

# NORTH WEST CONGENITAL HEART DISEASE NETWORK

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**Patient Experience  
Report  
6th June 2024**

15th May - 31st December 2023

**2024**

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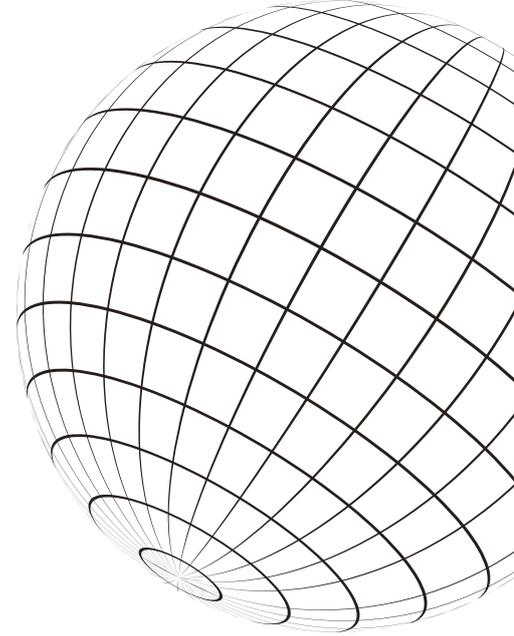
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# INTRODUCTION

## Background

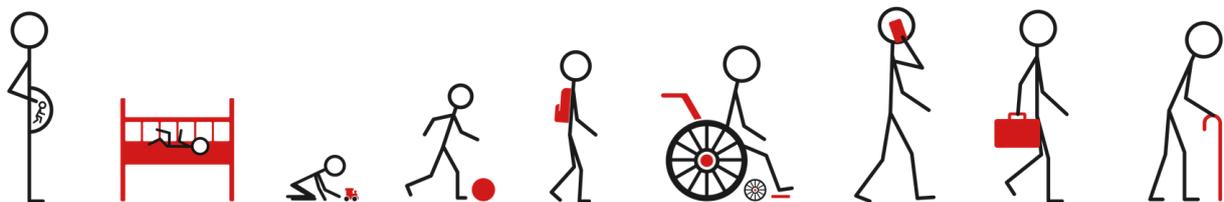


The Network Patient and Public Voice (PPV) Group was established in May 2020 at the height of the pandemic. They quickly established themselves as a group of committed users of the service with a combination of people with lived experience. This included family members with children, adults with congenital heart disease and people representing the charity sector.

One of the first concerns raised was about communication and how this was often at the heart of any problems that patients and families experienced. As a result of this a project was initiated to try and establish what patients and families were experiencing. A number of focus groups were held with families and adult patients to listen to their shared experiences. These focus groups were transcribed and the information used to create two patient experience questionnaires. One for paediatric cardiac patients and their families and one for adult congenital heart disease patients.

These surveys are hosted on a platform called “IQVIA” based at Alder Hey Children’s NHS Foundation Trust. The surveys have been live since May 2023.

This is a report looking at the results of those surveys covering the period 15th May 2023 - 31st December 2023.

