# Patient, Public Involvement (PPI):

# Northern Ireland Congenital Diaphragmatic Hernia Conference

## 10th August 2024

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### Aim

We aimed to bring together patients and families affected by Congenital Diaphragmatic Hernia (CDH) living in N.Ireland for information giving and engagement in future research.

### Methods

Families were invited to attend through the national CDH UK network (social media and personal contacts), QUB PPI network and Rare Disease Ireland network. The event took place in a seminar room in W5, Belfast. Patients were invited to respond to interactive questionnaires. Small group discussions were facilitated by local health care professionals to identify patient priorities in this population.

### Results

In total 18 parents or family members, 2 adults affected by CDH and 18 children attended the event. Major issues raised included the need for long term follow-up, transition to adult services and the risk of CDH recurrence. Electronic and written feedback was positive; all said they found the day helpful and would attend another event.

### Conclusion

The NI CDH population are willing to participate and support local research into the disease.

## Background

Congenital diaphragmatic hernia (CDH) is a rare disease in which infants are born with a diaphragmatic defect, usually on the left side. Most of these patients (>70%) are diagnosed antenatally. The diaphragmatic defect permits movement of the abdominal contents into the fetal chest and requires diaphragmatic repair in the early neonatal period. Survival in CDH is improving with recent advances in antenatal treatment, namely fetal endotracheal occlusion (FETO) which improves postnatal survival in those most severely affected by CDH (1). Overall survival of infants born with CDH is around 73% (2).

In Northern Ireland, between 1-5 children per year are born with CDH. Pregnancy, until the time of first hospital discharge, represents an intensive period of medical input for families affected. In the UK, CDH UK is the leading charity for these families. It offers complimentary care to patients and their families in the form of information, emotional and practical support and by conducting, encouraging and funding research https://cdhuk.org.uk/about-cdh-uk/. They have a network of CDH patients which have contributed to surveys to inform future research and an understanding of the patient journey(3,4).Within QUB, Dr Patrice Eastwood is establishing a clinical and laboratory research line with the focus on the CDH population.

We aimed to invite our local CDH population to an information session and to help identify our local population needs. Reporting of this workshop is structured recommended GRIPP2 reporting checklist (5).

## Methods

We reached out to the public through the national CDH UK network (social media and personal contacts), QUB PPI network and Rare Disease Network Ireland. A flier was designed and all attendees were invited to registrar on Eventbrite (appendix 1). The event was arranged at a seminar room in W5, Belfast. Families were given free entry to the science exhibition at W5 following the session. The event opened with presentations by CDH UK chair (Mrs Beverely Power) on resources available for CDH patients and Dr Patrice Eastwood (Academic Clinical Lecturer, QUB) on current research at QUB. Patients were invited to respond to interactive questionnaires (VEVOX, QUB platform). Small group discussions were facilitated by local health care professionals to identify patient priorities for research. Participants were asked the major issues facing the CDH population, what would help in Northern Ireland, what needed more research in CDH, role of laboratory studies in CDH and willingness to partake in studies. Permission was asked for all photographs. The event was funded by CDH UK.

## Results

In total 18 parents or family members, 2 adults affected by CDH and 18 children attended the event. Five healthcare professionals, the CDH UK committee lead and 3 other helpers attended. Participants were broken into four small groups with a play area for the children (appendix 2). The themes arising from the group discussion are given as follows with comments given in the appendix 5.

### *Need for long-term follow-up*

One of the major themes of the workshop was the need for long-term follow-up. Current follow-up tends to be with respiratory physicians. Adult patients feel the transition from paediatric to adult services needs to be improved. Many issues raised would be best addressed in an annual clinic in a multidisciplinary team setting. A few families mentioned bespoke clinics for CDH available in other parts of the UK i.e. Glasgow.

### *Risk of Recurrence*

A major anxiety for families was the risk of CDH recurrence. There was a concern due to lack of awareness what the symptoms of this might be. One family requested more information regarding emergency treatment for recurrence and the need for first aid training. Many families suggested the use of routine imaging for surveillance of recurrence.

### *Feeding Issues*

Many families felt their child with CDH was a fussy eater compared to their other children. Some explained children were slow eaters or had a selective diet with particular attention to textures and meat content. Appetite issues were also raised.

### *Chronic issues*

There was a desire for more information on the long-term outcomes in CDH. This included long-term respiratory function and the impact chronic lung disease. Other sources of anxiety were the risk of bowel obstruction, future pregnancy in females, the impact of chest wall deformity. In general families wanted to advice on modifiable factors that could be impcated by lifestyle changes. Some children had neurodevelopmental issues and were slower to reach milestones.

