The Experience of Parents and Children using Paediatric Spina Bifida Services

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# Workshop Evaluation

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FOREWORD

The Belfast Health and Social Care Trust continues to seek new ways of actively involving and working in partnership with users of our services, carers and the wider community with a view to influencing and improving how services are provided.

As Director of Specialist Hospitals, Women’s and Child Health I am pleased to present this report on parents and children and young peoples’ experiences of the Royal Belfast Hospital for Sick Children’s Spina Bifida Services.

This report is mainly representative of the views of parents and children who attended focus groups, responded to postal questionnaires, took part in face to face interviews over a six month period and finally a workshop.

The document should be viewed against the backdrop of BHSCTs commitment to continuous service improvement and to improve the quality and effectiveness of user and public involvement.

While there are many positive aspects, challenges were also set for the Trust by parents of children with spina bifida and I am pleased to say there has already been many encouraging developments.

I am pleased to say that RBHSC staff fully embraced the report and that the implementation of many of the report’s recommendations is underway. I hope that the findings will form the basis of future work in partnership with parents, carers, children and young people and SHINE who play a pivotal role in supporting families in all aspects of care of spina bifida.

I would particularly like to thank all the parents and young people who gave up their time to engage and actively participate in talking to the Belfast Trust, I hope the report reflects the views and ideas received and demonstrates the Trust’s commitment to improving services.

Yours Sincerely
Introduction

1.1 Background

Belfast Health and Social Care Trust (BHSCT) delivers health and social care services to approximately 340,000 people in Belfast and part of the Castlereagh Borough, and also provides a range of specialist adult and paediatric services on a regional basis for Northern Ireland in its entirety. The Trust has stated that its purpose is to “improve health and well-being and reduce health inequalities”, (Belfast Health and Social Care Trust, 2012). The Trust is committed to working in partnership with service users, their families, carers and the voluntary, community and independent sector. They consider that by making a united effort, the best possible outcomes for the population can be achieved.

1.2 Personal and Public Involvement

As part of working in partnership, the Trust takes the ethos of Personal and Public Involvement (PPI) very seriously. PPI is the process “...by which service users and the wider public become actively and genuinely involved in the delivery of health and social care” (DHSS&PS, 2007). If the involvement is effective, the experience shared can lead to service improvements.

PPI is now an essential part of everyday working practice, underpinning communications and decisions regarding care or treatment. It is also an integral part of service planning and commissioning. In practice this means involving those who use health and social care services and the public in:

- Sharing and discussing their ideas and their experiences
- Decisions about plans, policies and how to make best use of resources
- Facilitating discussions about why services need to change
- Providing opportunities to let people say what people want from services
- Discussions about how to improve the quality and safety of services.
Involvement of patients, clients, service users, carers and communities is now a statutory requirement.

The Belfast Trust continues to seek new ways of actively involving and working in partnership with users, carers and the wider community with a view to influencing and improving service provision.

It is within this context, a consultant Paediatrician involved in the delivery of regional services to children with Spina Bifida approached the Community Development and PPI Team and it was agreed that a review of the current provision of outpatient services be undertaken to determine if improvements could be made. It was agreed at the first meeting the Experience Based design Approach (EBD) was an appropriate tool for engaging with a regional service as it involves a number of methods of involvement and has been successful in its approach with other Trust service areas.

2.0 Methodology

2.1 ‘Experience-Based Design Approach’

The Experience Based Design approach (EBD) is a method of designing better experiences for patients, carers and staff. It has been designed by the NHS Institute for Improvement and Innovation (2009). The approach captures the experiences of those involved in or availing of healthcare services by looking at the care pathway and the emotional journey people experience when they come into contact with a particular service. Whilst many improvement projects will include a degree of service user involvement, there are few that focus as closely on drawing out and understanding the patient experience. This model goes beyond looking at what people liked or didn’t like about a service but aims to understand how an individual’s contact with the service made them feel.
The approach centres on **4 key steps:**

**2.11 Capture**

The first step begins with helping people (parents, service users and carers) to tell the story of their personal experiences in their own way. It is through these stories that we can begin to understand not just the care journey but also the emotional journey people experience when they come into contact with health and social care services.

For the purpose of this review a number of tools were used to capture the experiences of service users and their carers which were as follows:

1. An EBD questionnaire was developed in consultation with medical and nursing staff. The questions asked reflected the patient’s care pathway and the emotional journey to date. The questionnaires were posted out to the parents/guardians of the 186 children known to the Spina Bifida Services. 43 questionnaires were returned. (Appendix A)

2. The questionnaires were used to do 1:1 interviews with parents/guardians at several Spina Bifida Outpatient clinics in the Royal Belfast Hospital for Sick Children (RBHSC). 12 interviews were carried out.

3. An age appropriate questionnaire was designed for the users of the service, the children and young people. 9 interviews took place on a one to one basis at 2 out-patient clinics. Parents were present while their child was being interviewed. One young person completed the survey questions on line.
2.12 Understand

This step in the process is about understanding people’s experience. It allows us to map what they feel when they use the service and when they feel it. Service users and carers work in partnership with staff to analyse and understand the information captured.

After the questionnaires were completed, two focus groups were held, one in Lurgan and the other in Ballymena. These groups were facilitated by the BHSCT Community Development Team. Parents and Carers, staff from SHINE discussed themes that had arisen from the questionnaires and 1:1 interviews. All those present were able to confirm their understanding of the issues.

The next 2 steps in the EBD approach are:

2.13 Improve

This step is about ‘co-designing’, working in partnership with staff, and patients to develop potential solutions to improving the experience. (Action Planning)

In order to do this, a workshop was held on 25th March 2014. Invitations were extended to staff working in the Royal Belfast Hospital for Sick Children multi-disciplinary Spina Bifida team; parents and carers of children with spina bifida and staff from SHINE. (Spina Bifida.Hydrocephalus.Information.Networking.Equality) SHINE is a national charitable Organisation who provide support to families, individuals, health professionals, and schools and other interested organisations. SHINE also offers information and practical advice, and can provide (much needed) contact with other families. Area advisors and specialist advisers play a pivotal role in giving personal advice and support to individuals on all aspects of care of spina bifida and hydrocephalus.