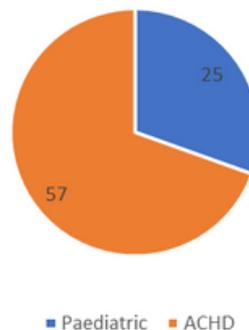


# WHO COMPLETED THE



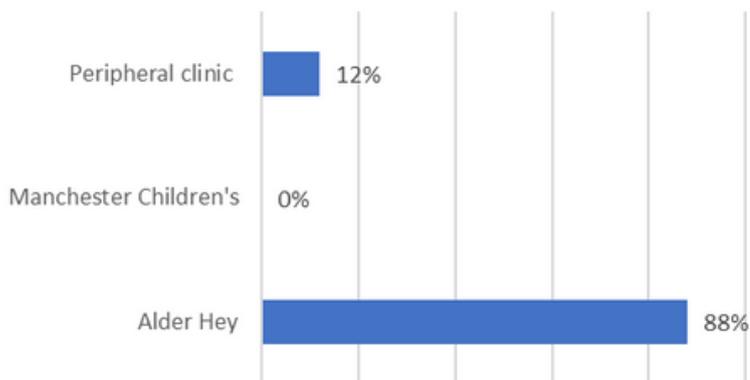
Survey

Total number of surveys completed  
15th May - 23rd December 2023

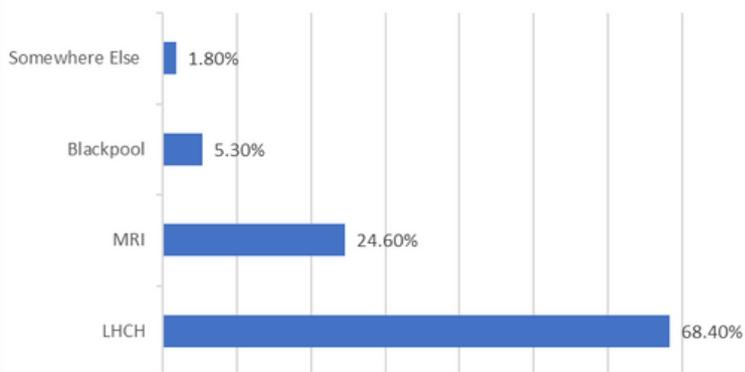


## From which hospital?

Children's Survey



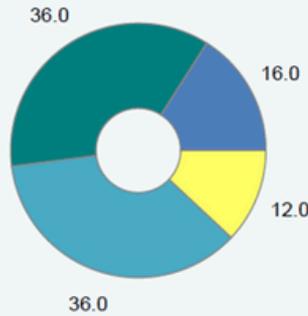
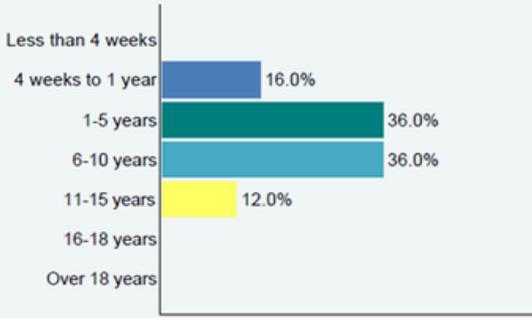
Adult Survey





# AGE OF CHILDREN

1. How old is your child?

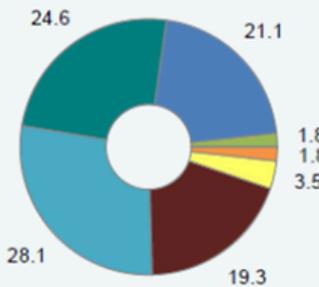
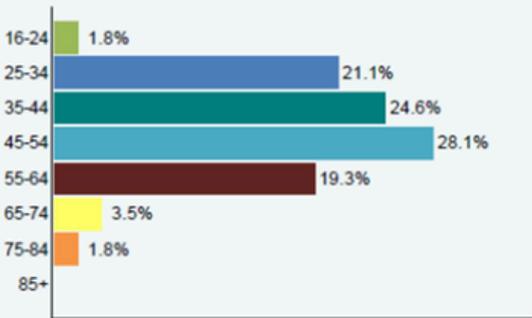


Less than 4 weeks	0.0%
4 weeks to 1 year	16.0%
1-5 years	36.0%
6-10 years	36.0%
11-15 years	12.0%
16-18 years	0.0%
Over 18 years	0.0%

Non Scoring, 25 responses

# AGE OF ADULT PATIENTS

106. How old are you?

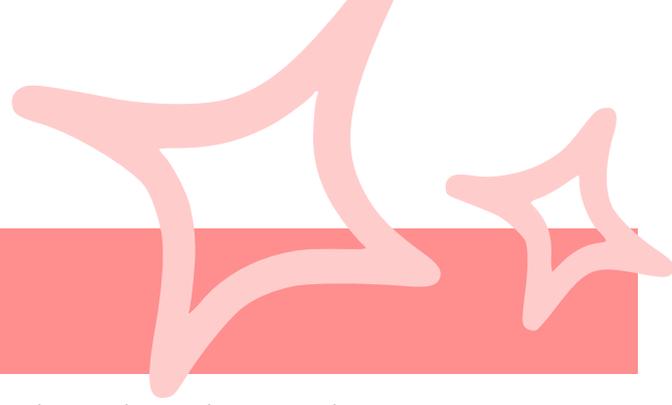


16-24	1.8%
25-34	21.1%
35-44	24.6%
45-54	28.1%
55-64	19.3%
65-74	3.5%
75-84	1.8%
85+	0.0%

Non Scoring, 57 responses



# Main Highlight



The report demonstrated the vital role that the nurse specialists play in supporting patients of all ages. from antenatal diagnosis, through childhood and into the adult service. The vast majority of people who had an encounter with a nurse specialist said it was helpful.

**96.3%** Seeing ACHD nurse in clinic was helpful

**100%** Found pre-op visits helpful at Alder Hey

**92.5%** Found the ACHD helpline useful

**95.7%** found visit by nurse specialist on the ward helpful

**100%** able to ask questions in ACHD Clinic

**91.2%** ACHD patients were treated with dignity & respect

**100% of families supported by the Fetal Cardiac Nurse Specialists found it helpful**



**100%**

**IMPORTANT**

# Important Points



**37%**

**Fathers had to wait for mother to be present before information was given to them**

“Just had heart surgery didn't help me carry my bags down flights of stairs on the way out or help me to the car park”



