SCOTTISH NATIONAL OBSTETRIC BRACHIAL PLEXUS INJURY SERVICE

Annual Report 2019/20

NHS Greater Glasgow & Clyde

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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: [redacted]@nhs.net

Executive Summary

The Children's Brachial Plexus Injury Service is based at the Royal Hospital for Children (surgery and clinics) and the New Victoria Hospital (administration) within NHS Greater Glasgow & Clyde.

The Children's Service became a designated National Service for Scotland in April 2006.

The brachial plexus is a complicated network of nerves which controls the muscles in the shoulder, arm, elbow, wrist, hand and fingers, as well as providing them with feeling.

In children brachial plexus injury usually occurs during birth. It can also occur as a result of traumatic brachial plexus injury (e.g. falls, road traffic accidents, sporting accidents) or tumours involving the brachial plexus.

Children are referred from throughout Scotland by maternity units, paediatricians, orthopaedic surgeons, or plastic surgeons who have carried out initial assessment. Referrals are also accepted from Northern Ireland and occasionally from the north of England.

The service provides assessment, intervention, treatment and outpatient follow-up care for patients through an integrated multidisciplinary service for obstetric brachial plexus injury, traumatic brachial plexus injury, and tumours involving the brachial plexus, including:-

- Diagnosis: clinical examination, MRI, ultrasound, neurophysiology.
- Surgery: early surgical exploration and nerve repair; secondary reconstruction for shoulder and other deformities.
- Physiotherapy.
- Occupational therapy.
- Psychological support.

In 2019/20 the service undertook the following activity for patients from across Scotland:

- **34** assessments.
- [redacted]procedures (including [redacted] primary operations such as nerve explorations and nerve reconstructions and [redacted]secondary operations such as tendon transfers).
- **189** follow-up appointments.

The onset of the Coronavirus pandemic in March 2020 presented a particular challenge for the service. The initial response to the situation is included in the report.

Further details can be found on the dedicated website at
https://www.brachialplexus.scot.nhs.uk

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1. Service Delivery

The Obstetric Brachial Plexus Injury Service (OBPIS) provides integrated multidisciplinary management for obstetric brachial plexus injury, traumatic brachial plexus injury, and tumours involving the brachial plexus including:

- Diagnosis: clinical examination, MRI, ultrasound, neurophysiology.
- Surgery: early surgical exploration and nerve repair; secondary reconstruction for shoulder and other deformities.
- Physiotherapy.
- Occupational Therapy.
- Psychological support.

Target Patient Group

Children with obstetric brachial plexus injury are the main group managed by the service.

Patients with traumatic brachial plexus injury or benign or malignant tumours involving or arising from the brachial plexus are also seen.

Patients are typically referred by neurologists, paediatricians, orthopaedic surgeons, or plastic surgeons.

In the year 2019/20 a total of **30** children with suspected obstetric brachial plexus injury were referred to the service. [redacted] were referred with a traumatic brachial plexus injury. Most were referred from within Scotland, with [redacted] patients referred from Northern Ireland.

[redacted] was given advice or referred back to local services as being outwith the remit of the Obstetric Brachial Plexus Injury Service.

Referral Process

Referral forms are available on the service website and are emailed or posted to the administration office. Referral letters are also accepted provided the referring Health Board provides sufficient background information on the injury. Patients can also be referred by their general practitioner via the electronic GP Gateway.

Patients are usually referred by paediatricians, orthopaedic surgeons or plastic surgeons who have carried out initial assessment, after which the Obstetric Brachial Plexus Injury Service provides assessment, intervention or treatment, and outpatient follow-up care for patients.

Description of Service/Care Pathway

Clinical Assessment

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.

Care Plan

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 and optimal handling, age-specific sensorimotor developmental assessments, activity-based interventions, provision of aids, fit-for-schooling assessment, school visits and educational liaison role), psychological optimisation (screening assessment, to arrange therapeutic intervention where appropriate, primarily addressed at the parents' needs during infancy, and the child's needs during later development), investigations when necessary (neurophysiology, imaging studies), and monitoring of progress (developmental milestones, school progression, body-image development, pain, psychosocial welfare, fit-for-life).

Clinical Psychology

A clinical psychologist was appointed to the service in summer of 2018 and is contributing to the above. The clinical psychologist undertakes screening assessment and therapeutic support both during clinics and outwith clinic times (either on an on-one basis or with telephone consultations), and can liaise with local services where capacity is available.

Surgical Intervention

Surgical decisions on nerve surgery and prophylactic shoulder interventions are made at 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.

Continuation of Care

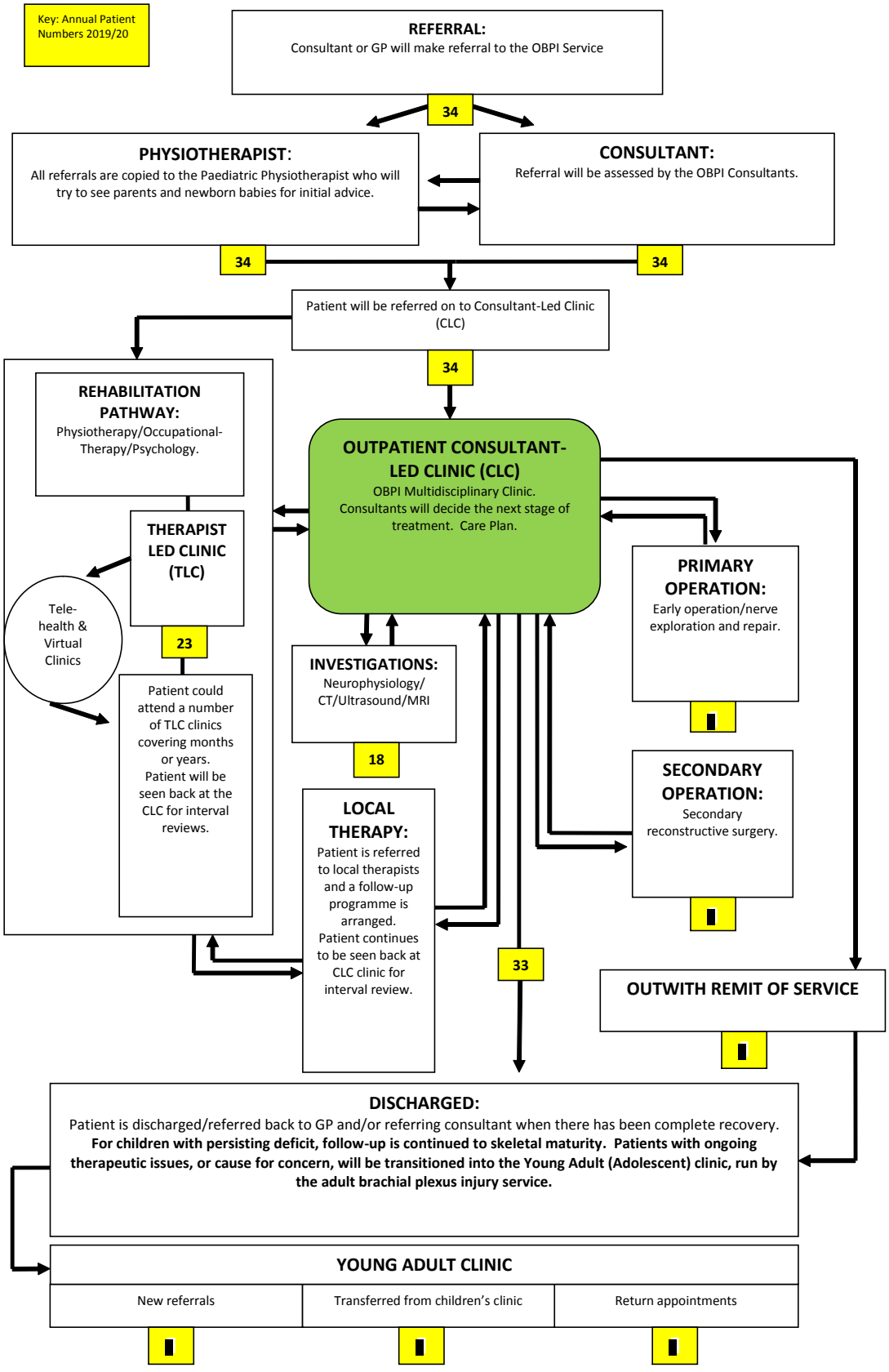
Children with persisting deficit are followed up in outpatients at least until skeletal maturity.

Patients who live in the north of Scotland can be seen for a review appointment at outreach clinics held at Woodend Hospital in Aberdeen up to twice per year.

Patients can be transitioned into the Young Adult Clinic once they are deemed to have reached an appropriate level of physical and cognitive development, and if they have ongoing issues best addressed through adult services.

(See flowchart on next page)