The aim of the workshop was to identify opportunities for improving the experience of parents and children who use the Belfast Trust paediatric spina bifida services.
There were 3 objectives:

1. To agree the key issues/findings from the questionnaires, interviews and focus groups
2. To get a better understanding of what the key issues experienced by parents/children using our services are
3. To work together to make meaningful changes to services provided.

The assistance of an external facilitator was used to help facilitate the action planning part of the workshop.

2.14 Measure

This step is about evaluating the impact and success of the intervention. The most important part of the process is about bringing all participants back together to inform them what happened as a result of their engagement.

Children’s services will be responsible for the implementation and monitoring the effectiveness of the Action Plan. Several suggestions were made with reference to keeping parents informed of the outcomes from their involvement, for eg It has been suggested that a reference group comprising of staff, interested parents, service users and carers be established who can then be consulted and meet once a year.

3.0 Findings

3.1 Questionnaires

The questionnaires which were designed with the aid of the medical and nursing staff were firstly sent out to all the parents/guardians of the service users. They were also used in twelve 1:1 interviews.

The EBD questionnaire asked parents to indicate their feelings around specific times when they came into contact with Trust services. Questions nine and ten asked for general descriptions and comments. (A summary of Key points in Appendix B)

The following is a summary of the responses received from the 43 postal returns and the twelve 1:1 interviews.
Question 1

Did you receive Pre-Natal Counselling in the maternity hospital before your baby was born? How did you feel during and following your appointment? (Respondents could tick as many words/feelings that were appropriate)

A high proportion of respondents indicated that they felt worried and/or scared. On examination of the comments, it appeared that often the response was dependent upon where the initial diagnosis took place.

Comments made in association with these feelings included;

- “I was scared and worried as I was on my own when I was given the diagnosis of my unborn son and even though I was told he might not survive, I was reassured that everything possible was going to be done for him once he was born to give him the best chance.”

- “....worried as only discovered late in pregnancy that baby had Spina Bifida and so there wasn’t a lot of time to receive information.....”
• “...Informed/scared/terrified..Initially I felt very daunted by the whole idea of having a child with Spina Bifida, but after seeing some professionals in the Royal and I did see quite a few during lots of appointments, I became more reassured and well informed. But still a bit overwhelmed.”

• “Scared....Didn’t want any more information as I felt I had enough to cope with at this time. Prior to birth went to see different consultants that my child didn’t need. Felt this added to the stress.”

• “..at 20 weeks I had scan at XXX, I felt really scared. Hospital supportive but uncertain of condition. Once I got to Royal a lot of info very quickly.......Info well structured. “
Question 2

How did you feel about the amount of information provided when your child was born? Please consider where it was provided and how it was provided? (Respondents could tick as many words/feelings that were appropriate)

Responses showed a wide range of emotions.

Remarks included:

- “.....I was reassured by the staff and doctors at the time. I had support from the nurses in the hospital.”

- “....it wasn’t until we met the staff at the Royal that we felt our questions were being answered.”

- “..information was provided in a caring and sensitive way – not all at one go but bit by bit.”
“My son was transferred to the Royal Victoria Hospital to have surgery for Spina Bifida and I felt the staff and doctors supported me very well.”

“...son was not born in Belfast and hospital he was born in had absolutely no information on his condition which was horrible. After transfer to RBHSC information received didn’t stop the worry but at least we were informed and all questions were fully answered.”
**Question 3**

How do you feel when you receive your letter before each of your appointments to the Spina Bifida Outpatients Clinic? (Respondents could tick as many words/feelings that were appropriate)

- Reassured
- Supported
- Satisfied
- Worried
- Safe
- Relieved
- Nervous
- Informed
- Sad
- Overwhelmed

A large number of respondents indicated that they felt Reassured and/or Supported. This is demonstrated in the following notes:

- “...I have every confidence in the professionals we are seeing.....they always have my son's best interests at heart.”

- “...sometimes worried about the visit, but most of the time feel reassured that he was getting seen to.”

- “…safe in the knowledge that the condition is monitored.”
• “...the RVH are keeping a good eye on XXXX and the doctors are excellent at keeping us well informed.”

**Question 4**

After your journey, how do you usually feel on arrival at the Hospital Site for your Outpatient appointment? (Respondents could tick as many words/feelings that were appropriate)

Many respondents indicated that one of the emotions they felt was frustration. The majority commented that the frustration was due to parking issues, such as:

• “Frustrated generally because of parking problems.”

• “...I am relying on getting one of the few disabled parking spaces. When I arrive and find cars parked literally everywhere, I worry I will be late....”

• “...sometimes a little tired due to travelling etc. and parking can be a huge hassle....”
A number of positive comments were also made;

- “..safe because I don’t worry about his appointment.”

- “...staff always pleasant and supportive....”

- “...we always feel very supported when we arrive at the clinic. Staff are very pleasant and take time to discuss all matters with us....”
**Question 5**

How do you usually feel on arrival at the clinic waiting area for your appointment? (Respondents could tick as many words/feelings that were appropriate)

Numerous respondents advised that they felt Good / comfortable and/or supported. This is demonstrated by the following comments;

- “...I know we’ll be meeting child-friendly doctors who ask my child how he is and listen to any fears or questions, no matter how tiny they may be. ..”

- “All the consultants are here in one place, you can go round them all in one afternoon.”

- “…nice open space, bit warm at times, but great for keeping in contact with other parents...”
Question 6

A range of specialist staff review your child at each clinic visit. (Neurology, Urology, Urodynamics, Orthopaedics, Radiology, SHINE, etc) How does this make you feel? (Respondents could tick as many words/feelings that were appropriate)

A high proportion of respondents advised that they felt Supported and/or Reassured. Comments included;

- “...it makes me feel that every aspect of my child’s health is being monitored/addressed....”

- “...all the professionals are there in one place....”

- “...reassured that all consultants are there if we need to see them...”
Question 7

You are taught by Continence Nurse Specialists very soon after birth how to perform Clean Intermittent Catheterisation (CIC). How does this make you feel? (Respondents could tick as many words/feelings that were appropriate)

Many respondents advised that they felt Supported. Positive remarks included:

- “…this was a traumatic time – I felt very supported and safe.”

