

KIDS IMMUNE DEVELOPMENT: COMMUNITY CONVERSATION

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WE WOULD LIKE TO ACKNOWLEDGE THE FOLLOWING

We acknowledge the traditional custodians throughout Western Australia and their continuing connection to the land, waters and community. We pay our respects to all members of the Aboriginal communities and their culture and to Elders past and present.

Thank you to all of the consumers and community members who attended the event. We couldn't have done this without any of you.

We'd also like to acknowledge the team from the Telethon Kids Institute and the Consumer and Community Health Research Network (CCHRN) support team for their hard work in successfully delivering the Community Conversation. Our heartfelt thanks.

WHO IS THE CONSUMER AND COMMUNITY HEALTH RESEARCH NETWORK?

The Consumer and Community Health Research Network (CCHRN) supports consumer and community involvement across the Western Australian Health Translation Network (WAHTN) partner organisations.

CCHRN's Vision is to improve lives by ensuring the community's voice is heard and understood in health research

CCHRN's Mission is enabling consumer and community involvement in health research by supporting and connecting community with researchers, partners and policy makers

In order to achieve CCHRN's Vision we:

- Are inclusive
- Trust, respect, support and value each other and those we work with
- Work as a team
- Are relevant and sustainable

so as to make a difference

WHAT IS A COMMUNITY CONVERSATION?

A community conversation is an event using an abridged version of the **World Cafe Method**, known internationally as an easy-to-use format for creating open conversations around questions of importance to a specific topic.

To effectively capture what's discussed, around 6-10 community members are grouped at tables with a facilitator who directs the conversation. Specific questions relevant to the subject matter are discussed in an open and friendly environment.

All comments are written on butchers paper and used to develop a report from the conversation.

The benefits of using this method include:

- Everyone having an opportunity to answer all questions
 - Community members are encouraged to engage in conversations in a comfortable space
 - Having diverse perspectives which are valued and respected
 - Community members are encouraged to hear and explore different ideas
 - The opportunity to build a foundation of trust among community members and facilitators
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WHAT IS A COMMUNITY CONVERSATION?

Sometimes the community conversation method is also used in conjunction with an additional tool known as a **Dotmocracy**

This tool is used to help community members to vote on their chosen options using a limited number of dot stickers. This is a quick and simple method for prioritising a long list of options. Community members are given a set number of stickers and asked to vote by placing the dots next to the answers or ideas they believe are the most important. Community members can spread their stickers across multiple ideas or place all of the stickers against one item.

The options with the most stickers at the end of voting 'win'. This helps the researchers identify the community members priorities relating to the community conversation subject.

THE COMMUNITY CONVERSATION TEAM

Deb Langridge, CCHRN Head: Has worked in the public health and prevention space at all levels of government - Federal, State and Local - and the not for profit sectors to contribute to the health and well-being of communities. She has worked to capture the voices of all parts of the community including access and inclusion, Aboriginal and Torres Strait Islander people, Culturally and Linguistically diverse communities, children and young people, mental health and community services. Deb has been the chair of Advisory Groups both in NSW and WA connecting community, government and well-being and was a member of the NSW Commission for Children and Young People's work with the NSW Parliamentary Inquiry on Children and the Built Environment. She was also a representative for WA Local Government on the recent WA Sustainable Health Review.

Associate Professor Deb Strickland, Lead Researcher: Completed her PhD at the University of Western Australia (UWA) in the regulation of immune homeostatic processes in the respiratory tract. Associate Professor Strickland's research program is targeted towards addressing key fundamental gaps in the understanding of immune development, homeostatic mechanisms and how the immune system can be programmed to drive increased disease susceptibility, or trained to mitigate disease risk. With the overarching goal of developing potential preventative strategies. Assoc Prof Strickland's current positions are as Team Leader Experimental Immunology, Athena Swan Chair, Early Environment Research Focus Area chair, and Adjunct Associate Professor UWA.

Thanks also to Tanya Jones and Elysia Hollams for their support of the community conversation.

ABOUT THE KIDS IMMUNE DEVELOPMENT COMMUNITY CONVERSATION

The aim of this event was to allow for an open discussion of views from community members. Community involvement is essential in research as it enables researchers to gain an understanding of some of the issues faced by people in certain communities.

The identification of these issues allows for the development of more important research questions and encourages community members to participate in data collection

23 community members attended and shared their perspectives on child immune development and research. Community members are referred to as attendees in this report.

KEY QUESTIONS DISCUSSED

- What do you think is important to understand about child immune development?
- What specific things in life do you think influences child immune development?
- What **would** you be prepared to do for you or your child to prevent disease?
- What **wouldn't** you be prepared to do?
- What do you think we need to do to inform the public on immune development?





REPORT PREAMBLE

The conversation was run using an abridged version of the World Café process with the four table facilitators staying with their tables for the entire community conversation. There was one table for young people as there was sufficient attendance of youth to form a table. Other attendees able to sit on a table of their choice.