**Good communication is vital between family, carers and all health care professionals**



**The care I received was outstanding!**



# What did you tell us?



Not everyone knows how to access support

Some people experienced confusion about appointments



No one saw a cardiac link nurse at a peripheral clinic

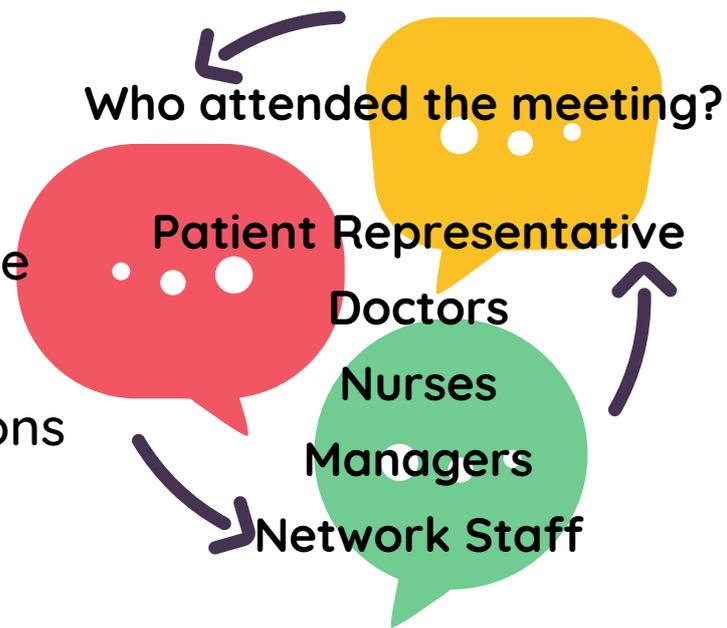
Only 5.3% of adults were offered a copy of their own ECG at clinic



CONTINUOUS IMPROVEMENT

# What did we agree to do?

The report highlighted many positive aspects of care that people experience and also highlighted many areas where we can improve. Everyone at the meeting agreed some key actions to work on to improve patient experience



What we will do?	How will we do it?	How will we know?
Create a series of videos to help families know what support is available and how to access it	<p>We will ask families what they need</p> <p>We will create 5 short videos based on what they tell us</p>	<ul style="list-style-type: none"> <li>The videos will be available on Network website</li> <li>Improvement in survey results</li> </ul>
We will agree minimum standards for peripheral clinics	We will work with local paediatricians with expertise in cardiology and support them to develop link nurse roles	<ul style="list-style-type: none"> <li>Network standards for peripheral clinics will be available on our website</li> <li>We will start to see link nurses</li> </ul>
Everyone should be offered a copy of their ECG	Work with ECG departments to remind them to offer a copy of the ECG to the patient	<ul style="list-style-type: none"> <li>Patients offered a copy of their own ECG</li> <li>Improvement in survey results</li> </ul>
For appointment times to be clear prior to MR scans	Liaise with MR departments to make sure that appointment times are clear and take into account preparation time	<ul style="list-style-type: none"> <li>Appointment letters are clear</li> <li>Improvement in survey results</li> </ul>



# NEXT STEPS

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## What else do we need to do?

The network, staff and patient representatives will continue to work hard to deliver the following:

# 1

### **ENCOURAGE MORE PEOPLE TO COMPLETE THE SURVEY**

Especially families attending Royal Manchester Children's Hospital, Cardiac Maternity and Fetal Cardiology

# 2

### **DEVELOP 2 MORE SURVEYS**

We are in the process of developing a survey for young people going through transition and one for people with learning disabilities and their families

# 3

### **ADVERTISE THE SURVEY**

QR code to be added to nurse specialist business cards. Network to promote use of survey across all providers

# 4

### **ADMIN ISSUES**

Operational managers to look at problems with admin, to find solutions and to appreciate impact on patient experience

# CONCLUSION

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**We have a lot of work to do and we would like to thank everyone who helped agree what the top priorities should be**



## **PRIORITY 1**

Development of 5 videos to sign post families to what support is available and how to access it

## **PRIORITY 2**

We will agree minimum standards for peripheral clinics that meets NHS England standards and promotes the role of the link nurse



## **PRIORITY 3**

Ensure that every ACHD patient is offered a copy of their own ECG

**We look forward to working with clinical staff, managers and patients to work towards these goals!**

# THANK YOU!

## ACKNOWLEDGEMENTS

We would like to thank the significant role that our Patient and Public Voice (PPV) group have played in helping the Network get to a position where we are able to review patient feedback. To be able to work together to agree what needs to improve has been a privilege. We thank all of the staff for promoting the survey and being involved in reviewing the results too. Most of all we thank all of the families and patients who took the time to complete the surveys. Be assured your feedback will make a difference!



### The surveys are always open

click here



scan here



or

**Contact**

Linda Griffiths  
Lead Nurse

NW CHD Network

Email: [northwestchdnetwork@alderhey.nhs.uk](mailto:northwestchdnetwork@alderhey.nhs.uk)

X @NwchdN