- “…the staff are very supportive, patient and communicate the information very well to parents and child.”

- “…The nurses have been very helpful and supportive, life would be more difficult if it wasn’t for them…”
Question 8

Are you usually offered information or support by any Voluntary/Support organisations when you visit the clinic? How does this make you feel? (Respondents could tick as many words/feelings that were appropriate)

Numerous respondents advised that they felt Supported and/or Good. It was noted in the responses that there is usually a representative from SHINE\(^1\) present at outpatients and they offer great support. Comments included:

- “…ASBAH\(^2\) representative always present which is a great support.”

- “…SHINE are amazing. They are the only support we’ve been offered. XXXXX is fantastic, always helps and answers anything we need to know….”

- “…yes, SHINE (ASBAH) have always been there with a lot of support and advice, which have been invaluable through all the different stages and ages of the condition…”

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\(^1\) SHINE – Europe’s largest organisation that provides support and advice to individuals and families affected by Spina Bifida and Hydrocephalus

\(^2\) ASBAH was the former name of SHINE
**Question 9**

In general, how would you describe your overall experience about the follow up care you receive? (e.g. phone calls, appointments, procedures, staff, venue, information, copies of clinic letters). Please feel free to give your own examples.

**Positive Responses**

In general the replies were of a positive nature. Many of the replies commended the nursing and medical staff for their professionalism and the level of care given. (See Appendix C for Positive Feedback, although a sample is given below;

- “Excellent follow up care. The copy of the clinic letters is most helpful....”
- “…our experiences over the past 5 ½ years have always been positive. Very thankful that we have such good care at this clinic.”
- “Extremely positive as we feel XXXX has been given the highest level of support in all aspects.....”

**Areas for Improvement**

In this section, there were some less positive comments. Several of these were concerning the ability to contact staff and obtain information over the phone. It was also noted that there is often a delay with some services, e.g. the provision of splints. Examples of such responses are;

- “...very very hard to get answers when you call.”
- “…the only negative comment would be about the length of time our daughter has to wait to be a) cast for splits, b) have them made, c) have them fitted.....”
- “…I have had to leave stern messages to get someone to ring back.”
Question 10

Do you have any other comments regarding your overall experiences of our services?

In this section, most of the responses were similar to those provided in previous questions. Again, many commended all staff and the services, whilst others remarked on issues such as parking, waiting time delays and difficulty in making contact in between appointments.

3.2 Focus Groups

There were two focus groups held, one in Lurgan and one in Ballymena. At these meetings, we were able to advise the attendees of the recurring themes that had been raised from the postal questionnaires and 1:1 interviews, ascertain if we had understood the issues and then discuss them in greater detail. The themes were:

- Counselling
- Information / Communication
- Appointments
- Staff
- Role of SHINE

An additional issue was identified during these meetings, which was the failure and/or delay in equipment.

3.3 Analysis of Findings

Key Themes

3.31 Counselling

Whether parents were offered counselling appears to be dependent upon where and when the diagnosis was made. If the diagnosis was made pre-natal in Royal Jubilee Maternity Services (RJMS) it would seem that generally some counselling ie support/advice was given. This counselling is supplied by obstetricians, neonatologists and paediatric surgeons. Some of replies mentioned “neurologists”. Neurology are not involved and it is possible that the parents have mistaken paediatric urology for
neurology. However, when the diagnosis was made in another hospital (DGH\textsuperscript{3}), the amount of information and counselling varied considerably.

Similarly, if the diagnosis was made post-natal, the amount of counselling/support given, if any, was dependent upon the individual and location.

SHINE plays a major role in supporting parents both before and after diagnosis, but this very much depends whether parents are referred by mainstream services or self refer.

3.32 Information / Communication

This is an area where experiences varied considerably, depending on who gave information and when the event occurred. The key issues/findings were:

- How the information was conveyed was a recurrent theme. The parents expressed shock and being scared, and often the reaction of the radiographer at the 20 week scan when diagnosis first made.

- The terminology was often confusing

- Too much information given at one time and parent(s) not able to understand it all

- Often conflicting and/or disjointed information between Paediatricians and Neonatalists

- Literature is often out of date

- Literature that is age appropriate should be available

- Need a point of contact for general enquiries, - not just an answering machine. Parents noted that after leaving a message on the answering machine, a reply could take 2-3 weeks, if at all.

\textsuperscript{3} DGH – District General Hospital
3.33 Appointments

Under this heading, we are considering all aspects of attending appointments at outpatient clinics. Key findings included:

- Car Parking was a major issue. Feelings of frustration/stress were used regularly. Nearly every one interviewed mentioned it. For those parents who travelled long distances for outpatient appointments, any issue was compounded by the car parking problems, which range from the very long time to wait to get parked through to lack of disabled spaces.

- How important it is for follow-up letters to be sent after the appointment to confirm what has happened and been decided at the last visit.

- Outpatient appointments were for most parents a very positive experience. Most parents liked to see a range of staff/specialists i.e. neurosurgery, urology, paediatricians etc. Staff were spoken of very highly, consultants were mentioned by name as well as nurses, reception staff, SHINE representatives also. Words such as reassured, supported were used frequently. Parents really appreciated follow-up letters received after their appointment, consolidating all the information from the clinic visit.

- Contact at the clinics with other parents important, along with being able to talk to SHINE.

- Despite what staff thought, generally most parents don’t mind travelling to Belfast because they do get to see a range of staff. Many view RBHSC as a centre of excellence for the treatment of their child.

- Waiting Area- comments ranged from the need for it to be revamped to mentioning the seats with their backs to the television. There is insufficient equipment to keep the children occupied, and some that is there, is broken.

- Contact outside clinics is an issue. Takes ages for appointments to be organised, appointment process for some parents very frustrating, follow-up appointments in particular. Phone calls go unanswered, difficulties rearranging appointments. No one calls you back when you leave message, results are hard to get.
3.34 Staff

In general, staff that were mentioned throughout the research process were described as helpful / supportive / brilliant/ excellent. It was also noted by several that seeing a Paediatrician prior to the birth was very useful.