### *Early years*

Several families felt that more extensive antenatal conselling would be helpful. They also explained the hospitalization and surgery took them away from home, other children and ultimately their family support.

### *Education*

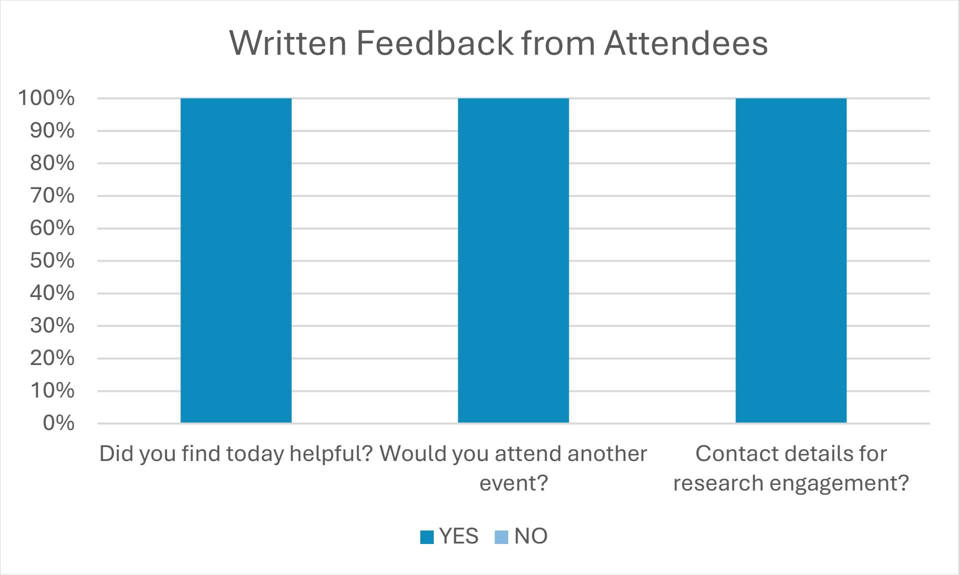
One of the major themes of the event was the desire for more education regarding CDH. Participants suggested this should be available for the extended family to include siblings, other family members and those provide care for children such as teachers.

### *Research*

Barriers to participating in Research included work commitments and school timings. Travel could be a barrier but was not felt to be insurmountable. Participating in research was felt to be important as it would “offer hope to other families”. One family stated “the risk has to be worth it – good evidence interventions are safe.”

### Feedback

Written feedback (appendix 3) and VEVOX polling was used for interactive feedback (appendix 4). 12 sets of written feedback were given (Graph 1). All said they found the day helpful, would attend another event and give details to be contacted for involvement in research projects. A list of comments were provided (appendix 5). The majority were positive, with “best bits” sited as the information given and ability to meet other families and survivors. Points for improvement centered around the audio and preferences for future events. Vevox feedback (appendix 4) during the presentation reflected this with all families wanting to partake in studies and feeling laboratory research had a role in treatment of CDH.



*Graph 1: Written feedback given from participants*

The event was disseminated on local media outlets https://armaghi.com/news/armagh-news/co-armagh-families-affected-by-rare-medical-condition-cdh-come-together-in-belfast/248903, within Belfast Trust and QUB networks.

## Conclusion

CDH is a lifelong condition, this PPI event reflected the need for lifelong input by healthcare professionals. Annual attendance at a bespoke CDH clinic run by members of the MDT would address many of the concerns and anxieties for families in this population. There was overwhelming support for research in the local population and all attendees would engage with future initiatives.

## References

1. Deprest JA, Nicolaides KH, Benachi A, Gratacos E, Ryan G, Persico N, et al. Randomized Trial of Fetal Surgery for Severe Left Diaphragmatic Hernia. N Engl J Med [Internet]. 2021 Jul 8 [cited 2022 May 31];385(2):107–18. Available from: https://pubmed.ncbi.nlm.nih.gov/34106556/

2. Snoek KG, Reiss IKM, Greenough A, Capolupo I, Urlesberger B, Wessel L, et al. Standardized Postnatal Management of Infants with Congenital Diaphragmatic Hernia in Europe: The CDH EURO Consortium Consensus - 2015 Update. Neonatology [Internet]. 2016 [cited 2017 Feb 27];110(1):66–74. Available from: http://www.ncbi.nlm.nih.gov/pubmed/27077664

3. Power B. The CDH patient perspective journey. Front Pediatr. 2023;11(February):1–6.

4. Power B, Shibuya S, Lane B, Eaton S, De Coppi P. Long-term feeding issue and its impact on the daily life of congenital diaphragmatic hernia survivors: results of the first patient-led survey. Pediatr Surg Int [Internet]. 2020;36(1):63–8. Available from: https://doi.org/10.1007/s00383-019-04570-6

5. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. BMJ. 2017;358.