Obstetric Brachial Plexus Injury (OBPI) - Patient Pathway



2. Activity Levels

Referrals and Interventions

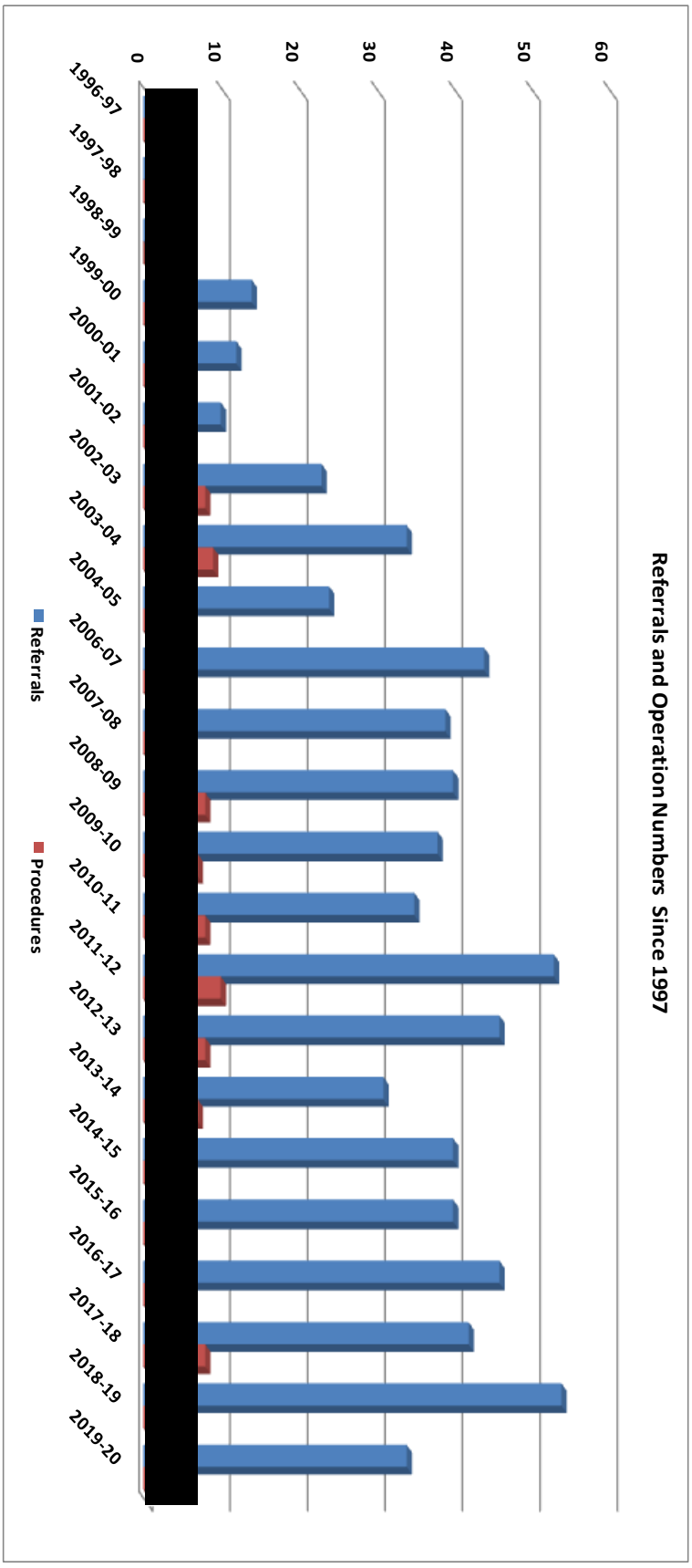
Referrals and Interventions				
	SA Level	**2019/20**	**2018/19**	**2017/18**
New patient referrals				
Referrals received	*40*	**34**	**54**	**45**
Referral does not meet criteria		**0**	[redacted]	[redacted]
Assessments				
Accepted for treatment by service	*30*	**34**	**52**	**42**
Did not attend (DNA)		[redacted]	**0**	[redacted]
Discharged following first assessment		**17**	**30**	**25**
Discharged from treatment		**31**	**34**	**36**
Outpatient Follow-Up Appointments	*190*	**189**	**169**	**161**
Intervention /procedures				
Nerve		[redacted]	[redacted]	[redacted]
Other (shoulder/elbow)		[redacted]	[redacted]	[redacted]
Total Procedures:	*7*	[redacted]	[redacted]	**8**
Ward Bed Days				
HDU/ITU		**0**	[redacted]	[redacted]
Nerve Surgery		**7**	**10**	**22**
Other Surgery		**6**	**9**	[redacted]
Total Ward Bed Days		**13**	**20**	**31**
Day Cases		[redacted]	**0**	[redacted]
Average length of stay for inpatients (days)		[redacted]	[redacted]	[redacted]

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

Trends in Activity (1)

Referrals and Operation Numbers Since 1997		
Year	Referrals	Surgical Procedures
1996-97	6	[redacted]
1997-98	[redacted]	[redacted]
1998-99	[redacted]	0
1999-00	14	[redacted]
2000-01	12	[redacted]
2001-02	10	[redacted]
2002-03	23	8
2003-04	34	9
2004-05	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
2018-19	54	[redacted]
2019-20	34	[redacted]
Total:	713	125

Trends in Activity (2)



Diagnostics

Neurology/Neurophysiology

A consultant neurologist provides clinical assessment for some of our patients, along with neurophysiology investigations, which is particularly useful in those who may require surgical intervention.

A dedicated OBPI/Neurology appointment slot is available at the start of every OBPI consultant-led clinic to cater for urgent brachial plexus patients. This arrangement has proven to be very beneficial to the service and means that referrals to Neurology can be expedited via the appointments office without affecting the consultant neurologist's pre-existing neurology patients.

Location of Children's Neurology

The Neurology clinics are held in the outpatient department of the Royal Hospital for Children in Glasgow on a Monday.

Neurophysiology Activity (within NHS GG&C)			
	2019/20	2018/19	2017/18
Assessments	6	12	13
Maximim Wait (Weeks)	10	11	14
Minimum Wait (Weeks)	[redacted]	0	0
Median Wait (Weeks)	[redacted]	[redacted]	7
Did not attend (DNA)	0	0	[redacted]

Neurophysiology Activity (carried out in other centres)			
Assessments	[redacted]	[redacted]	0
Maximim Wait (Weeks)	0	0	0
Minimum Wait (Weeks)	0	0	0
Median Wait (Weeks)	0	0	0
Did not attend (DNA)	0	0	0

[redacted] *assessment arranged prior to referral as part of the patient's care plan*.

[redacted] patients were seen at NHSGG&C Neurology on the same day as their OBPI/Erb's clinic review to minimise travel. [redacted] was seen at NHSGG&C Neurology the day after their first review to save making two trips to Glasgow.

Imaging/Radiology

X-Ray, CT, MRI and Ultrasound

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.

Radiology Activity (within NHS GG&C)			
	2019/20	**2018/19**	**2017/18**
MRI	[redacted]	[redacted]	*
CT scan	[redacted]	[redacted]	*
Ultrasound	[redacted]	[redacted]	[redacted]
Total Imaging	**7**	**8**	*
Maximim Wait (Weeks)	**4.4**	**3.4**	*
Minimum Wait (Weeks)	**0.0**	**0.0**	*
Median (Weeks)	**0.7**	**0.0**	*
Did not attend (DNA)	**0**	**0**	*

Radiology Activity (carried out in other centres)			
	2019/20	**2018/19**	**2017/18**
MRI	[redacted]	[redacted]	*
CT scan	**0**	**0**	*
Ultrasound	**0**	**0**	*
Total Imaging	[redacted]	[redacted]	*
Maximim Wait (Weeks)	**0**	**0**	*
Minimum Wait (Weeks)	**0**	**0**	*
Median (Weeks)	**0**	**0**	*
Did not attend (DNA)	**0**	**0**	*

**Imaging activity was not previously routinely recorded on the children's service database.*

X-rays continue to be routinely provided at clinic when necessary and are outwith the scope of the above tables.

3. Performance and Clinical Outcomes

3.1 Equitable

NHS Board for Referrals

NHS Board for Referrals						
	2019/20	% of total	**2018/19**	% of total	**2017/18**	% of total
Ayrshire and Arran	**0**	0	**0**	0	**0**	0
Borders	**0**	0	**0**	0	**0**	0
Dumfries and Galloway	**0**	0	**0**	0	**0**	0
England	**0**	0	**0**	0		
Fife	**0**	0				
Forth Valley						
Grampian						
GG&CHB	**18**	53	**30**	56	**18**	43
Highland			**0**	0		
Lanarkshire			**11**	20	**8**	19
Lothian						
Northern Ireland	**6**	18				
Orkney	**0**	0	**0**	0		
Shetland	**0**	0	**0**	0	**0**	0
Tayside	**0**	0				
Western Isles	**0**	0	**0**	0	**0**	0
Total:	**34**	100	**54**	100	**42**	100

Distribution of Referrals

Referrals remain well distributed from around Scotland. The referrals from Greater Glasgow and Clyde were thought to be appropriate for the Obstetric Brachial Plexus Injury Service. There has been an increase in referral from Northern Ireland.

Travelling to Clinics

Information on how to claim travel expenses is routinely issued to new patients with their first appointment letter and highlighted on the service website. This is to encourage patients from outlying areas to attend clinics in Glasgow without encountering prohibitive financial constraints.

NHS Board for Inpatient Procedures

NHS Board for Admissions						
	2019/20	% of total	**2018/19**	% of total	**2017/18**	% of total
Ayrshire and Arran	**0**	0	**0**	0	**0**	0
Borders	**0**	0	**0**	0	**0**	0
Dumfries and Galloway	**0**	0	**0**	0	**0**	0
England	**0**	0	**0**	0	**0**	0
Fife	**0**	0	[redacted]	[redacted]	**0**	0
Forth Valley	[redacted]	[redacted]	**0**	0	**0**	0
Grampian	[redacted]	[redacted]	**0**	0	**0**	0
GG&CHB	[redacted]	[redacted]	**0**	0	[redacted]	[redacted]
Highland	**0**	0	**0**	0	**0**	0
Lanarkshire	**0**	0	**0**	0	[redacted]	[redacted]
Lothian	**0**	0	[redacted]	[redacted]	[redacted]	[redacted]
Northern Ireland	**0**	0	[redacted]	[redacted]	[redacted]	[redacted]
Orkney	**0**	0	**0**	0	**0**	0
Shetland	**0**	0	**0**	0	**0**	0
Tayside	**0**	0	**0**	0	**0**	0
Western Isles	**0**	0	**0**	0	**0**	0
Total:	[redacted]	[redacted]	[redacted]	[redacted]	**8**	100

Outreach Clinics

Aberdeen

The Aberdeen outreach clinic was set up to improve assessment and follow-up for patients in the north of Scotland. Utilisation of these clinics is variable. Both children and adults are seen at these clinics. The need for outreach clinics is kept under review according to the numbers of patients in each area.

An outreach clinic was held in Aberdeen in October 2019. [redacted] patients were seen ([redacted] children and 7 adults). All of the child patients were return appointments. The next clinic is planned for autumn 2020.

Campbeltown

One long term patient was seen in the orthopaedic outreach clinic in Campbeltown. The patient's family had difficulties with travelling to Glasgow and had missed some review appointments. An OBPI consultant was attending this clinic to see routine Orthopaedic patients as a once-yearly commitment. It is hoped the patient will be followed up at this clinic in the future.

3.2 Efficient

Efficient

a) Actual v Planned Activity

See Section 2: Activity Levels

b) Resource Use

See other parts of the report.

c) Finance & Workforce

See Section 6: Financial report and workforce

d) Targets (Referral to appointment to treatment)

See Section 3.3: Timely

3.2.1 Cost efficiencies

Not applicable.

3.3 Timely

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 **4.9** weeks and the median was **4.6** weeks (range **0** to **15.4** weeks).

Time from Referral to Treatment			
	2019/20	**2018/19**	**2017/18**
% within target	**68**	**85**	**79**
Maximum Wait (weeks)	**15.4**	**12.0**	**13.6**
Minimum Wait (weeks)	**0.0**	**0.0**	**0.4**
Median Wait (weeks)	**4.6**	**3.6**	**3.9**

NOTE: the maximum wait of 15.4 weeks relates to one older child from Northern Ireland with an historic injury and no immediate surgical options, requiring mainly therapy input and support; the family preferred to wait for a convenient appointment. Of the [redacted] patients seen outwith the 6 week target 9 were seen within 8 weeks and [redacted] were seen within 16 weeks. [redacted] of these [redacted] patients were from Northern Ireland.

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

Age at First Review (Weeks)				
	SA Level	**2019/20**	**2018/19**	**2017/18**
Maximum Age	*8*	**833.7**	**704.9**	**669.0**
Minimum Age		**1.1**	**0.3**	**1.3**
Median Age		**7.2**	**7.4**	**8.9**

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.

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

   Of the [redacted] nerve-surgery cases during 2019-20 one was an obstetric brachial plexus injury and surgery was carried out by age 6 months. The other case was [redacted] with a traumatic brachial plexus injury and surgery was carried out within days of injury.

   Prompt theatre access remains difficult within RHC, although senior management support has been of critical assistance when needed, and is greatly appreciated.

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

   All clinic letters and operation notes were typed and checked within a few days of dictation.

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

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

3.4 Effectiveness

A full report on OBPP Nerve Exploration/Repair Cases 2004 to 2017 was carried out in 2017-18.