3.35 Role of SHINE

SHINE (formerly ASBAH) has a pivotal role to play, particularly post diagnosis. This was very apparent in parents’ responses. They talked regularly about the information, time and reassurance that SHINE provided. A number of parents found out about SHINE through word of mouth, or the internet. Information about SHINE was not always passed on by staff.

A couple of families not currently engaged with SHINE, felt they there was less of a role as the child got older. It was also noted that SHINE has been more proactive over recent years.

3.36 Delay and Failure of Equipment

An issue that arose from the focus groups and 1:1 interviews was the delay in obtaining equipment such as splints. It was noted that it can take 10-12 weeks for splints to be made, during which time the child may have none.

Urodynamics equipment can breakdown which is frustrating. It may then take 3 months for the equipment to be fixed / replaced.
4.0 Conclusion

This work was undertaken in response to a BHSCT consultant paediatrician requesting a review of the provision of regional services to children with Spina Bifida (SB) in order to see where improvements could be made. Using the approved “Experience Based Design Approach”, postal questionnaires were initially sent to the parents/guardians of all known service users and also used to carry out 1:1 interviews at SB outpatient clinics with parents and the users of the service, the children and young people. The information provided highlighted several key issues which have a significant impact upon the delivery of these regional services. These issues could be identified under the headings of:

- Counselling
- Information / Communication
- Appointments
- Staff
- Role of SHINE
- Delay and Failure of Equipment

These topics were then discussed and elaborated upon at two focus groups (Lurgan and Ballymena) which were attended by parents/guardians/carers of the children and representatives from SHINE. By using the specific EBD approach, the most comprehensive and detailed information possible was acquired. Having obtained this insight and knowledge around the emergent issues/themes, we were able to focus upon finding solutions through the production of the Action Plan and having Trust staff, SHINE representatives and parents/guardians/carers work collectively.

A final workshop was then held to which medical and nursing staff, parents, service users, carers and SHINE were invited. As a result, all participants were able to contribute and aid in the development of an Action Plan to address these matters – see section 7.00 (page 28).

The Action Plan will be implemented by BHSCT who will also monitor and evaluate its effectiveness.
4.1 Examples of improvements to spina bifida services as a result of engagement with parents and children

- New urodynamics computer has been upgraded, this should minimise disruption to appointments.
- As a result of building on the established good relationship between Royal Belfast Hospital Sick Children’s spina bifida team and fetal medical team at Royal Jubilee Maternity Services, the following has occurred:
  
  The existing guidelines have been emphasised including early referral to SHINE. The spina bifida team were invited to speak about antenatal counselling at the Ulster Obstetrics and Gynaecology meeting in June 2014, and this led to a very fruitful dialogue between the fetal medicine team and the spina bifida team on the positive outlook for the quality of life that most children and young adults with spina bifida can now expect. As a result, the spina bifida team have now been invited to repeat their presentation at another meeting in autumn 2014, where the discussion will also include both the neonatal and genetics teams.

- An information sheet is currently being compiled for families which lists contact details and clarifies roles of the various members of the spina bifida team. This is nearly ready for distribution.
- SHINE are populating a box with their literature for parents and children at Out Patients Department.
- A number of issues relating to the car parking have already been addressed. However parents need to keep us informed on how this is in reality as it is difficult to police on a regular basis.
## 5.0 ACTION PLAN