**Appendix 1:**

QUEEN'S UNIVERSITY BELFAST

IN PARTNERSHIP WITH QUEEN'S UNIVERSITY BELFAST

# 'CDH Community Conference'

**When?**
We are getting together in Belfast,
Northern Ireland
on Saturday 10th August 2024

**Where?**
Seminar 1 & 2, W5, The Odyssey
Trust Company
2 Queen's Quay | Belfast | BT3 9QQ

**What time?**
2pm - 4pm
then free entry to W5 afterwards

Come along and meet other families and learn about what research is going on and how you can get involved!

**Email events@cdhuk.org.uk**

cdh UK The Congenital Diaphragmatic Hernia Charity

**FREEPHONE: 0800 731 6991** www.cdhuk.org.uk

## Appendix 2: Photographs

1. Group photo: all delegates

2. Event cake

3. Small group sessions

## APPENDIX 3: FEEDBACK

### CDH Community Conference

### 10th August 2024

1. *Did you find today helpful?*

   Yes ☐ No ☐

2. *What was the best bit?*

3. *How could we have improved today?*

4. *Would you attend another event?*

   Yes ☐ No ☐

5. What would you suggest is included in future events?

***If you are willing to be contacted*** to be involved in clinical research studies please include your name, contact details, age and name (if your child has CDH) below?

Name…………………………………….

Child with CDH name (if applicable) ……………………………………………………

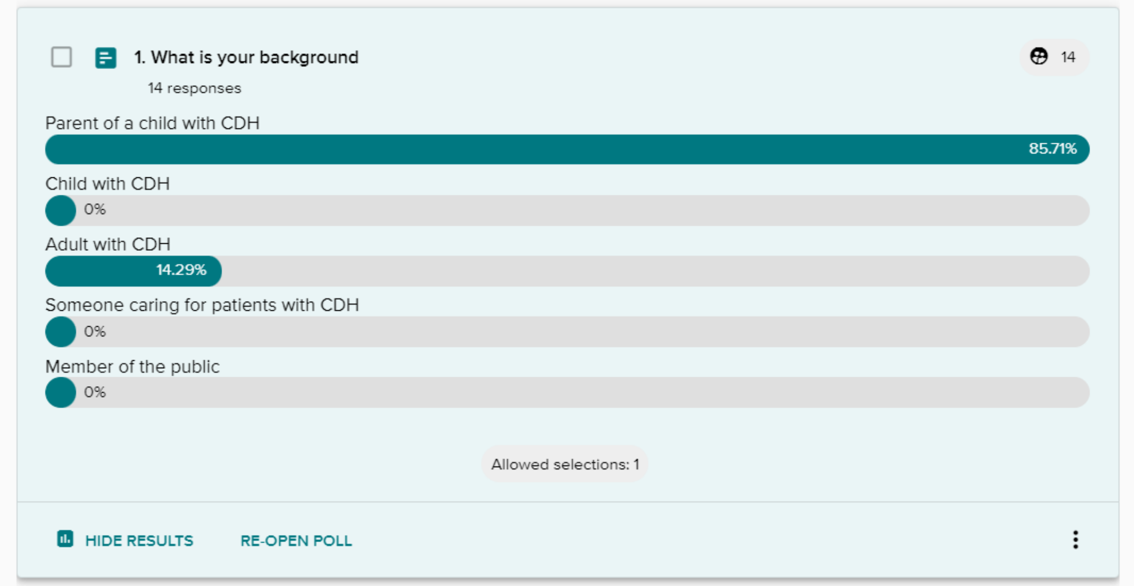
Date of Birth (person with CDH)…………………………

Email address………………………..

Mobile number……………………………….