(Please see section B2 a) of the 2017-18 report)

3.5 Safe

Staff Vetting

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.

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 2019-2020.

Compliance

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 2019-20.

Child Protection

Child protection level 1 LearnPro was completed by all staff.

Child Protection level 2, risk assessment, maltreatment in infants LearnPro was completed by Prof. Hart, Miss Murnaghan, & Mr Hems.

Miss Murnaghan has Child Protection training to Level 3 and has completed all mandatory Paediatric training modules on NES and LearnPro, plus she is registered with the Royal College of Paediatrics and Child Health.

Safe Transfusion Practice for Paediatrics completed by Prof. Hart & Miss Murnaghan.

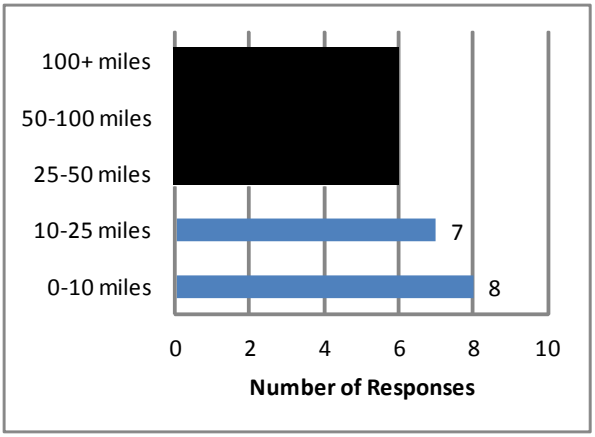
3.6 Person centred

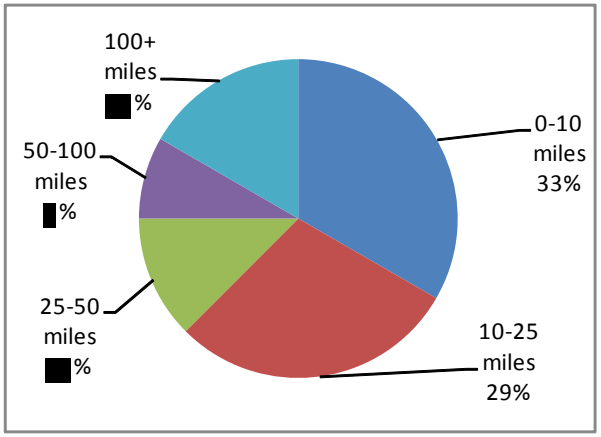
Patient Satisfaction Surveys

Consultant-Led Clinic

Patient Satisfaction Survey 2019-20
OBPI Consultant-Led Clinic
[Sample Group = 24]

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

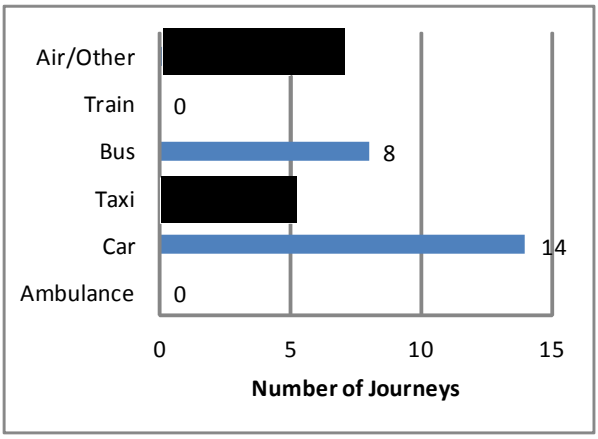


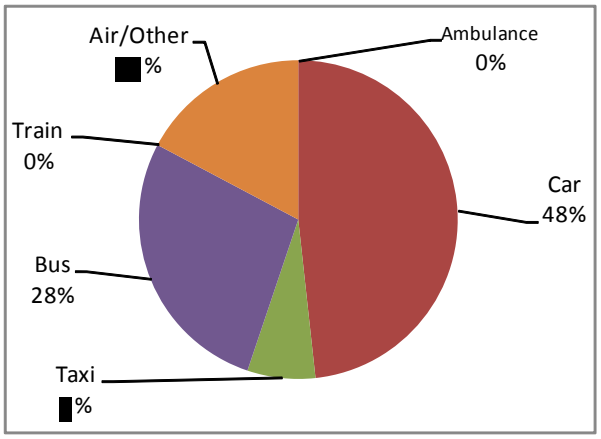


Comments

Coming fom Northern Ireland

Q2: What mode of transport did you use?

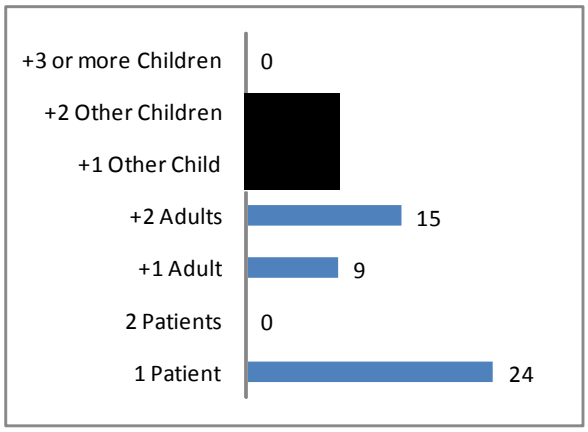




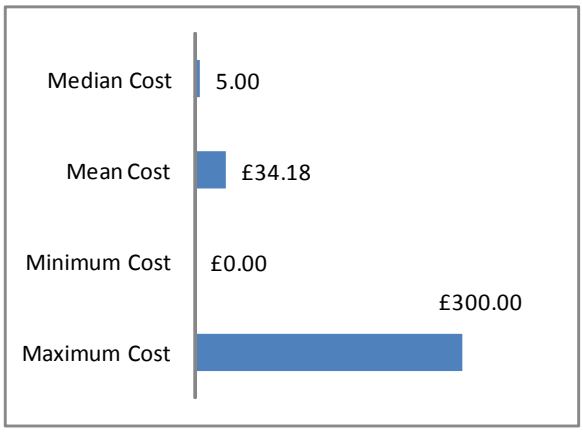
Comments

Aeroplane
Car, Bus & Plane
Plane & Bus
Taxi + Aeroplane
Bus + Flight

Q3: How many came to the clinic?



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

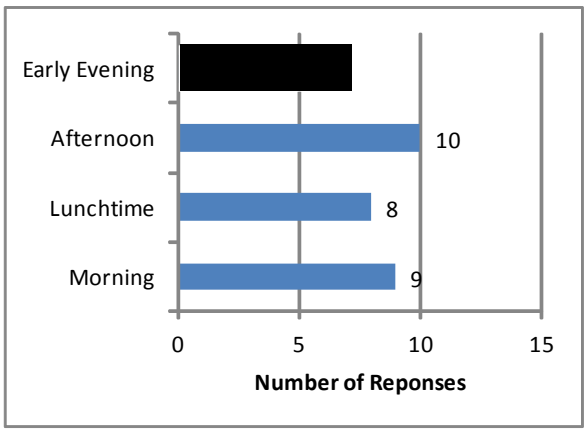


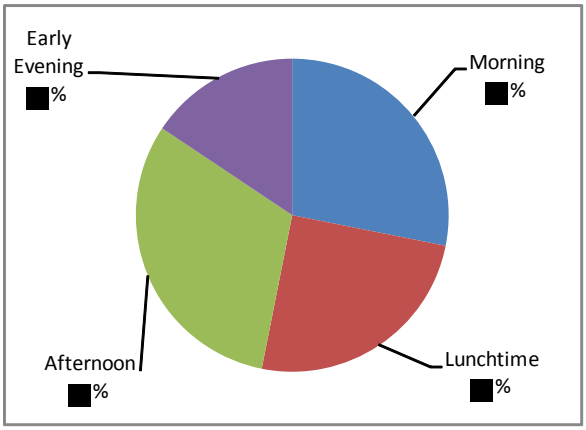
Comments

Don't know

Cost covered by NHS as no service available in N Ireland

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



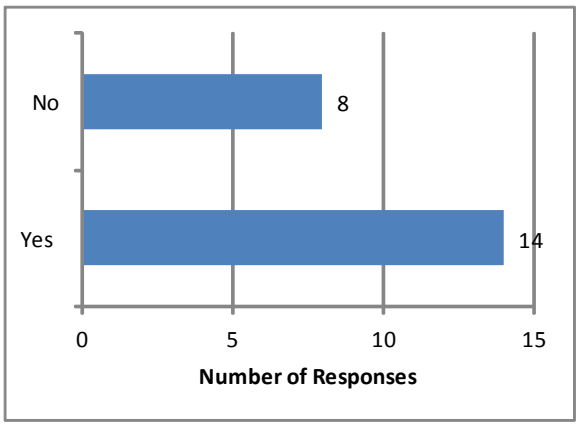


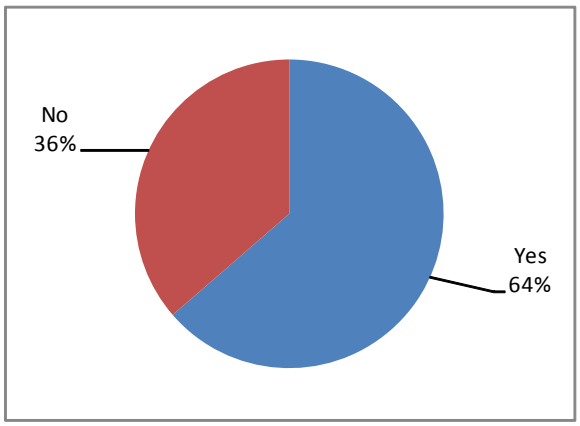
Comments

Any time on a Monday

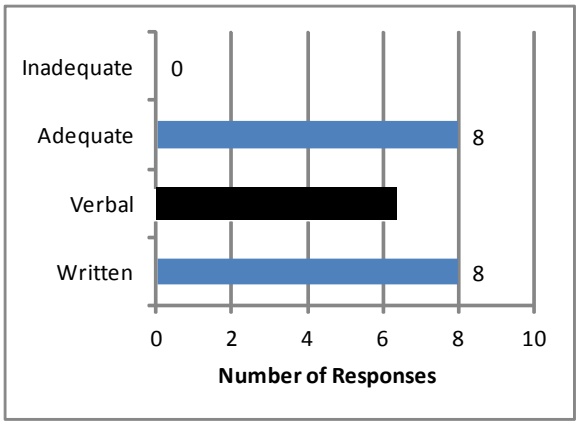
No preference

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





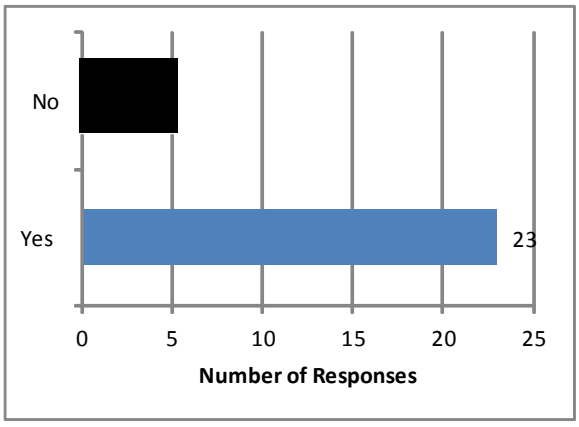
Q6A: If Yes was this information:

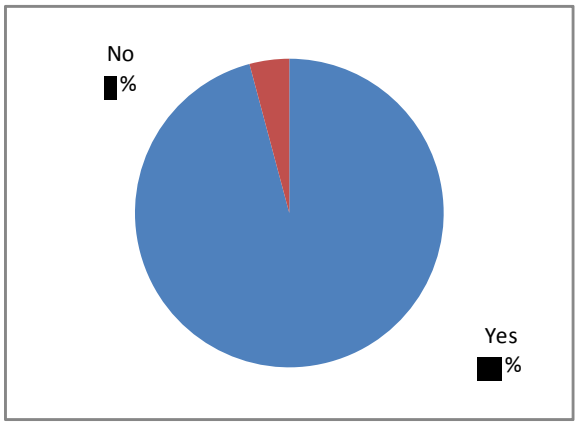


Comments:

Annual consultation

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

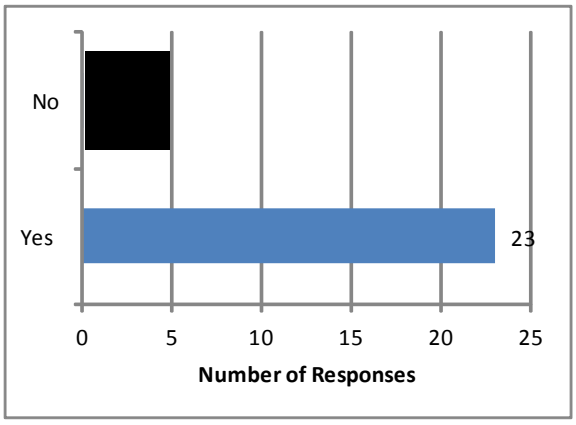


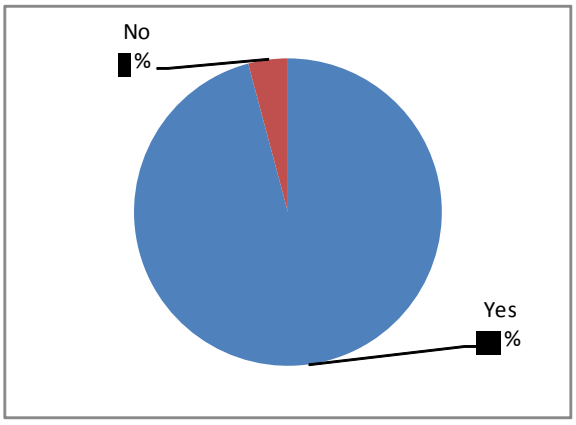


Comments

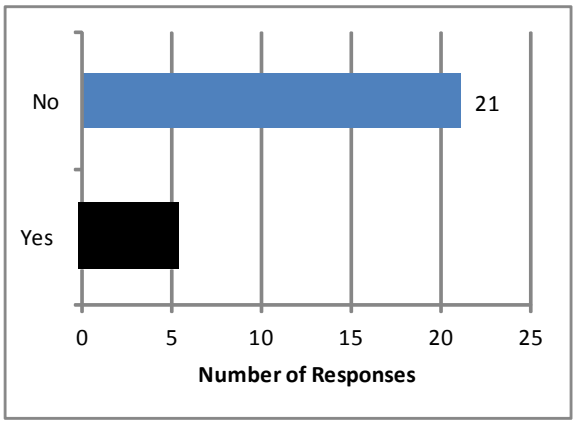
Sometimes

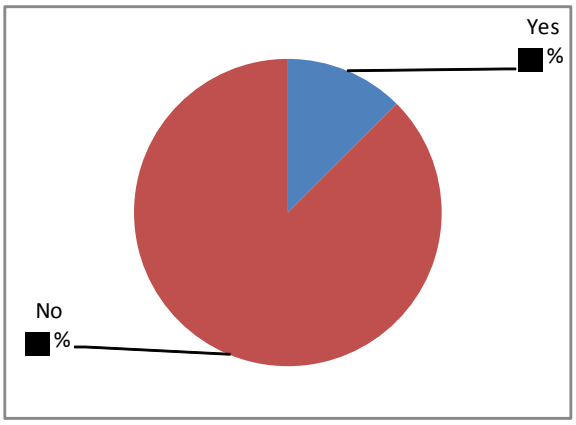
Q8: Were you introduced to the staff in your Clinic Room?





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

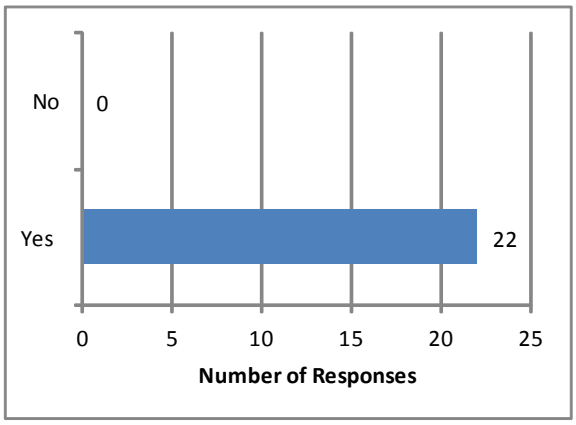


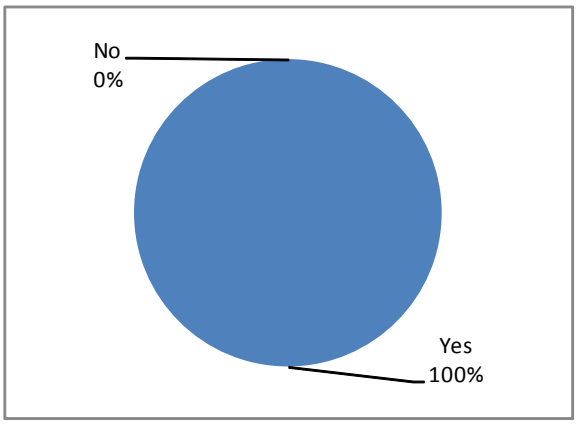


Comments

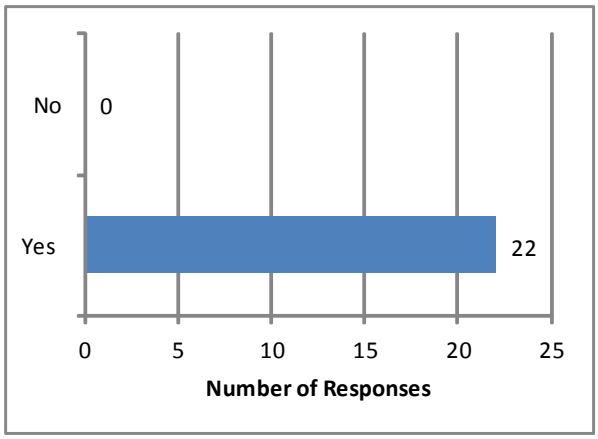
At times there can be a lot of people in the room. More when he was a baby.

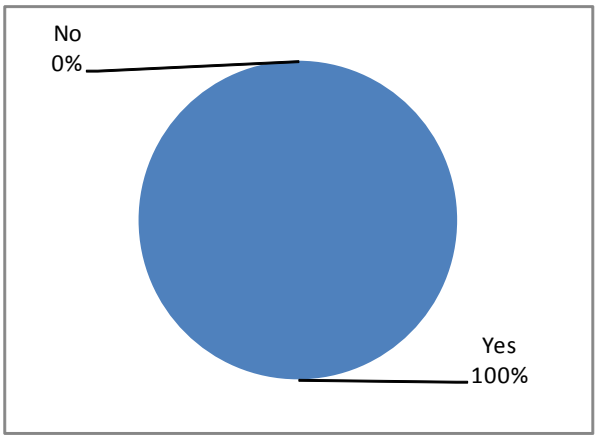
Q10: Do you feel that the Clinic Room was a suitable setting for the consultation and assessment of your child's function?



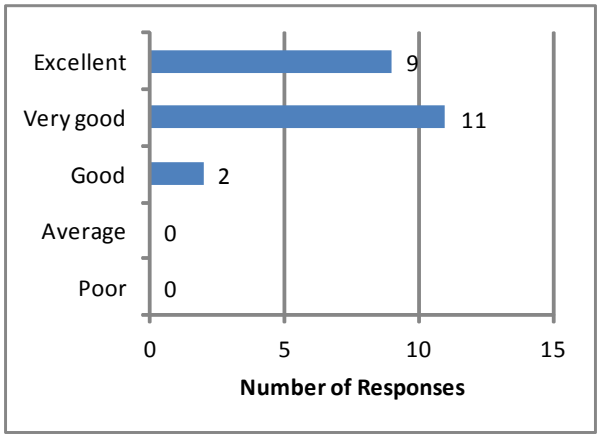


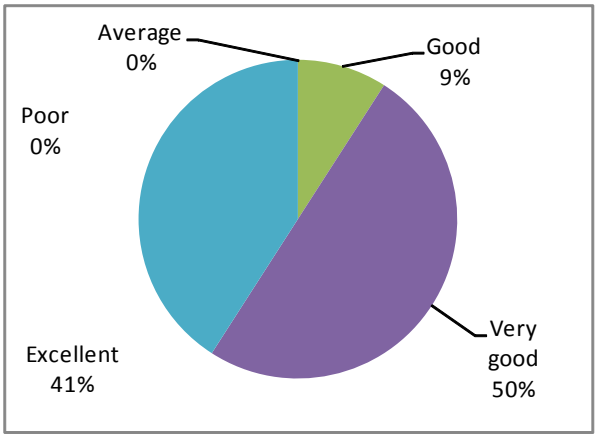
Q11: Did you have enough time to discuss your child's condition with the team members?



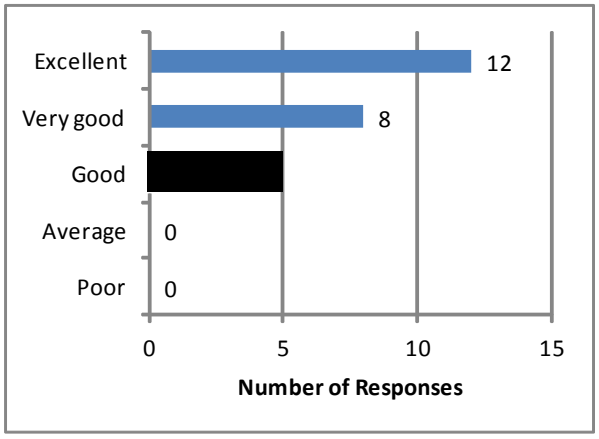


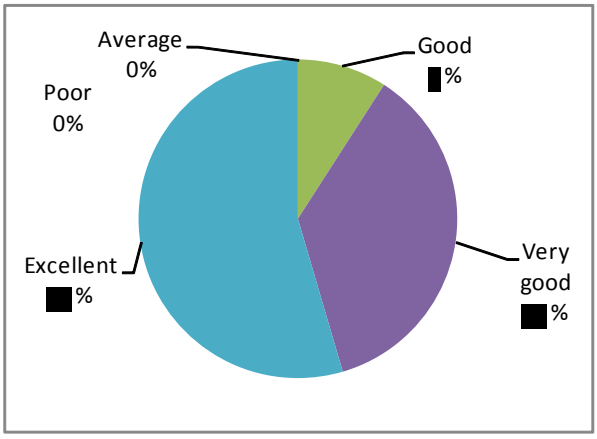
Q12: Overall how would you rate your child's care at the clinic?