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| How information is conveyed                                                         | • Information Pack, which can be added to: including an information matrix, a glossary of terms, a ‘who’s who’, and which specialist teams parents and children will engage with (and when).  
|                                                                                     | • Signpost / make aware to Shine at time of diagnosis, and explicit explanation of their role  
|                                                                                     | • Note the importance of receiving the right information at the right time for parents  
|                                                                                     | • The Trust should use the Shine Newsletter as a means of communicating information to parents  
|                                                                                     | • Role of Shine at the 20 week in-depth scan and diagnosis at the Royal Jubilee Maternity Hospital and linkages to midwives (see Role of Shine below) | BHSCT Shine     | 2         | • Standardised information available to all parents; but a flexible phased ‘drip-feed’ approach to giving information meeting needs and wishes of different parents.  
|                                                                                     |                                                                                       |                 |           | • Awareness that at point of diagnosis (20 week scan or birth) the first conversations are very important; the initial focus should be on human issues rather than medical. |
| Terminology Used                                                                    |                                                                                       |                 |           |                                                                                 |
| Information ‘overload’                                                              |                                                                                       |                 |           |                                                                                 |
| Outdated leaflets and a need for age appropriate information                        |                                                                                       |                 |           |                                                                                 |
| Disjoint between Paediatricians and Obstetricians                                   | • Need to seek a meeting with Foetal medicine team                                 | BHSCT Shine     | 2         | Increased cross-medical-discipline communication and joined-up approach         |
|                                                                                     |                                                                                       |                 |           |                                                                                 |
| Need for a contact point for general enquiries                                       | • One individual as the named contact  
|                                                                                     | • Set up a contact email address and process for dealing promptly with enquiries  
|                                                                                     | • Give parents contact numbers and accessible points of contact for different health support | BHSCT           | 1         | Improved communication between Hospital appointments                             |
| Doctors sharing information                                                         | • NI Electronic Care Record will increase information sharing between medical staff. Parents will be made aware of this development.  
<p>|                                                                                     | • Flagging system for District General Hospitals; so if a diagnosis is given, parents are signposted to and receive Shine contact details | BHSCT           | 1         | Increased cross-medical-discipline and health organisation communication         |</p>
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<td><strong>Counselling</strong></td>
<td>• Terminology: distinguish between counselling, active support and advice, and ‘genetic counselling’&lt;br&gt;• Need to look at current pre natal-counselling, availability.&lt;br&gt;• Prepare parents (do not take away hope)&lt;br&gt;• A referral pathway needs to be developed so that information, advice and support is available for parents at the right time</td>
<td>BHSCT  &lt;br&gt;Shine</td>
<td>2</td>
<td>Increased information, advice and support available to parents at the right time</td>
</tr>
<tr>
<td><strong>Postnatal separation</strong></td>
<td>• Maternal preparation during antenatal; taking them to the ward so they have greater understanding and are more prepared for the postnatal separation&lt;br&gt;• Train obstetricians in the delivery of bad news – RJMH Consultant can do this at the annual Obstetrician’s meeting&lt;br&gt;• Need contingency plan in place for babies who arrive before the expected date</td>
<td>Shine and BHSCT  &lt;br&gt;BHSCT</td>
<td>2</td>
<td>Increased understanding for parents about what will happen immediately after the birth. Potential for improved bonding. In the longer term there may be a corridor between the RJMH and the Children’s Hospital</td>
</tr>
<tr>
<td><strong>Experience of Hospitals outside Belfast</strong></td>
<td>• To standardise information given to all outlying Hospitals&lt;br&gt;• Increased education of staff in local hospitals&lt;br&gt;• Explore whether time can be freed up for Neurosurgeons (so parents can meet them in the antenatal phase)&lt;br&gt;• Ensure all medical disciplines involved in family care share information</td>
<td>BHSCT</td>
<td>2</td>
<td>Improved communication (linkages to Communication actions) and greater understanding and awareness of staff at outlying Hospitals.</td>
</tr>
<tr>
<td><strong>Role of Shine: Awareness of what they can do</strong></td>
<td>• Signposting families to Shine could be formalised in the Care Pathway across NI (in addition to Belfast Hospitals) – educate staff about Shine at all hospitals&lt;br&gt;• Shine engagement in outpatients clinics at Royal Jubilee Maternity Hospital scan (following initial diagnosis) to gather a more in-depth diagnosis - working closely with mid-wives to provide parents with information and support&lt;br&gt;• Have Shine information leaflets and packs available for families at key points along the Care Pathway</td>
<td>Shine  &lt;br&gt;NI Trusts</td>
<td>3</td>
<td>Ensure that all parents are aware of the role of Shine and how they can provide information, support and advice to families. Parents need to have the choice. Parent engagement and relationship with Shine can combat information overload</td>
</tr>
<tr>
<td>Issues</td>
<td>Action</td>
<td>Lead and others</td>
<td>Timescale</td>
<td>Outcome / Output</td>
</tr>
<tr>
<td>--------</td>
<td>--------</td>
<td>-----------------</td>
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<td>------------------</td>
</tr>
</tbody>
</table>
| Car parking issues | • Protect visitors car park disabled spaces and drop-off point  
• Review number of disabled car park spaces  
• Park and ride shuttle service on site  
• Free car parking for inpatients  
• Angling of disabled car parking spaces  
• Continue car park audit | BHSCT | 1 | Protected disabled access at main entrance and side, resulting in easier parking |
| Importance of Follow Up Letter following appointments | • Letters go to parents, but copy to GP should happen as a matter of course following every Hospital appointment – model of good practice  
• Communication from Neurosurgeons and all services  
• Coordination of follow-up appointments to be included in the Coordinator role (potential for Coordinating Role raised during the Communication action plan discussions) | BHSCT | 1 | Staff from all disciplines should report back to parents (copied to GP) following all appointments |
| Reappointment process ‘not fit for purpose’ | • Examine mechanism and explore issues  
• One point of contact: telephone number and email address (add details onto Intranet)  
• Review letter to include line advising parents to contact the hospital if they do not receive an appointment date within a given time (see urology letter example)  
• Ensure protocol is attached to notes and that staff are aware of the language that should be used  
• Protocol for reappointment to be attached to the front of each child’s notes | BHSCT | 1 | Identified point of contact  
Contact telephone number and email on BHSCT Intranet |
| Accident and Emergency | • Explore potential for a ‘fast-track’ for children who are currently being seen by the spina bifida team if they arrive in Accident and Emergency  
• A basic card / information sheet that parents have on them at all times and can take to A and E, including key contact person/s | BHSCT | 3 | Easier pathway through A and E |
### Hospital Appointment continued

<table>
<thead>
<tr>
<th>Issues</th>
<th>Action</th>
<th>Lead and others</th>
<th>Timescale</th>
<th>Outcome / Output</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orthopaedics</td>
<td>• Need to ensure that orthopaedics is included in the spina bifida multi-disciplinary clinic</td>
<td>BHSCT</td>
<td>2</td>
<td>Full multi-disciplinary service</td>
</tr>
</tbody>
</table>
| Poor waiting area / children get ‘bored’ with long waiting times and nothing to entertain them (toys, pens, paper etc) | • The waiting area needs a revamp  
• Explore opportunity for WiFi in the area (currently locked, under corporate review). Beneficial to children and parents  
• Toys to be height appropriate for wheelchair users  
• Application for funding for new toys for Outpatients Department (range of age appropriate toys)  
• Potential for Play Therapist or volunteers to engage with children, and maintain stocks of pens, paper etc  
• Increase Starlight entertainment systems  
• Review seating layout, with particular reference to television  
• Self-check in booth                                                   | BHSCT           | 2         | WiFi available  
Age appropriate range of toys accessible for children and young people in the waiting area.  
More welcoming and reassuring environment for families                  |
<table>
<thead>
<tr>
<th>Issue</th>
<th>Action</th>
<th>Lead and others</th>
<th>Timescale</th>
<th>Outcome / Output</th>
</tr>
</thead>
</table>
| Lengthy waiting time for splints     | • Inform parents of the increase in weekly clinics from two to five a week (in response to issues raised)  
• Splints should be a priority  
• Review process of referral and issuing splints  
• Encourage parents to advise earlier if there are problems with teenagers (for example teenagers do not tell parents or medical staff when the splints are too small)  
• Look at interaction methods with older children – teenager events | BHSCT Shine | 2         | Weekly sessions have been increased  
Teenagers aware of importance through Shine events |
| Slow review time for Shunts          | • Neurosurgeons need more support; recruit a Specialist Neuro Nurse could be the first port of call and who can do the initial assessment  
• Funding for Specialist Neuro Nurse  
• Issues about attending A and E – information sheet for person in casualty – fast-track  
• Possibility that Shunt review is carried out by paediatricians | BHSCT | 2 – 3      | Better communication between Neurosurgeons and parents; better accessibility through a Neuro Specialist Nurse |
| Urodynamics breaking down frequently | • Currently room is being refitted and software issues have been resolved. Actual equipment is reliable but due an update in next few years.  
• Service impacted upon by cover  
• Urodynamics equipment on capital requisition list  
• Inform patients when equipment breaks down, so that they understand when there are delays | BHSCT | 3         | Software kept up to date  
Equipment review every two years  
Prompt replacement of outdated equipment and software |
| Children’s apprehension of needles | • Parents to highlight worries to outpatient manager (who is excellent and reassuring); and be supported in preparing their children  
• Support for parents, and help them not to pass on their own fears  
• Identify patients and make referral to clinical psychology if necessary  
• Use spray or ‘magic cream’  
• Distraction techniques | BHSCT | 2 | Support and reassurance for all the family |

