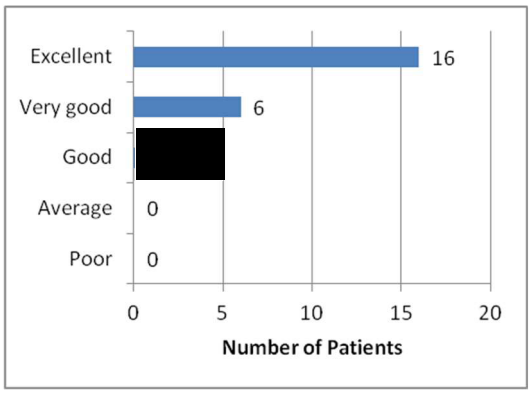
Q12: Overall how would you rate your child's care at the clinic?

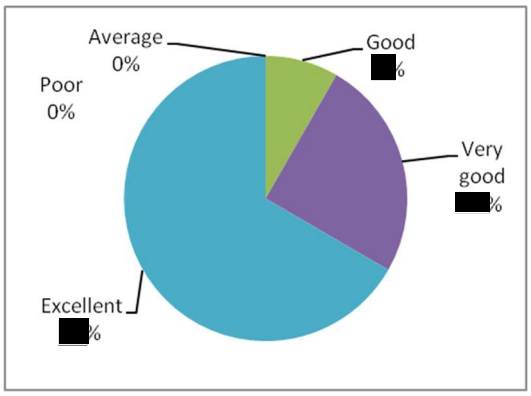




Comments:
"Child always looks forward to appointments. Staff are very kind and attentive to individual needs."
"Always excellent."

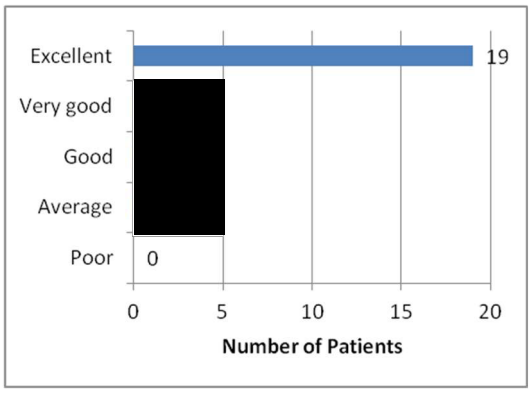
Q13: Overall how would you rate your child's care by Physiotherapy?

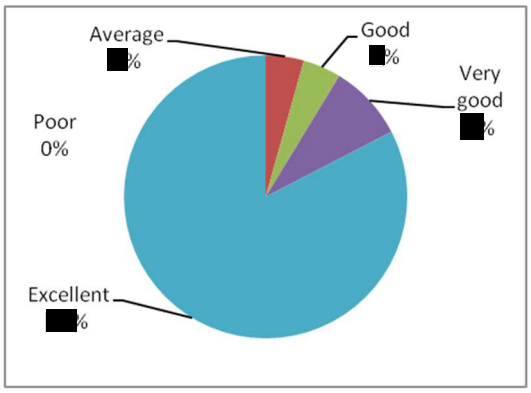




Comments:
"Again adequate time and care taken for individual circumstances."
"Always [excellent]"

Q14: Overall how would you rate your child's care by Occupational Therapy?





Comments:
"At last appointment a lot of care and attention was given to my child's needs as she had started school. Additional info and ideas were given to us to help her."

General Comments:

"Excellent Hospital & Staff"

"Service was very good. No complaints at all. I did not see an occupational therapist though."

"I think all staff are wonderful and really go above and beyond for my son. They are doing a great job and we look forward to our appointments."

"Unfortunately we waited over an hour for [my child]'s appointment which wasn't ideal given she was only a few months old, but everything to do with her care other than that has been excellent and I would not fault it. A big thank you to the team, you are fab."

"Could not rate this hospital, clinic and staff highly enough. We have always received top class care from [when] our daughter was only months old. It is always a long day of travel and prior planning for us but I have never come away feeling disappointed at care or time given. Prof Hart, Ms Murnaghan and all staff are all excellent care givers."

"Very pleased with how we are treated in Clinic 2. All staff extremely friendly and adore the child and always make him smile and laugh."

"All staff were excellent. Thank you!!"

B6 Equitable

B6 a) Fair for all: Equality & Diversity

The Scottish National Brachial Plexus Injury Service complies with NHS rules on Equality & Diversity in the appointment of staff. Similar care is taken in providing equal care standards to patients and relatives. Appropriate use of interpreters and awareness of cultural, ethnic and religious practices in regard to examination and interaction with parents is facilitated.