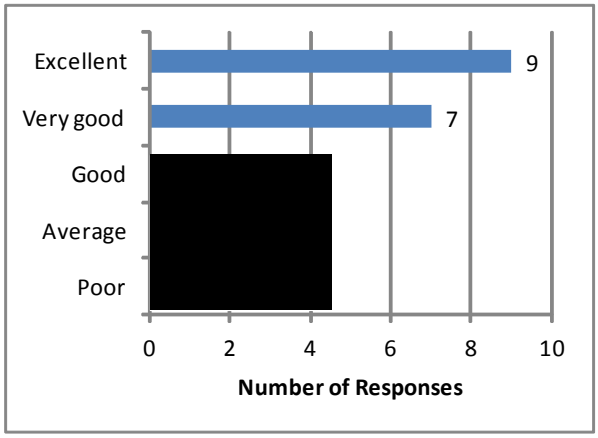


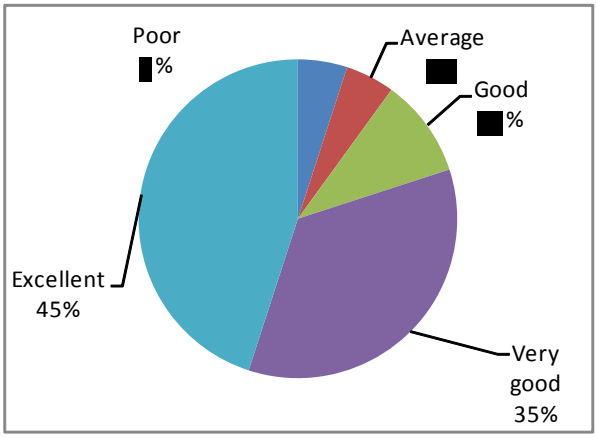
Q13: Overall how would you rate your child's care by Physiotherapy?





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





Further Comments

Would be great if a clinic could be provided in Northern Ireland.

V. Good. Thanks.

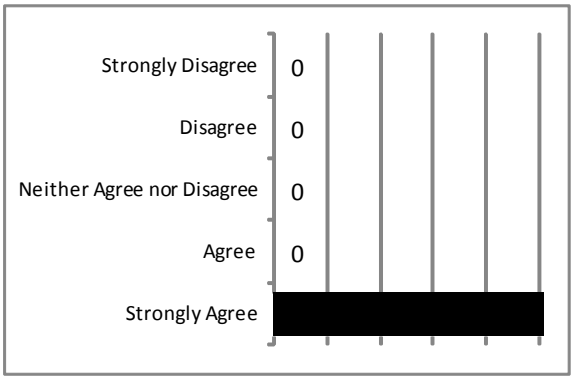
The service provided by this clinic is outstanding. We are very grateful for the opportunity for our daughter to attend. Staff are always considerate. We are particularly impressed by the way they put her at ease, addressing her directly and asking if she has any questions. The waiting area is excellent - we often arrive early having travelled by plane - and the play area is a great distraction.

Therapist-Led Clinic

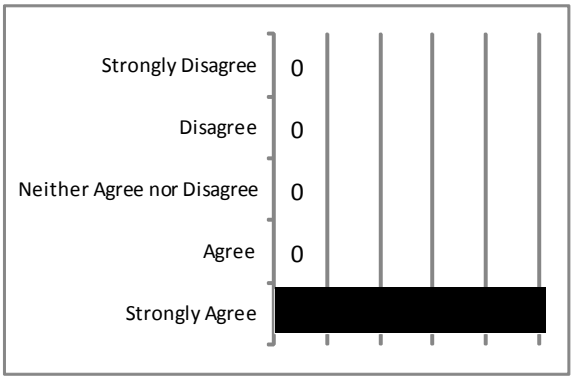
Patient Satisfaction Survey 2019-20
OBPI Therapist-Led Clinic (TLC)

[Sample Group =]

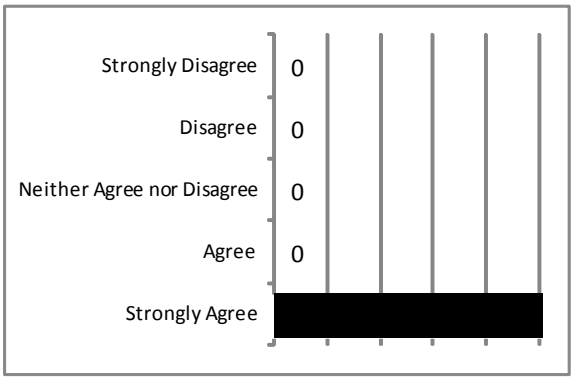
Q1. I understand the reasons for attending the Therapy-Led Clinic:



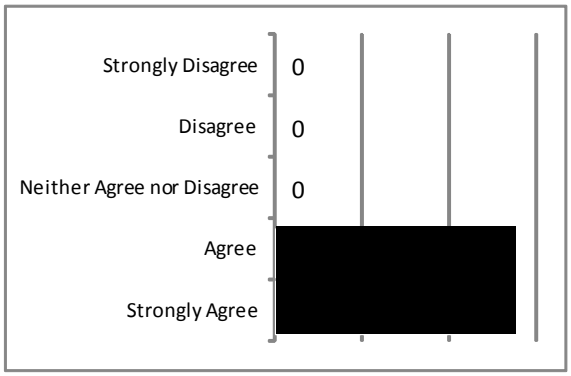
Q2. I understand the role of the Occupational Therapist for children with a Brachial Plexus Injury:



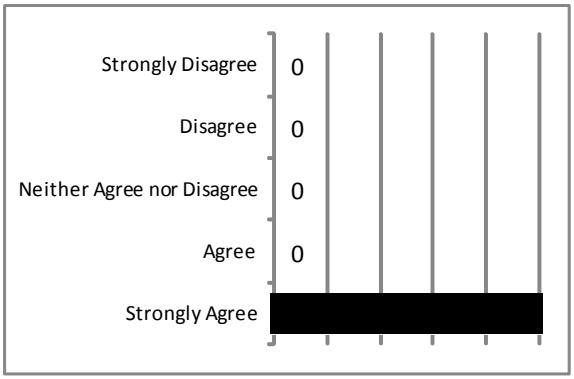
Q3. I understand the role of the Physiotherapist for children with a Brachial Plexus Injury:



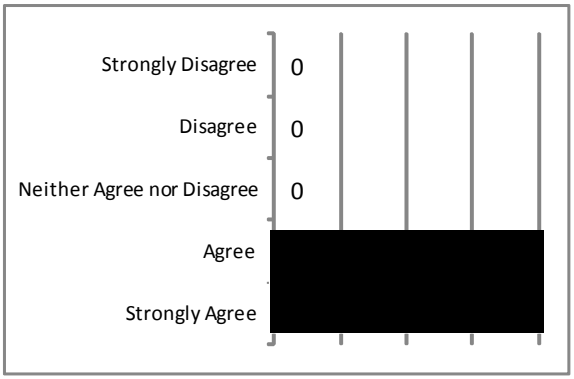
Q4. I understand the role of the Clinical Psychologist for children with a Brachial Plexus Injury



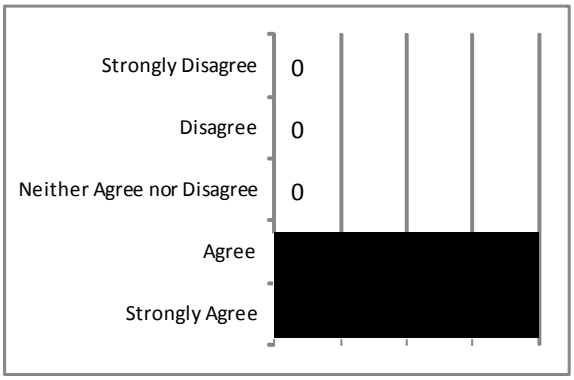
Q5. The aims of the session were clear:



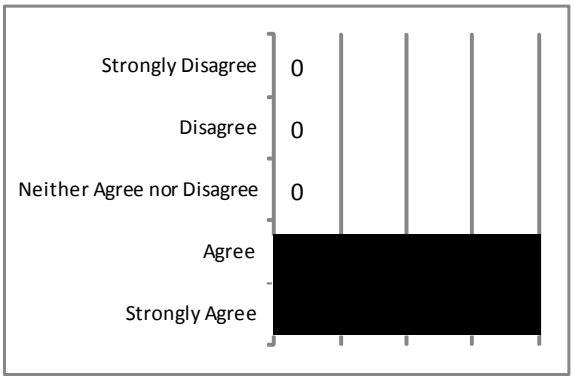
Q6. I learned about new strategies that I will try out at home with my child:



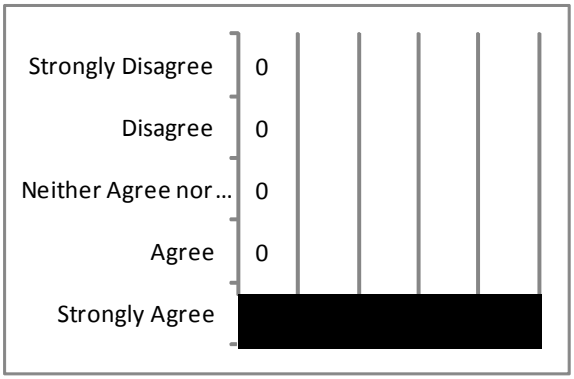
Q7. The Therapy-Led Clinic has increased my confidence to help my child's participation in everyday activities:



Q8. The clinic session length of 30 minutes was just right:



Q9. The therapy session accommodation was comfortable and clean:



Further Comments

Clearly explained purpose of session. Exercises clearly demonstrated. Thank you for your help and time!

Taking [name withheld] to play areas has been very helpful. Playing with different toys has encouraged her to use her left arm more frequently which is helping with her stretching. My only worry is that her right shoulder is now clearly higher (longer) than left shoulder. Also her arm (left) is smaller than the right one, other than that, she is using it very well.

Young Adult Clinic

Patients previously seen in the children's obstetric 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. A robust pathway is therefore in place for patients to transition from child to adult care.

The young adult clinic is held twice per year 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 referred to the service and are usually seen first at the young adult clinic.

4. Quality and Service Improvement

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

During the 2019-20 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*).

Members of the team travelled to Belfast in October 2019 to provide an instructional session at a meeting of the Irish Paediatric Orthopaedic Society. The program is detailed in the appendix.

