

Gloucestershire Listening Event

March 2017

Working with



Contents

Introduction	1
What happened?	1
What we learned	4
Inside Story	5
Last Story	6

Introduction

Thank you for attending our Listening Event. It was wonderful to see so many of you and we really hope you found the event useful.

We wanted to share a brief report with you about what we've learned and what we are planning to do as a result of the event, but also summarise the event to share with families who weren't able to attend.

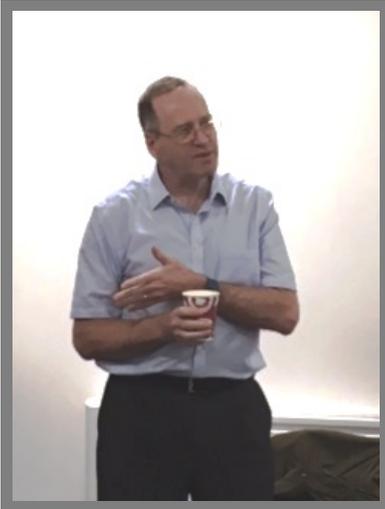
What happened?

Session 1 - Feedback from previous events

Mr Parry explained the background to the Listening Events and why we had decided to change the format. He highlighted the key work from previous events:

- Extensive review of written and web information which is ongoing. Updated leaflet drafts have been sent out to the families on the current involvement circulation list and additional changes have been made. This will also be made on the website so that all information is consistent. Information sheets providing more detailed risk and benefit information are also being developed which can be given in a sealed envelope allowing families the option as to whether they would like to read them.
- Review of consent process including research project looking at family perceptions of their level of preparation, both prior and after surgery. This had raised some interesting challenges as although in preparation and prior to the operation, families had felt adequately prepared, some had felt following surgery that in hindsight, they had not been as prepared as they

as they anticipated. The team will be exploring this further to see whether this seems to be a natural response to a difficult time or whether there is more that could be offered to help families feel better prepared.



Session 2 - Question and Answer session

Professor Tulloh and Mr Parry took questions from families which had been submitted in advance and also from the floor. These have been formatted into an FAQ list which we have added to the hospital website. Parents were also able to ask questions informally during the event or to write them down to be added to the list.

This list will be added to the website and further questions added as they arise, either through further Listening Events or direct patient. Some questions have been developed into video clips to better support families who were unable to attend the session and are available on the hospital website.

Parents were also able to share their own personal experiences with other parents, providing opportunity for peer support and reassurance.

Session 3 - Consultation on the Virtual pathway

Vanessa Garratt explained the development of the virtual pathway to date and asked the families present to undertake a final review for any further comments. Families were specifically asked to suggest how the pathway might be designed to appear accessible and engaging for parents. Families were show a range of styles and asked to comment on which ones they felt worked best, and also highlight anything they felt had been missed.

The key points made are summarised below:

- Add 'support' to the pathways as a box in its own right – particularly important for those not diagnosed through 'normal' route
- Make sure there is a signpost to support groups
- Include a 6 months later or post op box for families and for patients
- Create easy to follow flow charts with clear instructions
- Keep it simple – Step by step pathways with ability to click for more info – maybe even just the Word version
- Good layout, colours and clinical feel of the current Word pathway – should have a medical feel, maybe emotionless? Are pictures necessary?
- Emergency scenario – you need to mention this as process can change

Professor Tulloh and Mr Parry answering questions from families attending the event.”



- . Access to support when you are waiting for your diagnosis
- Should bereavement be included on first page – or at all?
- Good generic process but never going to capture every experience

As part of this exercise, a couple of other areas were highlighted where families felt things could improve:

- Access to psychology in your own area – not just in Bristol
- Psychology dept needs to have more people available
- Consent – families need TIME to think about it
- Families might prefer to have to ask for additional information rather than be given it routinely – you might feel tempted to look even if you don't want to!
- It can be difficult for patients when they are on other wards or at St Michaels hospital where they don't have the support of Ward 32 team.
- Please advertise the support groups through Gloucester Carers group as there may be other families who have not heard about it.



“Informative with an opportunity to talk at length with professionals post surgery.

I wasn't really sure what to expect but it exceeded my expectations.

Additional issues raised were predominantly around challenges on returning home from hospital and coordinating a range of local services which were not always set up to meet the specific needs of the patient. These are captured in the action plan together with a proposal for how these may start to be addressed.

Very grateful to all who gave up their time.”

What we learned

It's much easier to run an event in collaboration and we feel that the number of families attending showed that working with the support group was positive for families too. Also, choosing a location close to home and a time more suitable for families seems to have helped.

We were delighted to hear from everyone who completed the evaluation that the event was either what you expected or better. You felt that the question and answer session was the most helpful but also appreciated talking to other families in the same situation and to the professionals in a more informal setting.

Your main suggestion for improvement was to advertise more widely, run a longer session (although you recognised this could be difficult) and provide opportunities to split into diagnosis or condition based groups for more detailed discussion. New developments, research and technology was also suggested and we have already linked with the cardiac research team to offer a session on current projects as part of the next event.

We are pleased to be running a similar listening event in Exeter on 15th May for our families based in Devon and Somerset with the support of Heart Families South West.

Want to get directly involved in the work that the Bristol Royal Hospital for Children are doing in developing cardiac services?

Why not join our parent involvement group?

This will make sure you receive email updates and invitations to all of our events.

LIAISE FAMILY SUPPORT TEAM

Family Information Room
Level 2
Bristol Royal Hospital
for Children
Upper Maudlin Street
Bristol
BS2 8BJ

PHONE:
0117 342 8065

E-MAIL:
bchinfo@UHBristol.nhs.uk

We're on the Web!

See us at:

www.uhbristol.nhs.uk/bristol-royal-hospital-for-children

What happens next?

Based on what you told us, it felt that the following were important to look at further:

- Wording on discharge letters can have an impact on DLA applications etc – needs to be explicit that child has ongoing needs after surgery
- Please add information on chest closure, risk of imbalance and chest clicking to post op information
- Help us understand who is responsible for what aspect of our care once we are discharged
- Help us manage the longer term psychological effects of the experience of heart surgery
- Make it easier for us to get the medication and equipment we need once we are discharged so we don't have to fight
- Educate GPs and community staff so they don't just send us to hospital every time.

We have created an action plan based on these issues and have agreed who will take responsibility for taking things forward. In some cases, we may be asking for further help from you to really understand the problem and agree the best solution, so if you haven't completed your involvement form to allow us to contact you, please let us know.

Want to get involved?

Based in Gloucestershire?

Join the Heart Children Gloucestershire Support Group

This group is managed via Facebook. You can send them a request to join and they will contact you to get you registered.

Based elsewhere in the south west?

Heart Families South West fun a similar group.

They can also be contacted via Facebook or via their website:

www.heartfamilies.org.uk

Interested in the Network?

To get involved in how the Congenital Heart Disease Network is developing in the South West?

Contact the Network Manager, for more information:

James.Dunn2@UHBristol.nhs.uk

heart children
gloucestershire