B6 b) Geographical access

Outreach Clinics

In order to assess and follow-up patients from the north east of Scotland a clinic was held at Aberdeen's Woodend Hospital in January 2018. Clinics are held approximately every 6 months, depending on demand and seem well received by the patients.

Adult brachial plexus patients and children are seen in the same clinic.

The need for clinics in other locations is kept under review.

Section C:

Looking Ahead/Expected Change/Developments

Psychological Support

The absence of dedicated clinical psychology input was identified from comparison with other services, and from assessment of patient and family care needs in discussion with families and the national patient support group (Erb's Palsy Group). A case for funding provision was previously submitted to NSD and after negotiations notification was received on 22/1/18 that approval was granted for 20% FTE (2 sessions/week) of Band 8a salary.

As with other professionals in the team this funding is routed to be part of a full job plan hosted by RHC (Glasgow). Dr Sue Robinson (Clinical Psychology Lead) liaised around the person and role specification. Agreement was reached that funding was insufficient for personal therapy delivery to the majority of patients and families and that greater care impact would be achieved by directing the position at these deliverables:

1. Early Phase:

    a. Building a professional support network with clinical psychologists already active in the field.

    b. Developing a set of screening tools appropriate for use in this patient group (Patient and Family) at differing phases of care in order to profile care needs and set baselines against which to measure interventions:
        i. Time of diagnosis, information processing, and prognostic uncertainty
        ii. Bonding, parental guilt/blame attribution, relationship stressors between parents
        iii. Decision making issues around nerve surgery
        iv. Decision making around secondary surgery (e.g. shoulder procedures)
        v. Parental and patient concerns around long-term physical, holistic, employment, and body image outcomes
        vi. Schooling
        vii. Peer interactions, positive and negative images, bullying
        viii. Psychosexual development
        ix. Anxiety and depression
        x. Building compliance with therapy interventions

    c. Familiarisation with the social, surgical, and therapy needs of this group, management pathways, and the Scottish service model.

2. Interim Phase:

    a. Building a descriptive/quantitative picture of the psychological morbidity/welfare of patients and families.

    b. Building a network of local clinical leads in all regions across Scotland, and educating in best practice for this patient group.

    c. Developing systems for local delivery of care packages/screening assessments.

    d. Targeting key areas for future interventional studies.

e. Formalising systems for outcome reporting, and monitoring care need, and equity of provision across Scotland.

f. Principle care delivery for a small number of more severe cases.

3. Long-term role:

a. Building clear position as a national lead for this condition, with a high profile amongst clinical psychologists nationally and internationally.

b. Research and quality improvement activity, with output through local, national, and international meetings / publications.

c. Building educational packages for patients and families.

d. Developing preventative care strategies and monitoring implementation.

e. Education of clinical psychologists, AHPs, midwives and neonatologists.

f. Quality improvement activity.

The post was combined with a local service post in RHC and advertised promptly. Six applicants were assessed by the SNBPIS and briefed on the job description and person specification prior to interview by the Psychology Service. Of these, four were excellent candidates with strong records in relevant areas. One has been appointed, Helen Lowther, to come into post on 23rd July after completing a period of maternity leave.

Induction meetings are being arranged, with close liaison between senior psychologists prior to the candidate's start date. The need to ensure that time allocated for brachial plexus work is ring-fenced, irrelevant of local service needs, has been agreed and should be included in reporting to NSD.

Patient Information

Information on OBPI for parents has been included in the new website. Availability of this information seems to have been well-received by the parents and we have decided to direct patients towards this valuable source of information rather than trying to produce a leaflet which could be distributed in the outpatient department.

Contact has been made with the Glasgow School of Art to begin preparing an animated patient and a parent information media platform. This will be developed in further meetings with Dr Brian McGeough, and patient/parental representation to a development group agreed by the Erb's Palsy Group.

Electronic Patient Record (EPR)

Introduction of an electronic patient record in NHS Greater Glasgow & Clyde has presented a challenge to the service. The EPR currently doesn't provide an equivalent method of recording information, including consecutive measurements on brachial plexus patients to replace the paper records. The methods of documenting patient information, monitoring activity, assessing function, and recording outcomes for the brachial plexus service are under review.

We have met with the EPR development team and requested that specific E-forms for the service can be developed for inclusion in the EPR.