Physiotherapy

Annual Report prepared by the Specialist Paediatric Physiotherapist

Role of Physiotherapy

- Attending consultant and therapy-led clinics.
- Assessing new babies/children referred to physiotherapy with concerns of OBPP.
- Liaising with physiotherapists across Scotland and Northern Ireland regarding children with OBPP.
- Promoting early intervention of babies born with OBPP by ensuring early referral to physiotherapy from the maternity hospitals.
- Continuing to educate junior physiotherapy staff and students in the role of physiotherapy in OBPP.

Patient Numbers

The following table shows the patient numbers seen by physiotherapy:-

Number of Patients Seen by Physiotherapy				
		2019-20	**2018-19**	**2017-18**
Consultant Clinic	New	10	22	27
	Return	50	51	55
Physiotherapy	New	10	14	8
	Return	19	25	25
Therapy Clinic	New	0	0	0
	Return	21	23	14

Therapy-Led Clinic

The therapy-led clinic continues to run well. This clinic allows longer appointment times for additional assessment/management strategies to be discussed with families. It also allows joint working between physiotherapy, occupational therapy and psychology.

Update letters for all patients attending the therapy-led clinic are sent to GPs and uploaded to the clinical portal along with the assessments that are carried out to ensure communication is maintained.

Patients Appointed to Therapy-Led Clinic (TLC) by Health Board						
	2019/20	*% of total*	**2018/19**	*% of total*	**2017/18**	*% of total*
Ayrshire and Arran						
Borders	**0**	*0*			**0**	*0*
Dumfries and Galloway						
England	**0**	*0*	**0**	*0*	**0**	*0*
Fife	**0**	*0*	**0**	*0*	**0**	*0*
Forth Valley					**0**	*0*
Grampian	**0**	*0*	**0**	*0*	**0**	*0*
GG&CHB	**14**	*61*	**21**	*70*	**11**	*61*
Highland	**0**	*0*			**0**	*0*
Lanarkshire						
Lothian						
Northern Ireland		*9*	**0**	*0*	**0**	*0*
Orkney	**0**	*0*	**0**	*0*	**0**	*0*
Shetland	**0**	*0*	**0**	*0*	**0**	*0*
Tayside	**0**	*0*	**0**	*0*		
Western Isles	**0**	*0*	**0**	*0*	**0**	*0*
Total:	**23**	*100*	**30**	*100*	**18**	*100*

Paediatric Occupational Therapy

Annual Report prepared by the Specialist Paediatric Occupational Therapist

During the past 12 months Nicola Hart, Advanced Occupational Therapist, has continued to perform the requirements of the Obstetric Brachial Plexus Injury specialist post. Job requirements have continued as outlined in previous annual reports.

The Therapy Led Clinic (TLC)

The TLC is run collaboratively with Physiotherapy colleague Heather Farish and Clinical Psychologist Helen Lowther. The clinic is run on alternate dates to the consultant-led clinic

(CLC). The aim is to provide specific occupational therapy, physiotherapy and psychology intervention sessions when indicated by the patient.

The following patients have attended the therapy led clinic:–

Attendance at Therapy-Led Clinic			
	2019-20	2018-19	2017-18
Under 5 years	8		
5 to 10 years	8	12	7
10 to 16 years	7	8	6
Did not attend		7	

The Brachial Plexus Outcome Measure (BPOM) is used specifically for these patients attending the therapy led clinic. It is an outcome measure for 4 to18 year olds. It takes approx 15 to 20 minutes to administer and assesses the capacity of the affected arm whilst performing everyday activities. This outcome measure is being used widely throughout the UK, Europe, and North America by therapists working with this patient group.

New Developments

The AHP Collaborative Meeting was hosted by Andrea Shaarani, physiotherapist in the Adult Brachial Plexus Service, and Nicola Hart, on 5th and 6th September in the Queen Elizabeth University Hospital. Occupational therapists and physiotherapists from Leeds, Oxford, London, Sweden and Denmark attended. It was agreed that future meetings would be split into two sessions, for therapists working in Paediatrics and a separate session for those working solely for Adult services. The agenda and minutes of the meeting are in the *Appendix*.

The next AHP Collaborative Meeting was due to be held in Stockholm in September 2020, but had to be postponed because of Coronavirus.

In November the multidisciplinary team was invited to present in Belfast. Both Nicola Hart and Heather Farish presented their roles in the treatment of Obstetric Brachial Plexus Injury. They received excellent feedback from their Northern Ireland colleagues.

Future Developments

As we enter into the ‘new normal’ way of working virtually with patients, this will no doubt be a challenge for the team. So far the children’s specialist occupational therapist has been involved in one consultant-led virtual clinic and one therapy-led clinic. Both have been successfully received by the patients.

Clinical Psychology

Dr Helen Lowther, Principal Clinical Psychologist

Clinical Psychology has provided 0.2 WTE (one day per week) NSD funded resource dedicated to and ring-fenced for the Obstetric Brachial Plexus Injury since the service began in July 2018. Planning for the Clinical Psychologist's role in the service was outlined in the Annual Report 2017-18.

Over the past 12 months the Psychologist has focused on service development and an emphasis on MDT working with regular attendance at clinics. Some patients identified with particular psychological need have been seen on a one to one basis by the Psychologist, however the focus of service delivery has been on taking a strong MDT approach so as to maximise the limited psychology resource and provide the best service possible to the widest number of families possible.

Quantitative data

Patients seen at either the consultant led or therapy led clinic:

Patients Seen by Psychology			
	2019-20	**2018-19***	**2017-18**
Under 5 years of age	25	24	n/a
6 to 10 years of age	19	17	n/a
11 to 16 years of age	20	13	n/a

* The clinical psychologist began seeing patients in August 2018

There have also been 32 one-to-one psychology appointments in 2019-20.

Current work

The current focus has been on continuing to provide a psychology presence at clinics but also to collect data which may be useful for further development of the service. A presence at clinics has been important in terms of providing early intervention, brief targeted psychoeducation to patients and families. In addition, this ensures that those who travel from further afield are able to have face to face contact with a Psychologist and be signposted onto local services if appropriate.

Being part of the MDT at medical clinics has ensured timely, seamless and early access to one to one support if needed by patients. It has been especially useful to be part of the Therapy Led clinic whereby patients are able to have more time in order to explore bio-psycho-social issues in more detail and provide intervention where necessary. Working in an MDT team has proved to be successful for patients whose psychosocial issues impact their ability to engage with the medical model.

A short audit has also very recently been completed. Questionnaires were sent to all parents of current patients, and 27 were returned (25% return rate). The questionnaires were sent mid-March 2020, and the timing of this with the Covid-19 situation may or may not have affected the return rate. There are summary points from the audit outlined below. The questionnaires

consisted of a short audit questionnaire developed by Dr Helen Lowther (See appendix for full report).

Audit summary points

- Psychology input is overwhelmingly deemed important for this patient group.
- Key times for psychology input appear to be following the birth, but there was also a sense that any psychology input at any time of the child's illness journey would be helpful, for both the patient and parent.
- Having more information about what a Psychologist does, how to access the service and likely waiting times may be helpful for reducing barriers for patients.
- Parents had constructive ideas about what might be helpful to be able to access during and after clinic visits i.e. self-help information to take away, an opportunity to see the Psychologist or understand how to access this service, potential groups that they may attend.
- Parents would generally be happy to fill in psychology related screening measures when coming to clinic.

Possible Future developments

a) Patient information leaflets: information gathered from the audit is extremely important in terms of developing leaflets for this population. A patient information leaflet has now been designed to try to answer common questions that come up for families, and to try to reduce anxiety and stigma that may affect accessing psychological support.
b) Self-help: a list of helpful self-help websites, apps and information should be developed to give out to patients. Links to recommended apps and websites could also be provided on the Scottish Brachial Plexus Website.
c) Groups: The audit also suggests that parents and families may benefit from being able to access groups. This population may benefit from a 'new diagnosis' group which could be given by the Therapists in the team (physio, OT and psychology). This could be run at a frequency that would suit the diagnosis rates. In addition, adolescent patients may benefit from a therapeutic group focussed on acceptance and support for body image issues.
d) Screening measures: A team wide discussion will take place to ascertain whether validated measures should be used in clinic, or whether to use 'distress thermometer' measures (these are already utilised in BMT and Cardiology medical clinics in Glasgow). Screening measures will ensure that patient distress is not being missed, and all patients are offered the relevant psychosocial interventions, matched to their distress levels.
e) Birth Trauma: it would be ideal to have a 'birth trauma' pathway, whereby new parents are given the opportunity to access support in a timely, sensitive way whilst having challenging feelings normalised. Helping parents understand their feelings and know when to seek support is important with this vulnerable group.
f) Research: Undertaking formal research would be beneficial in a number of key areas and could be carried out with a Clinical Psychology Trainee for their Doctoral Thesis. Ideas include: parenting toddlers with a Brachial Plexus injury and the challenges this brings; considering the rates of anxiety and depression in the post-natal period for mothers of children with a birth injury, compared to population norms; social phobia in adolescents with Brachial Plexus Injury; teenage experiences of living with a visible difference.

Due to the limited Psychology resource, it will be necessary to discuss with the wider OBPI team about which developments should be prioritised over the next year and which can be developed in future years.

Administration

Administration continues to be overseen by the service administrator at the New Victoria Hospital, with access to offices and clinics at the Queen Elizabeth University Hospital and Royal Hospital for Children when required.

Young-adult clinics (for adults with OBPI) take place at the New Victoria Hospital whilst children's OBPI clinics take place at the Royal Hospital for Children. Both clinics are set up and administered by the service administrator. Outreach clinics in Aberdeen encompassing both the adult and children's services are organised by the administrator, up to twice per year.

Service Website (www.brachialplexus.scot.nhs.uk)

In 2019-20 the service administrator continued to update and improve the service website.

Patients can access the patient information booklet (PIB) via the website as well as obtain general information on the nature and treatment of brachial plexus injury, along with links to outside resources such as support groups. Overall patient feedback continues to be positive.

Clinicians continue to use the website to access referral forms and referral guidelines and to contact the service. Feedback from clinicians has also been positive.

In 2020 the plan is to extend the website to include narrated video presentations. These presentations are intended to serve as guides for medical professionals who may encounter patients with brachial plexus injury. The specialist physiotherapist is currently working on the production of these presentations.

The site continues to be kept under review and is maintained on a weekly basis. The intention is to keep developing it in line with service requirements and feedback from patients and clinicians.

Referrals

The service administrator is the main point of contact for referrals to the children's service, ensuring they are processed and vetted within twenty-four hours of receipt where possible. Referrals are received either by post, email or via the electronic GP Gateway. The generic brachial plexus email mailbox is forwarded to other members of the team in the administrator's absence to ensure constant monitoring of referrals. Standard referral forms are available on the service's website. Email referral continues to be highlighted to referrers as the speediest method.

Database

The adult 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 both in the electronic patient record (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.

Attend Anywhere (Virtual) Appointments

Due to the COVID-19 crisis children's clinics for the brachial plexus service had to be cancelled at short notice in March 2020. A relatively new video consultation system called Attend Anywhere had already been set up for some departments within NHS Glasgow and was highlighted by both the adult specialist physiotherapist and the children's clinical team as a very useful resource.