**Thank-you for attending- enjoy W5!**

Appendix 4: VEVOX POLL


☐ 1. What is your background

14 responses

Parent of a child with CDH 85.71%

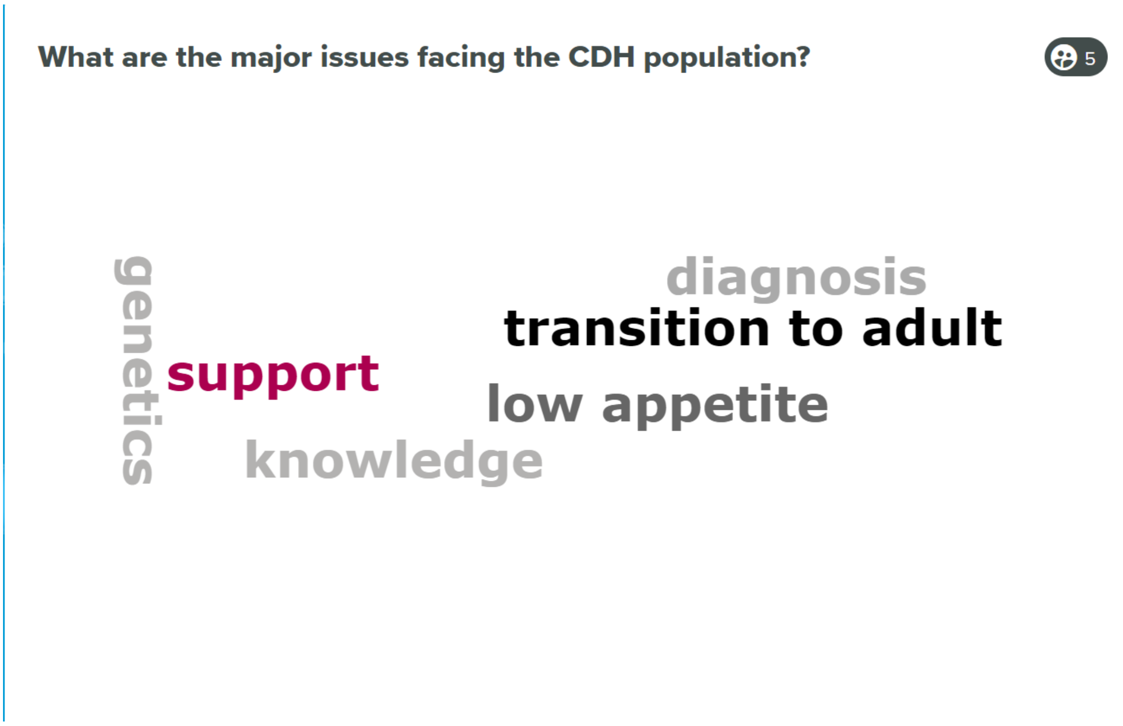
Child with CDH 0%

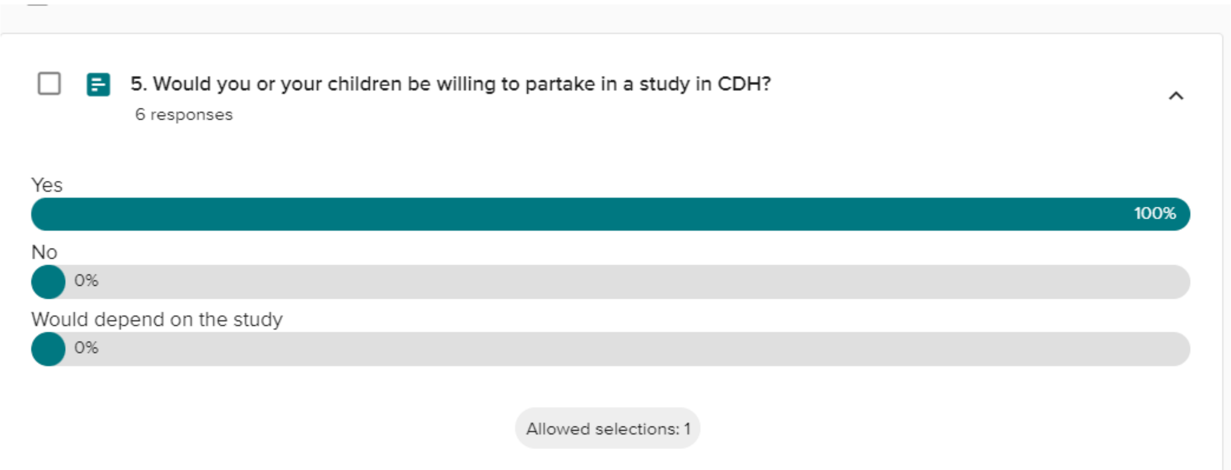
Adult with CDH 14.29%

Someone caring for patients with CDH 0%

Member of the public 0%

Allowed selections: 1


What are the major issues facing the CDH population?



