

# Exeter Listening Event

## May 2017

Working with



# Heart Families

South West

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## Introduction

Thank you for attending our Listening Event. Whilst it was a small group 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

Dr Tometzki explained the background to the Listening Events and described the journey that led us to the current format for the events highlighting the key work from previous events including:

- Extensive review of written and web information which is ongoing for both the hospital and the Network. 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 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.

Dr Tometzki also talked a little about the role of the Network and the importance of continued family involvement in helping to drive forward the national standards for our cardiac families across the region

He then introduced Guido Pieles who is one of our newest Consultant Cardiologists in the hospital. Guido gave the room a run-down of his career to date and his current areas of interest.....

### Session 2 - Question and Answer session



The whole team then took questions from families in attendance and also some that had been sent in via the facebook page. Parents were given the opportunity to ask questions informally during the event or to write them down to be added to the list. These have been formatted into an FAQ list which we have added to the hospital website.

This list will be added to the website and further questions added as they arise, either through further Listening Events or direct patient contact. 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 We are working with the team to expand on these to cover as many of the common themes as we are able.

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

### Session 3 – Family involvement in Cardiac Research

Karen Sheehan, Paediatric Cardiac Research Nurse attended the event to talk to families about how they and the patient groups could help us to drive forward research. Karen talked to the group about how they could get involved in research, what they could expect if they were involved in a research project and the fact that often reasonable out of pocket expenses can be repaid. Karen was interested to hear back from the group how and what they would like to hear about research studies. The group felt that the face book group could be a good approach to getting information about research out to a wide audience but if you have other

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*Doctors Tometzki and Pieles, Consultant Cardiologists attended the session to answer family's questions.*



## 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 consider alternative timings perhaps on a weekend when potentially more people could attend; you wanted more time and perhaps a mix of clinicians including a surgeon or local paediatric cardiologists and more psychology information.

We are currently planning a similar listening event in for our families in Wales later on in the year.

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

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Bristol Royal Hospital  
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Upper Maudlin Street  
Bristol  
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0117 342 8065

E-MAIL:  
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We're on the Web!

See us at:

[www.uhbristol.nhs.uk/bristol-royal-hospital-for-children](http://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.

Based on feedback from other sessions we are also looking at:

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 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](http://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](mailto:James.Dunn2@UHBristol.nhs.uk)



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.



*"A good open discussion with the clinicians, they were all very open and honest."*

*"It was great to have a mixture of staff from different disciplines at the hospital"*

*"I enjoyed hearing other parent's experiences and question that I may not have thought about"*

*"It helpful to meet other people in similar situations and professionals who could support and advise us face to face"*

*"It was great being able to ask anything and everything lots of the team present"*