With that in mind a dedicated Brachial Plexus virtual waiting room was set up on Attend Anywhere and contact made with patients in all area of Scotland via this method to replace the usual face-to-face clinic appointments. A children's clinic was run on this basis and proved to be overall very successful, with very positive feedback from patients in outlying areas, particularly Northern Ireland.

With COVID-19 restrictions still in place at the time of compilation of this report the clinics for both the children's service continue to be run on a mainly virtual basis utilising Attend Anywhere where possible. A handful of patients continue to be permitted to attend the clinics face-to-face as long as social distancing is observed and numbers are limited. The clinics are expected to continue in this format at least until COVID-19 restrictions are fully lifted.

It has been noted by both clinicians and patients that the virtual video appointments have been extremely useful for maintaining contact with existing patients who require regular review. The format may therefore be incorporated into future clinics as a regular feature.

The service administrator has taken over administration of the service's Attend Anywhere waiting room and at the time of this report is engaged in requisitioning more video equipment for clinic rooms and extending the Brachial Plexus virtual waiting room to include both the adult and children's teams in order to streamline future multidisciplinary clinics.

Other Duties

The administrator continues to take responsibility for other administrative requirements of the service including typing and mailing of clinical notes and correspondence, setting up future clinics on the TrakCare system, issuing monthly and six-monthly activity reports, liaising with other departments and hospitals as required, appointing new and return patients, and corresponding with patients by telephone, email or letter where necessary.

5. Governance and Regulation

5.1 Clinical Governance

The brachial plexus team holds regular multidisciplinary meetings after clinics to discuss developments and any problems with the service.

Local governance reports for the Paediatric Orthopaedic Service are submitted monthly; incidents are reported, investigated and reviewed. Information is then passed to the quarterly Paediatric Orthopaedic GG&C Clinical Governance meetings and relevant information then passed to the GG&C groups attended by senior management.

Patients treated at the Canniesburn site also fall under that unit's own monthly governance and internal audit system.

No significant governance issues have been identified through these mechanisms during 2019-20.

5.2 Risks and Issues

No adverse events arose during 2019-20.

5.3 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 2019-2020.

5.4 Complaints and Compliments

The GG&C policy on complaint handling is followed. There have been no complaints relating to the Children's Brachial Plexus Injury Service during 2019-20. Compliments are directed specifically to the service providers.

5.5 Equality

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.

Staff have completed required LearnPro modules, as set by NHS GG&C (Module 004: Equality, Diversity & Human Rights).

6. Financial reporting and workforce

NHS Greater Glasgow & Clyde				
Women & Children's Directorate				
Obstetric Brachial Plexus			Actual Activity	5
Twelve Month Report: 19/20			Projected Activity	5
			Contract Activity	10
	Full Year Funded Value Of Agreement £	Twelve Month Funded Value Of Agreement £	Actual Outturn As At 31st March 2020 £	Variance £
FIXED				
Nursing/PAM	77,999	77,999	77,999	0
Medical	11,479	11,479	11,479	0
Other direct	48,466	48,466	48,466	0
Indirect	16,652	16,652	16,870	-218
Capital charges	58	58	58	0
Total Fixed	154,654	154,654	154,872	-218
VARIABLE				
Pharmacy	5,434	5,434	2,775	2,659
Travel & Training	2,276	2,276	1,162	1,114
Total Variable	7,710	7,710	3,938	3,772
TOTAL	**162,364**	**162,364**	**158,810**	**3,554**

7. Audit & Clinical Research / publications

Tim Hems

Natural history of elbow flexion contracture and restriction of forearm rotation after obstetric brachial plexus injury.

Flexion contracture of the elbow and limitation of forearm rotation are common deformities after OBPI. A study has been started to investigate the severity of these deformities and how they progress during childhood, using the service database. The project has received approval from the research ethics committee

A presentation with the initial results for the elbow flexion contracture was made at the Narakas symposium. Analysis is ongoing and an abstract has been submitted for presentation at another International meeting.

Presentations:

The Natural History of Recovery Elbow Flexion after Obstetric Brachial Plexus Injury managed without Nerve Repair.
Narakas International Symposium on Brachial Plexus Surgery, Leiden, May 2019.

Natural History of Elbow Flexion Contracture in Obstetric Brachial Plexus Injury.
Narakas International Symposium on Brachial Plexus Surgery, Leiden, May 2019.

Publications:

In press:
Tim Hems. Chapter. Obstetrical Birth Palsy: Late Complications and Treatment (Shoulder, Forearm and Hand). In: Operative Brachial Plexus Surgery. Edited by Alexander Y. Shin and Nicholas Pulos, Springer Nature.

Tim Hems. Commentary Re. Lombard, A., Bachy, M., & Fitoussi, F. (2020). C5-8 neonatal brachial plexus palsy. Operative findings, reconstructive strategy and outcome. *Journal of Hand Surgery (European Volume)*. https://doi.org/10.1177/1753193420902361

8. Looking ahead

Coronavirus

The onset of the coronavirus pandemic in March 2020 presented a particular challenge for the service. Outpatient clinics and planned surgery had to be postponed. However, with particular support from the service administrator, we rapidly introduced video and phone clinics. A small number of children have been seen in person in order to make immediate management decisions.

The video consultations, using 'Attend Anywhere', have been well received by the children, who often appear more relaxed in their own environment. The video clinics also address the long distance some patients need to travel to attend the outpatient clinic in Glasgow. It is likely that we will continue to use Attend Anywhere for review of some children and reduce the frequency of face-to-face appointments in the future.

Two children, who were waiting for surgery, had to be delayed, but their operations have now been carried out (July 2020). We appreciate the support of the management and theatre staff at RHC for facilitating these cases.

Electronic Patient Record (EPR)

Over the last year the EPR development team has been working to provide specific E-forms for the children's brachial plexus service for inclusion in the EPR. The development task was more complex and took longer than anticipated. At the time of writing this report (June 2020) the process was completed and due to go live on the EPR very soon.

National and International Interactions

Tim Hems recently attended and contributed to the Narakas Meeting held in Leiden, The Netherlands in May 2019. This is an international symposium on brachial plexus surgery which is held every 2 to 3 years. Team members have attended previous meetings. An expression of interest was submitted to hold a future meeting. We were unsuccessful on this occasion, with the next meeting to be held in Berlin in May 2021. Wet will develop our proposals and resubmit a bid to hold the meeting, probably in 2023-24.

Some members of the team were due to attend a meeting of the UK-Scandinavian Brachial Plexus Group in Helsinki in May 2020. The plans for the meeting had a particular emphasis on obstetric brachial plexus injury. Unfortunately the meeting was postponed due to coronavirus, but should be rescheduled, possibly in March 2021.

Appendices

Teaching and Education

Tim Hems

Teaching

6th September 2019	Data collection and the Scottish BPI service, Brachial Plexus Collaborative Therapists Group Meeting, Queen Elizabeth University Hospital, Glasgow
18th February 2020	Edinburgh Hand Surgery Course. “Principles of management of peripheral nerve injury”. “Management of Brachial Plexus Injuries”. Small group teaching on clinical examination of upper limb neurology.

Meetings Attended

16/5/19 – 18/5/19	Narakas Meeting, Leiden, The Netherlands. International symposium on brachial plexus surgery.
17/6/19 – 21/6/19	International Federation of Societies for Surgery of the Hand, Triennial Congress, Berlin.

Brachial Plexus Collaborative Group Meeting
6th September 2019
Glasgow, UK
Queen Elizabeth University Hospital
Therapies Department, Ground floor

Programme

9.30 - 9.45	Welcome	
9.45 – 11.00	Pain and BPI	Prof Andrew Hart
	Interpretation of Neurophysiology tests	
11.00 - 11.15	Coffee	
11.15 - 11.30	Feedback from Paediatric meeting Thurs afternoon	Nicky Hart
11.30 - 12.00	Data collection and the Scottish BPI service	Mr Tim Hems
12.00 - 12.45	Feedback and update on current projects/ work	Caroline Miller Bridget Hill Hazel Brown Suzanne Oxley
12.45 - 1.15	Lunch	
1.15 - 2.45	GMI and Sensory rehabilitation (and case studies welcome)	Kathryn Johnston and all
2.45 - 3.00	AOCB Naming group	

Minutes Brachial Plexus Collaborative Group Meeting

6th September 2019
Glasgow, UK
Queen Elizabeth University Hospital

1. Present: Andrea Shaarani, Anna Kallstromer, Bridget Hill, Caroline Miller, Graeme Miller, Graeme Lusk, Hazel Brown, Heather Farish, Helena Millkvist, Kathryn Johnson, Laura Falconer, Linda Eversson, Lynsey Warner, Monica Damholt Madsen, Nicola Hart, Sarah Taplin, Suzanne Beale, Suzanne Oxley, Sophie Dobbs.

2. Apologies: Kerri Dixon, Heather Farish.

3. Minutes of previous meeting were accepted.
    a. If any therapists have completed BrAT forms they are happy to share please contact BH directly.
    b. Linked in and Google share drive not working for communication so group going to try WhatsApp group to help with communication and emails still available.

4. Pain and BPI: Presentation by Andrew Hart, Plastic Surgeon, Glasgow

5. Interpretation of Neurophysiology: Presentation by Andrew Hart, Plastic Surgeon, Glasgow. AS will forward presentations.

6. Feedback from OBPI session previous day;
   Agreement that meeting would remain separate moving forward and at different times to allow everyone to attend both.
   Networking required with Lynden, Belgium and Iceland HB will coordinate.
   Areas to look at - Assessment and treatment strategies, patient information, projects and research and standardised assessments.

7. Data collection and the Scottish BPI service: Presentation by Mr Hems, Orthopaedic Surgeon, Glasgow

8. Feedback on current work.
    a. CM provided an update on her PhD topic “Outcome measures for BPI”.
       CM reported that she is part way through interviewing to explore what outcomes are important to adults with TBPI. CM will soon be compiling long list of outcomes from SR and interviews to develop the online Delphi. Online Delphi aims to be online in spring 2020. Discussed consensus meeting. Agreement that to coincide with next NARAKAS meeting in 2021 would be useful. CM to contact NARAKAS committee regarding running international BPI NAHP meeting in TBPI alongside their meeting and also running the consensus meeting
    b. BH provided a review of some of the issues when managing people with tetraplegia. (PDF attached)
    c. Hazel - feedback on iPLUTO, BPOM IRR study and Narakas Pain presentation – PowerPoint attached. Therapists to discuss with their consultant colleagues regarding the next round of iPLUTO which is due for release within the next month. Please ensure therapies are well represented within the team data as it pertains to functional outcome measures – which we should be more aware of than our consultant colleagues.

d. Suzanne: Presentation on Abstract Shoulder dislocations and BPI. PowerPoint attached.

9. GMI and sensory rehabilitation. Hazel presented presentation on theory behind GMI and sensory rehabilitation. Case studies and clinical implications briefly discussed. Group agreed would like to expand on this topic at next meeting.