☐ 5. Would you or your children be willing to partake in a study in CDH?

6 responses

Yes

100%

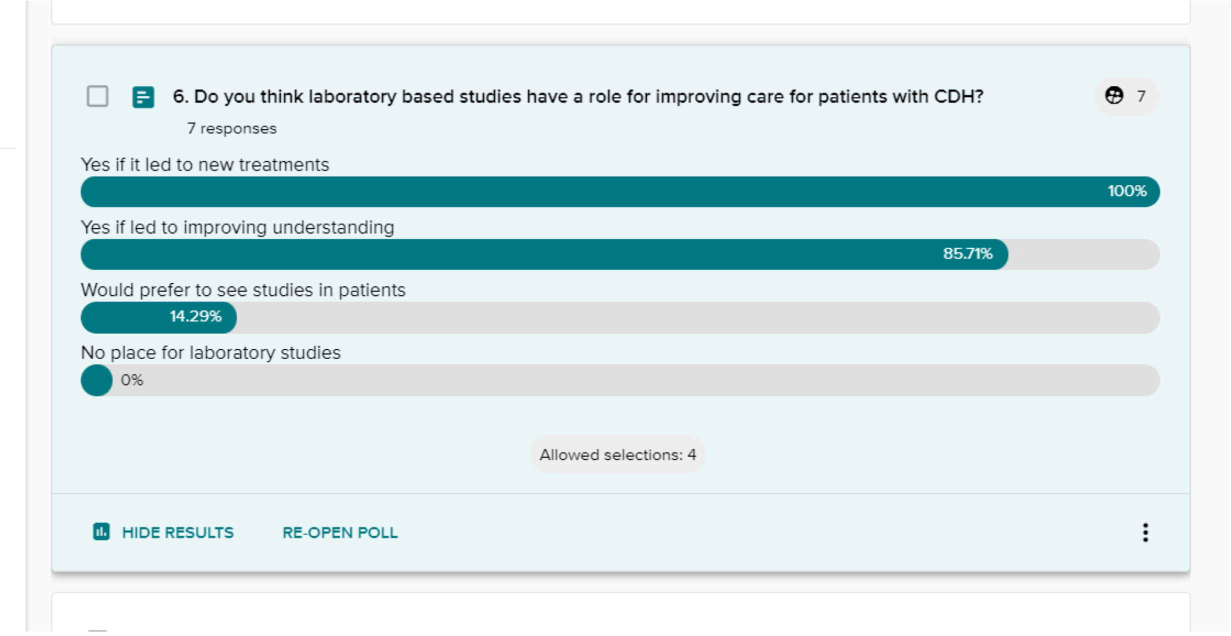
No

0%

Would depend on the study

0%

Allowed selections: 1



☐ 6. Do you think laboratory based studies have a role for improving care for patients with CDH?

7 responses

Yes if it led to new treatments

100%

Yes if led to improving understanding

85.71%

Would prefer to see studies in patients

14.29%

No place for laboratory studies

0%

Allowed selections: 4

## Appendix 5:

### What was the best bit?

“Having the opportunity to speak to health professionals as an adult survivor about care in adulthood.”

“To meet other people living with CDH and find out more about research.”

“Being able to talk to other parents with children with CDH.”

“Meeting other parents/ children. Asking questions.”

“More information. Group activities – discussing things with other parents.”

“Talking to others.”

“Information on future research plans and invitation to help/ be involved with this.”

“Meeting other parents of CDH children and talking about experiences.”

“Knowledge.”

“Information into research.”

“Presentation.”

“Information we never really thought about.”

### How could we have improved today?

“Maybe a way to connect with adult survivors as well as families. I find that as an adult survivor not many events, networks, online groups or websites are aimed at me. It would be good to meet other adults with the condition and have a space for just us to speak.”

“Microphone.”

“Meeting adults living with CDH and their journeys.”

“We at times found it difficult to hear the speaker. Conference was good information given and entertainments for kids.”

“Today was great – hard to say anything.”

### What do you suggest is included in future events?

“More about adulthood as a survivor. A space for kids to go as the noise made it hard to hear at times.”

“Hearing stories of older CDH patients. Updates on research/ developments.”

“It would be nice if parents introduced themselves- we met others at our table but not other tables.”

“Personal stories.”

“Keep it child friendly.”