5.1. **Human Resource issues arising from the Action Plan**

The need for one point of contact / coordinating role arose under a number of the actions discussed. This role could include:

• One individual as the named contact: telephone number and email address (add details onto BHSCT Intranet)
• Set up a contact email address and process for dealing promptly with enquiries
• Give parents contact numbers and accessible points of contact for different health support
• Supporting a referral pathway so that information, advice and support is available for parents at the right time
• Have Shine information leaflets and packs available for families at key points along the Care Pathway
• Letters go to parents, and a copy should be sent to the GP as a matter of course following every Hospital appointment – model of good practice
• Communication from Neurosurgeons and all services
• Coordination of follow-up appointments to be included in the Coordinator role
• Examine reappointment mechanism and explore issues
• Review letter to include line advising parents to contact the hospital if they do not receive an appointment date within a given time (see urology letter example)
• Ensure protocol is attached to notes and that staff are aware of the language that should be used
• Protocol for reappointment to be attached to the front of each child’s notes
• Support the development of a basic card / information sheet that parents have on them at all times and can take to A and E, including key contact person/s
• Work with members of the multi-disciplinary team to requisition capital equipment

Currently funding for the Health / Senior Advisor from Shine post ceases in September 2014. This role currently includes:
• Family home visits
• Network meetings
• Linkages with the Royal Victoria Hospital Spina Bifida multi-disciplinary team
• Coordinates Family Support Networks
• Attending Outpatient Clinics every other week, and facilitates parent networking
• Provision of information, support and advice
• Advocacy.

In additional, the proposal was made for the appointment of a Specialist Neuro Nurse.

5.2. ENGAGEMENT AND SHARED LEARNING

The final round table activity was an opportunity to consider two last questions:
• How often do you think the Trust should engage with parents and Shine in this or a similar format? Why?
• How have we benefitted from the shared learning?

Feedback from the three round table working groups is presented below.

How often do you think the Trust should engage with parents and Shine in this or a similar format? Why?
• This process should be ongoing. Shine should pass back information from parents and their experiences on an ongoing basis and be able to raise issues so that they don’t get lost.
• Joint role with Shine and BHSCT.
• Meet up with parents once a year
• Trust to report information and services through newsletter.
• Perhaps form a reference group – email people and meet once a year. Trust could give updates at Shine events.
• Comment forums at clinic (note: this is planned).
• Good to collect both negative and positive feedback.
• Clinicians are open to negative and constructive criticism.
• Re-engage with participants in relation to this process in twelve months time to give feedback on progress.
• Continue to use methods that have been used to date.
• Develop involvement on specific projects.
• Engagement at the clinic was useful.
• Use a variety of feedback methods.

How have we benefitted from the shared learning?
• Have seen action from being involved in this process.
• Parents feel reassured that things are being addressed and work goes on behind the scenes.
• Able to improve.
• Some people had pre-conceived ideas; this process actually demonstrated where they were good and where misinformed.
6.0. WORKSHOP EVALUATION
The Workshop participants were invited to complete a short evaluation questionnaire. Data from the Evaluation Questionnaire, completed by 13 people, is presented in this section of the Workshop Report.

The table below shows who completed the Evaluation Questionnaire.

<table>
<thead>
<tr>
<th>Participant Profile</th>
<th>No. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>A parent</td>
<td>3</td>
</tr>
<tr>
<td>Working with Shine</td>
<td>6</td>
</tr>
<tr>
<td>Working with the Trust</td>
<td>4</td>
</tr>
</tbody>
</table>

Six of the people who completed the Questionnaire had previously engaged in the consultation prior to the Workshop, completing surveys, participating in interviews, or participating in a focus group.

Five people gave comments about the consultation process:
- I would love to have been involved
- It was more than I anticipated – in a positive way
- It has been very beneficial to see the ongoing changes in the background and the willingness to make changes and ensure that they are as efficient and relevant as possible
- It has been very useful to get parent feedback
- Very professional process, and showed respect and empathy to parents.
Participants were invited to consider a series of questions related to the Workshop and provide a response (yes, not sure, or no). The data is presented in the table below.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Not sure</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was the Europa Hotel convenient for you to get to?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you like the venue?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the timing of the Workshop acceptable?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you receive sufficient information about the consultation feedback?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you find the round table discussions useful?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question continued</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel this morning has been a worthwhile use of your time?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel you were listened to this morning?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you learn anything during the Workshop?</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the Workshop been a positive experience?</td>
<td>12</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

As the table shows, the consensus of opinion is that the Workshop has been valuable at a number of levels.

Participants were invited to provide additional comments about how the Workshop was or was not useful. Feedback in full is presented below.
What did you find most useful about the Workshop and why?

- I found out more about the Spina Bifida survey – the bigger picture
- The impression that parent’s views are being taken on board
- Meeting people who can influence the development of future services at the Royal
- Being placed with a variety of stakeholders, and being made aware of the changes that are happening
- The parent’s story
- The open and honest discussions that took place; plus my opinions were noted down
- The opportunity to share experiences
- Open discussions to help bring parents’ concerns to the table
- Great to get feedback from all the work done. Great to get to hear parents opinions and their suggestions to improve services
- Looking at parents’ concerns especially in relation to reviewing time for shunts and developing specialised neuro nursing staff
- Round table discussions
- The knowledge that joined up working is felt positive by all.