Attendees had approximately 15 minutes to discuss each of the four questions with table facilitators noting what the attendees said. Question 3 had two parts to it - what would and wouldn't attendees do for their child's health.

Facilitators were asked to provide key point(s) from the discussion at the end of the event.

QUESTION 1

What do you think is important to understand about child immune development?

UNDERSTANDING CHILD IMMUNE DEVELOPMENT

Question 1

This question split the responses into two themes - understanding and the broader interaction between genetics, inter-generational influences, and the environment.

The amount people want to know differs:

- Some people want to know **everything**
- Some people want to know mainly (or only) what they can modify or control
- Some would like to know: "What is the best thing I can do as a parent for my children?"

Other themes and issues which emerged from the four group discussions:

- Control of immune development
 - Interactions between genetics and the environment
 - Inheritance and inter-generational influences
 - Parental and pregnancy influences
 - Broader environmental influences
 - Prediction and timing of immune-based issues
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QUESTION 2

What specific things in life do you think influences child immune development?

LIFE INFLUENCES

Question 2

A long list of topics were discussed and fell into the following broad categories:

- Genetics
 - Vaccinations - whether or not you decide to vaccinate and at what stage of life
 - Economic and social status
 - Awareness of child health issues
 - Where you live (or work) and related exposures
 - Reduced access to medical services for reasons other than location - including languages other than English spoken at home, poverty and high medical costs
 - Diet and child feeding practices
 - Medication use
 - Method of birth
 - Maternal health, pre-existing health of parents
 - Parenting and family
 - Exposure to day-care and travel
 - Illness history
 - Growth spurts
 - Age at which a child produces antibodies and how many
 - Immunity from the mother waning and being taken over by the child's own immunity
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QUESTION 3A

What **would** you be prepared to do for you or your child to prevent disease?

POSITIVE PREPARATION

Question 3A

Some people indicated that they would do **anything** and **everything** to be prepared to prevent disease in their children.

The following common themes emerged across the discussion groups:

- Medical tests and procedures
- Vaccinations
- Genetic testing
- Home and lifestyle changes
- Accessing services
- Education and advocacy

Interestingly it was the youth table who agreed they would do all standard tests (blood, urine, saliva) and would submit tissue biopsies under most circumstances. The other three groups had a range of views around what they would do, especially for testing in children - their decisions were based on how sick either the mother or the child were before deciding on what tests or procedure to engage with.

QUESTION 3B

What **wouldn't** you be prepared to do for you or your child to prevent disease?

BARRIERS TO PREPAREDNESS

Question 3B

Broadly there were some similarities between what people **would** do but also described particular things people **wouldn't** do:

- Medical tests and procedures - especially if the procedure was too expensive
- Genetic testing
- Home and lifestyle changes

The major points of this question which were discussed:

- Some people wouldn't want to do invasive procedures, or invasive tests they thought were unnecessary
- Some people also thought blood tests are too hard on children
- Each of the groups had differing concerns regarding the use of genetic testing



QUESTION 4

What do you think we need to do to inform the public on immune development?

AN INFORMED COMMUNITY

Question 4

Five major themes emerged from the response to this question:

- Sending the right messages
- Ways to spread information
- Health and family services
- Education in schools
- Research involvement

Opinions on one vital communication point differed between the youth table and the three other groups on the usefulness of social media. This shows a considered and multi-pronged approach to communicating information is vital.

The three other groups suggested using social media (including Facebook) to share information. This included tailoring messages to different demographics and locations e.g. messages to educated people would be different to people who were in lower social or economic levels.

The youth table suggested there's a large amount of false information on social media, so it would not be a good platform to use as it's too skewed towards misinformation.

There were also multiple points raised around increasing health literacy at primary and high school levels (starting at around Year 8). One suggestion was external consultants going to schools to discuss and educate alongside an endorsed health curriculum.

ATTENDEE FEEDBACK

Overall attendee feedback trended towards the positive around how informative the Community Conversation was, how useful the event was and the high levels of participation from all attendees.

The Conversation met everyone's expectations with the majority of attendees indicating the event completely met their expectations (the highest rating). The event covered areas which were important to our attendees with a majority of people again indicating the highest rating of satisfaction in this area.

The presentations were received with high satisfaction levels including enough information being provided, and attendees questions answered. Attendees indicated Deb Strickland gave a very informative, and easy to understand presentation. A majority of attendees also indicated high levels of satisfaction with the opportunities they were given to put their ideas forward.

Where negative feedback was indicated it revolved around not having enough time at the event, especially with one facilitator coordinating the conversation on each table and also acting as the scribe.

Attendees also wanted pre-reading to better leverage the time in the event, and the distance travelled to the event. A suggestion has been made to have Community Conversations in different areas like Rockingham, Bunbury or an online option.

Overall the the feedback and the perspectives recorded during the event was beneficial to the research team

DO YOU WANT TO KNOW MORE?

Visit the Consumer and Community Health
Research Network at

<https://www.involvingpeopleinresearch.org.au>

Where you can find us on social media:



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