10. Naming the group: Final decision was not agreed. Discussion can take place on WhatsApp group.
    Some suggestions: International Brachial Plexus Group (iBPG)
    Brachial Plexu**s** C**li**nical I**n**terest **G**roup (SLING)
    Brachial Plexus Special Interest Group (BPSIG)
    International Plexus Interest Group (iPIG)

11. Next meeting In Stockholm 24-25th September 2020. Details Meeting to be over 2 days one directed to BPBP (24th) and one adult BPI (25th). LE will coordinate.
    Main theme Adults: Sensory rehabilitation
    Main theme Paediatrics: TBC

Members of the team travelled to Belfast in October 2019 to provide an instructional session at a meeting of the Irish Paediatric Orthopaedic Society. The program is detailed below.

Irish Paediatric Orthopaedic Society Belfast 2019

Friday 11th October 2019

Session 3: Obstetric brachial plexus injuries

2pm – 2.30pm
Obstetric brachial plexus injury overview.
Ms Claire Murnaghan, consultant paediatric orthopaedic surgeon, Royal Hospital for Children Glasgow.

2.35pm – 3.05pm
Surgery for obstetric brachial plexus injuries.
Professor Andrew Hart, consultant plastic and hand surgeon, Royal Hospital for Children Glasgow.

3.10pm – 3.30pm
The shoulder and elbow in obstetric brachial plexus injuries.
Ms Claire Murnaghan.

3.35pm – 4pm
Coffee with sponsors.

4.05pm – 4.25pm
The hand in obstetric brachial plexus injuries.
Professor Andrew Hart.

4.30pm – 5pm
Non-operative management and rehabilitation of brachial plexus injuries.
Mrs Nicola Hart, occupational therapist, Royal Hospital for Children Glasgow. Ms Heather Farish, physiotherapist, Royal Hospital for Children Glasgow and Ms Heather Lowther, clinical psychologist, *Royal Hospital for Children Glasgow.*

OBPI Psychology provision, information gathering audit 2020

Background and method

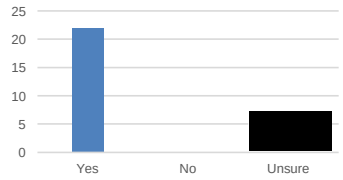
It was deemed appropriate and important to seek the views of patients currently attending the Obstetric Brachia Plexus Injury (OBPI) clinic about Psychology support for this population, particularly in view of this being a new role within a longstanding medical team. Therefore, every family currently attending the OBPI clinic (n=106) received a covering letter and a short audit questionnaire designed for this single purpose. The audit questionnaire was designed to gather the views and ideas from families' who are living with this medical condition, in order to help shape the Psychology part of the service. Key questions were asked in the hope that valuable information would be provided by families, in order to target development at the correct area of the service.

106 questionnaires were distributed to current patients, and 27 were returned, with a return rate of 25%. Questionnaires were returned without patient information, in order to preserve anonymity.

The Information Governance team in NHS GG&C was consulted, and consent from the Caldicott Guardian was gained to utilise patient information to enable the audit to be distributed.

Results

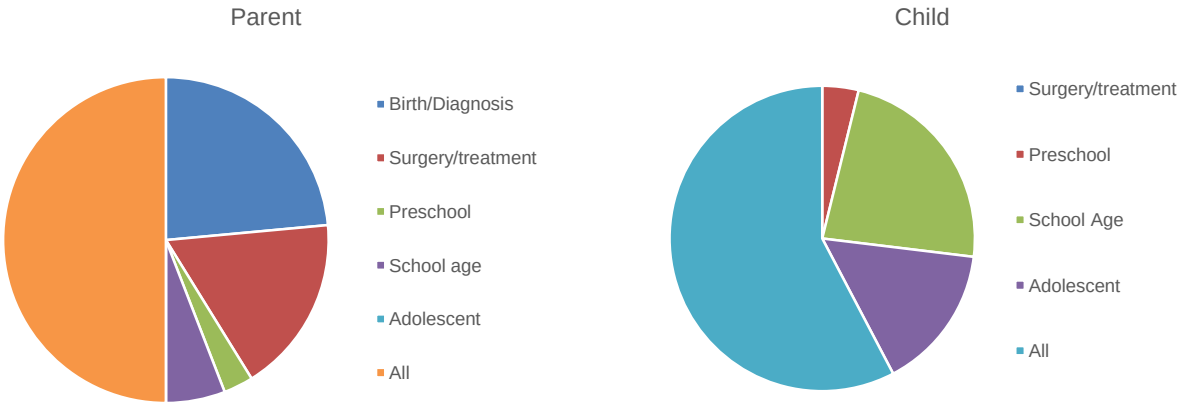
Question 1: *In your opinion, do you think Psychology support would be helpful for families attending the Obstetric Brachial Plexus Injury Clinic?*



Yes	**22**
No	**0**
Unsure	**1**

Question 2: *If so, at what stage do you think support would be most important?*

Parent		**Child**	
Following birth and diagnosis	**8**	Decisions surgery/treatment	**0**
Decisions surgery/treatment	**6**	Preschool	**1**
Preschool	**1**	School age	**6**
School age	**1**	Adolescent	**1**
Adolescent	**0**	All of the above	**15**
All of the above	**17**		



Question 3: *Can you think of anything that may be a barrier to accessing psychology support for you and your family?*

I don't know what a Psychologist does	[redacted]
I think Psychology support is only for other people	[redacted]
I think there may be a long waiting list	**12**
I am not sure it is available to us	**13**
I am not sure it is available where I live	**9**
Other	[redacted]

"It is difficult to focus on anything other than the child when you are in the eye of the storm. Guilt might stop folk."
"I am not sure who qualifies in needing or requiring a psychologist."
"I don't know the type of questions they ask."
"Not been told anything about a psychologist, if it is available or not. Though once offered I think a lot of people would find it useful."
"Live two and a half hours away from Glasgow."

Question 4: *What sort of psychology support should be offered during the medical clinic?*

Main points:

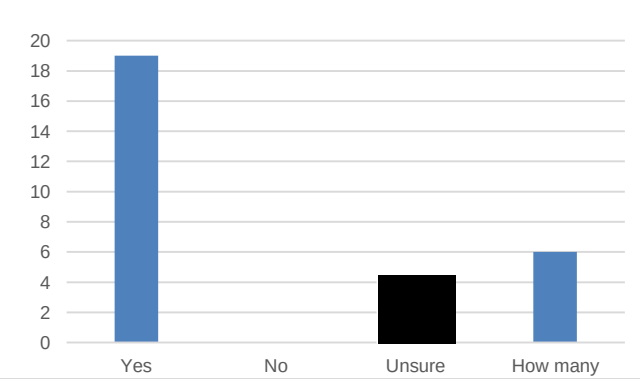
- **Support, information following birth and diagnosis**
- **Someone for child and parent to talk to**
- **Self-help materials, information about what services are available**

"I think Psychological support is vital in the aftermath of the injury, in our case after our child's birth, it was a traumatic experience."
"Being aware there is a service available, knowing how to access it. E.g. it's at least a year between clinic appointments so knowing how to get help in between would be useful."
"Self-help material."
"A chance to talk to someone as a whole family on how we feel about everything."
"Support should be available to child so they can talk to someone on how they are feeling/coping. Also, to mum who has had traumatic experience with childbirth, support should be given as soon as they have been told of their child's injury."

"One to one."
"Psychologists being more proactive in contacting families, some parents don't have time/forget to seek help/don't know how."
"After birth and diagnosis, very little support, felt at times we were being a 'pest'."
"Give my daughter a chance to talk to someone she might not be comfortable speaking to me about, in the knowledge they would be able to get her help/support if she needed it."
"Chance for a chat and look at self-help materials. Later on for my child to discuss mental health."
"Getting to know if you need a psychologist and how easy it is to meet them, any suggestions they can help to make things easier at home."

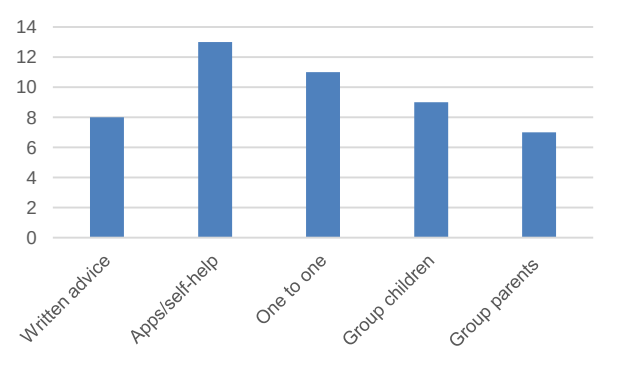
Question 5: *Would you be happy to routinely fill in psychology related questionnaires when coming to clinic?*

"Could be handed out at reception as there's often a wait for the appointment"



Yes	**19**
No	**0**
Unsure	**1**
It depends how many	**6**

Question 6: *What format of support would your family find helpful?*



Written advice on managing emotions	**8**
A list of helpful apps/self help	**13**
One to one input with a psychologist	**11**
Group support for children	**9**
Group support for parents	**7**

Question 7: *Have you got any other ideas about what type of support would be helpful?*

- **Having someone to talk to, reassurance**
- **Parent support groups**
- **Information/guidance about condition and longer-term impact**

"Reassurance that as parents we are giving the right care and support not to let our child down for the future"
"When our child was newly diagnosed, I would have loved a small support group, to share experiences and gain confidence. Just having a forum to talk with other parents and AHPs, when you have so many questions. I still don't know any other families and my child is 10."
"I would be lost without the Erb's palsy group, I don't think the doctors take Erb's palsy seriously that's why there is no extra support."
"In the beginning not much information/support available, as Glasgow Erb's palsy clinic has grown things are a lot better."
"Just having someone to talk to for 30 mins who understands how we are feeling, even a phone call appt would be helpful."
"Social prescribing to activities."
"A protocol to follow after birth trauma and not to expect to feel it's normal to have a birth and trauma like the one I suffered. Very little information and advice given."
"Some guidance/support on how condition will impact/influence things for my child as they develop and get older."
"Maybe on clinic days having an extra room where if parents want to meet and chat they can access, and kids can play.

Discussion

Psychology input is overwhelmingly deemed important for this patient group for both parents and children, at every stage of their illness journey. The sense from the returned questionnaires is that families would be open to and accepting of psychological support, but that having more information about accessing psychology support would be useful. Certain barriers to accessing psychological support were highlighted such as being unsure if psychology input involved a long waiting list, or if it was even available to them in their area. Creating a leaflet to specifically address parent's questions and concerns could help reduce barriers to accessing psychological support. This could be sent out with clinic appointments initially to all, and thereafter for first appointments.

Parents had constructive ideas about what might be helpful to be able to access during and after clinic visits, and how the service may develop in the future. Key ideas were providing patients with a list of where they could access self-help material (possibly apps or websites). In addition, due to new parents being highlighted as a particularly vulnerable group, it would be useful to have a robust pathway to address birth trauma and associated psychosocial needs following the birth injury. Parent and / or child groups may be of benefit to this group, as there was a sense that meeting other families in the same situation would help provide support and reassurance. In addition, parents would generally be happy to fill in psychology related screening measures when coming to clinic.

Overall, parents responded positively to the idea of psychology support and provided constructive ideas about how accessing psycho-social support may be made easier in the future.