What did you find least useful about the Workshop – and why?

6 participants noted that everything about the Workshop was useful; 5 did not make any comment. The two comments that were given were:

- Sad lack of attendance
- It’s a shame more parents were not here

Finally, participants were asked to provide any additional comments about your experiences during the consultation or the Workshop (for example, positives, negatives, ideas for improvement ....). Five people gave additional comments, which are given below.

- Very good morning. Thank you
- I will be in touch
• I think this has been a very useful process. I look forward to the Action Implementation plan
• Please let me know of any more as I’d like to be involved
• I think it would have been useful for the parents to have had time together to record issues as a group as well.
Appendices
Experience Questionnaire

This questionnaire will help you think about how you felt at different stages during the time you used our services.

This questionnaire has been designed using the Experience Based Design approach. For more information on this model please go to www.institute.nhs.uk/ebd

How did you feel?
Circle the words that best describe your feelings at each stage, or write your own words.

Why did you feel like this?
We’d like to know why you felt like this. Was it because of the journey, parking, staff, information provided, a long/short wait?
1. Did you receive Pre-Natal Counselling in the maternity hospital before your baby was born? How did you feel during and following your appointment?

<table>
<thead>
<tr>
<th>Satisfied</th>
<th>Supported</th>
<th>Safe</th>
<th>Reassured</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed</td>
<td>Scared</td>
<td>Worried</td>
<td>Lonely</td>
</tr>
<tr>
<td>Sad</td>
<td>Write your own words here</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please explain why you felt this way?

2. How did you feel about the amount of information provided when your child was born? (Please consider where it was provided and how it was provided)?

<table>
<thead>
<tr>
<th>Reassured</th>
<th>Supported</th>
<th>Satisfied</th>
<th>Worried</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe</td>
<td>Relieved</td>
<td>Overwhelmed</td>
<td>Informed</td>
</tr>
<tr>
<td>Confused</td>
<td>Scared</td>
<td>Write your own words here</td>
<td></td>
</tr>
</tbody>
</table>

Please explain why you felt this way?
3. How do you feel when you receive your letter before each of your appointments to the Spina Bifida Outpatients clinic?

<table>
<thead>
<tr>
<th>Reassured</th>
<th>Supported</th>
<th>Satisfied</th>
<th>Worried</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe</td>
<td>Relieved</td>
<td>Nervous</td>
<td>Informed</td>
</tr>
<tr>
<td>Sad</td>
<td>Overwhelmed</td>
<td></td>
<td>Write your own words here</td>
</tr>
</tbody>
</table>

Please explain why you felt this way?

4. After your journey, how do you usually feel on arrival at the Hospital site for your Outpatient appointment?

<table>
<thead>
<tr>
<th>Worried</th>
<th>Supported</th>
<th>Safe</th>
<th>Relieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfortable</td>
<td>Frustrated</td>
<td>Satisfied</td>
<td>Informed</td>
</tr>
<tr>
<td>Sad</td>
<td>Scared</td>
<td></td>
<td>Write your own words here</td>
</tr>
</tbody>
</table>

Please explain why you felt this way?
5. How do you usually feel on arrival at the clinic waiting area for your appointment?

<table>
<thead>
<tr>
<th>Satisfied</th>
<th>Supported</th>
<th>Safe</th>
<th>Good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfortable</td>
<td>Frustrated</td>
<td>Worried</td>
<td>Lonely</td>
</tr>
<tr>
<td>Relieved</td>
<td>reassured</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please explain why you felt this way?

6. A range of specialist staff review your child at each clinic visit. (Neurology, Urology, Urodynamics, Orthopaedics, Radiology, SHINE, etc) How does this make you feel?

<table>
<thead>
<tr>
<th>Satisfied</th>
<th>Supported</th>
<th>Safe</th>
<th>Relieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Confused</td>
<td>Worried</td>
<td>Reassured</td>
</tr>
<tr>
<td>Informed</td>
<td>Overwhelmed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please explain why you felt this way?
7. You are taught by Continence Nurse Specialists very soon after birth how to perform Clean Intermittent Catheterisation (CIC). How does this make you feel?

<table>
<thead>
<tr>
<th>Satisfied</th>
<th>Supported</th>
<th>Safe</th>
<th>Relieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overwhelmed</td>
<td>Confused</td>
<td>Worried</td>
<td>Reassured</td>
</tr>
<tr>
<td>Informed</td>
<td>Write your own words here</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please explain why you felt this way?

8. Are you usually offered information or support by any voluntary/support organisations when you visit the clinic? How does this make you feel?

<table>
<thead>
<tr>
<th>Satisfied</th>
<th>Supported</th>
<th>Safe</th>
<th>Relieved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Confused</td>
<td>Worried</td>
<td>Reassured</td>
</tr>
<tr>
<td>Informed</td>
<td>Write your own words here</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please explain why you felt this way?
9. In general, how would you describe your overall experience about the follow up care you receive? (e.g. phone calls, appointments, procedures, staff, venue, information, copies of clinic letters). Please feel free to give your own examples

10. Do you have any other comments regarding your overall experiences of our services?

If you would like any additional information, please contact: -Yvonne Cowan
Telephone 028 9504 6356
Appendix B

SPINA BIFIDA

Summary of Key Points

1. COUNSELLING

- Half of the parents who participated had a post natal diagnosis or a diagnosis very late in pregnancy. (Not as common now). Therefore most did not receive Pre Natal counselling or post natal counselling. A significant number of parents said they would have welcomed counselling.

- Need to clarify/differentiate between ‘genetic counselling’ and counselling

2. INFORMATION/COMMUNICATION

- Parents talked of being given the ‘worst case scenario,’ an overwhelming amount of information for a lot of parents particularly in the pre natal period, information too definitive. Talked of having their hope monitored throughout their child’s journey

- Parents scared and in shock. Hearing terminology that is new to them.