International Collaboration

Following the Narakas meeting in Barcelona in 2016 we plan to collaborate with other centres worldwide, for the iPLUTO project (International Plexus Outcome Study Group), an initiative hosted by the plexus service in Leiden, Netherlands.

The goal of the iPLUTO study group is to define a universal dataset to evaluate upper limb function of children with a neonatal brachial plexus palsy, pooling results to enable multicentre studies. This study should help to create an international standard on how to evaluate the condition and express results of treatment. We have contributed details of our evaluation system, which is regarded as very comprehensive, to the group designing the study, and responded to the online surveys regarding the outcome data which should be recorded.

A recent publication from the study group has defined an agreed minimum set of measurements of passive and active movements of upper limb joints, together with the Mallet shoulder score, which should be recorded at ages 1, 3, 5 and 7. We are already recording most of these measurements.

After fitful attempts over the past years, a U.K.-Scandinavian Brachial Plexus Workshop was established, initially between the Scottish Service and the new Swedish National Service who's structuring featured input from the Scottish Service (AH). This grouping now involves the majority of major UK centres (Scotland, Leeds and Stanmore) and key Baltic nations (Norway, Denmark, Sweden, Finland and Lithuania). It should become a forum for case discussion and service process optimisation, while also raising opportunities for CPD research and training exchange. The inaugural meeting was held in Stockholm in May 2017. Both Andy Hart and Tim Hems attended this meeting and contributed cases to the discussions. The event proved both enjoyable and very informative, highlighting new possible areas of development including increased use of MRI for diagnosis and delayed nerve transfers for children with slow recovery of shoulder movement.

Links with Other Centres, Nationally

In 2017 TH and CFM followed a patient pathway from the service here in Glasgow to a service at RNOH, Stanmore (funded by NSD) in order to observe a complex operation performed there by the team who described the procedure. We were able to discuss their service delivery and operative and non-operative strategies for patients with similar problems and hope to offer similar surgery in Scotland in the near future.

AH maintains close links with the service in Leeds regarding nerve surgery and secondary reconstruction.

We have also established links with Mr Jim Ballard (Consultant Orthopaedic Surgeon at Musgrave Park Hospital and the Royal Belfast Hospital for Children) who is in the process of setting up an appropriate service of paediatricians, obstetricians and therapists in Northern Ireland to ensure early capture of affected babies and their early assessment by skilled clinicians. This group includes members of parent support groups in the province as there has been no structured formal referral system in the past. Mr Ballard is playing a pivotal role in establishing national guidelines for their pathway (with input and advice from CFM).

Section D:

Summary of Highlights (Celebration and Risk)

Family Study Day 3rd June 2017

A very successful patient and family day was organised in conjunction with the Erb's Palsy Group at Glasgow Science Centre on Saturday 3rd June 2017. A full report on this event is attached as an appendix. Strongly positive feedback has been received regarding the Scottish Service from the Erb's Palsy Group.

Summary

The service has remained busy over the last year with many children requiring input from members of the multidisciplinary team. More nerve exploration procedures have been performed. We are grateful for the support from the management team, theatre and anaesthetic staff and Neurology/Neurophysiology for their support in carrying through these complex cases.

Appendix

Teaching and Training Activity

Tim Hems

Teaching

3rd June 2017 — Children's Brachial Plexus Parent Day, organised by the Erb's Palsy Group and the Scottish National Brachial Plexus Team. Glasgow Science Centre.

Talks on:-

"Development of the Scottish National Children's Brachial Plexus Injury Service."

"OBSTETRIC BRACHIAL PLEXUS INJURY: Current Evidence on Nerve Surgery."

13th March 2018 — Edinburgh Hand Surgery Course:

- "Principles of management of Peripheral Nerve Injury".
- "Management of Brachial Plexus Injuries".
- "Principles of Tendon Transfer".
- Small group teaching on clinical examination of upper limb neurology.

Education

27/4/17 – 28/4/17 — British Society for Surgery of the Hand, Spring Meeting, Bath (presented paper).

19/5/17 – 20/5/17 — Scandinavian and UK Brachial plexus workshop, Stockholm (case presentation and discussion for traumatic and obstetric brachial plexus injury).

21/6/17- 23/6/17 — Federation of European Societies for Surgery of the Hand, Congress, Budapest (presented paper).

Andy Hart

(Detailed in the Adult Service report)

Claire Murnaghan

Teaching

13/06/17	MSK group teaching of GPs of core trainees in Paediatrics.
07/09/17	STOTS meeting, Dunblane.
16/01/18	Unit teaching of Neonatal Brachial Plexus Injuries.