- How information is divulged is a recurrent theme, parents scared and in shock. Lot of mothers talked about reaction of the radiologist at the 20 week scan, being on their own when told the diagnosis, words and medical terms used that were not understood, not understanding the Dr. relaying the information because of language barriers, insensitivity etc

- The negative experience for parents having their babies in Hospitals outside of Belfast was a recurrent theme. Ranged from lack of information, to too much information, feeling scared and worried. Parents talked of having to google information. Significant number of parents, once they came to RJMH or RBHSC described it as being a very different experience, they felt very ‘reassured’ and ‘safe’.

- Referrals to Royal for level 2 scans etc from outlying hospitals can get lost, parents having to ring and track referral down to find not in the system

- Parents asked if they didn’t take their folic acid

- Post natally parents generally felt ‘incredibly supported’ and well informed, some did talk of feeling overwhelmed by all the information provided.

- Parents felt very reassured when they were transferred to the Royal, some talked again of feeling overwhelmed by the amount of professionals who
came to see them to talk about their role in their child’s care. Parents said it was a ‘lot to take in’.

- Paediatricians were described as much more knowledgeable and reassuring than the Obstetricians/ RJMS nursery staff. Often conflicting information given to parents, often felt the service between the 2 was disjointed
- A number of Parents said they would really have benefited from talking to a Neurologist in the antenatal period. It was felt they could provide lot of information and reassurance
- Some mothers spoke of concerns around bonding because they were separated from the baby while the baby went to RBHSC for surgery. Mothers spoke of feeling more involved in their child’s care once they joined their child in the RBHSC.
- Leaflets are outdated- shunt leaflet is out of date – Drs etc who are no longer with the Trust
- Communication outside appointments is an issue with a significant number of parents. No contact for general enquiries. Messages left on answering machines went unanswered often for many weeks.

3. ROLE OF SHINE

- SHINE/ASBAH has pivotal role to play, particularly post diagnosis, this was very apparent in parent’s responses. They talked regularly about the information, time and reassurance SHINE provided. A number of parents found out about SHINE through word of mouth, or the internet. Information about SHINE was not always passed on by staff.
- Couple of families not currently engaged with SHINE, felt they there was less of a role as the child got older.
4. APPOINTMENTS

- Car Parking was a major issue, feelings of frustration/s stress were used regularly. Nearly every one interviewed mentioned it. For those parents who travelled long distances for Out Patient appointments the issue was compounded by the car parking problems. Ranged from the very long wait to getting parked through to lack of disabled spaces.

- Outpatient appointments were for most parents a very positive experience. Most parents liked to see a range of staff/specialists i.e. neurosurgery, urology, paediatricians etc Staff were spoken of very highly, consultants were mentioned by name as well as nurses, reception staff, SHINE representatives also. Words such as reassured, supported were used frequently. Parents really appreciated follow up letters received after their appointment, consolidating all the information from the clinic visit.

- Contact at the clinics with other parents important

- Despite what staff thought, generally most parents don’t mind travelling because they do get to see a range of staff

- A few negative points regarding equipment, for e.g. Urodynamic equipment can break down and this can be frustrating, if the machine breaks it could be 3/12 before it is fixed. Waiting on SPLINTS is a big issue for a lot of families, can take 10-12 weeks for new splints, this meant for some children going without splints for that length of time.

- Dr.s reviewing shunts are very slow to review, you can be told review in 6 months but in reality can be 18 months

- There appears to be a lack of communication between consultants, eg neurology and orthopaedics don’t appear to share information

- Waiting Area, comments ranged from the need for it to be revamped to mentioning the seats with their backs to the television

- Contact outside clinics is an issue. Takes ages for appointments to be organised, appointment process for some parents very frustrating, follow up appointments in particular. Phone calls go unanswered, difficulties rearranging appointments. No one calls you back when you leave message, results are hard to get.
5. STAFF/SUPPORT

- Seeing Paediatricians prior birth very helpful.
- Staff in general throughout the report were described as helpful/supportive/brilliant/excellent

CHILDREN AND YOUNG PEOPLE FEEDBACK

- Positive responses to attending the clinic, children reported feeling good, happy, relaxed and supported. Talked of Consultants checking with them at appointments they understood what was happening, use of simple words to describe medical terms
- Some apprehension about needles- consistent worry even though it's not a major feature of the clinic- this was coming from younger children
- Long waits and hanging around was an issue- ‘boring’
- Children were very positive about all the staff- constantly referring to them as friendly and helpful.
- Liked to see other children with whom they had obviously made friends
- Lack of toys, etc to distract from the hanging around. Children talked about if there was, paper and pens to draw with, need for toys for older children, more entertainment for older children. Children talked about the having tables at a higher height for wheelchairs. Free/easy access to WI-FI would be great.
- Age appropriate information was suggested as being useful to take away from appointments or at key stages. Some children got their info from internet.
Appendix C

Good Practice and Positive Feedback

It should be noted that parents and children provided a lot of positive feedback during the consultation process. The following are not points for action … but we believe that it is important that good practice should not get lost.

- Post-natally parents felt incredibly supported and well informed
- Confidence of parents in Neurologists and Paediatricians
- Appreciation of follow up letters from appointments
- Parents spoke of the benefit of contact with other parents during Hospital appointments; and children also reported that they enjoyed seeing other children with whom they had made friends during hospital visits over time.
- Outpatient appointments were a very positive experience for most parents. Most parents liked the fact that they are able to see a range of staff and specialists on the same day (i.e. neurosurgery, urology, and paediatricians). This also links to the feedback that generally most parents do not mind travelling to the Royal Victoria Hospital because they get to see a range of staff when attending.
- Staff in general throughout the report were described as helpful, supportive, brilliant and / or excellent by parents and children
- Children reported feeling good, happy, relaxed and supported when they attended the clinics. They talked about Consultants checking with them during appointments that they understood what was happening, and that Consultants used simple words to describe medical terms.

All participants present had the opportunity to add to the information mapped on the wall chart and there were opportunities to ask clarification from staff as to why things happened as they did.
Positives were highlighted and opportunities were also provided to identify more negative experiences.

Time was set aside at the end of the workshop to identify and discuss priorities for action. This information was used to inform the development of an action plan which is included in this report.

_All the information from the process was collated and core themed into “positive aspects” and “areas for improvement”_