



# DCAA Community Conversation Report

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## 8<sup>th</sup> International CAA Conference: Public Forum Perth

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## Table of Contents

<a href="#"><u>Highlights:</u></a>	4
<a href="#"><u>1.0 Introduction</u></a>	4
<a href="#"><u>2.0 Rationale</u></a>	4
<a href="#"><u>3.0 Our goal</u></a>	5
<a href="#"><u>4.0 Method</u></a>	5
<a href="#"><u>5.0 Results</u></a>	6
<a href="#"><u>5.1 Question 1:</u></a>	6
<a href="#"><u>5.2 Question 2:</u></a>	7
<a href="#"><u>5.3 Solutions</u></a>	8
<a href="#"><u>6.0 Limitations</u></a>	8
<a href="#"><u>7.0 References</u></a>	8

### Highlights:

1. Community Conversation provided a great space for both researchers and family participants to share insights and knowledge.
2. The conversation yielded valuable reflections on what kind of treatment is possible and feasible.
3. Family participants highlighted that participation includes confrontation regarding the lived experience of DCAA.
4. A lack of knowledge especially amongst the younger generation was identified.

## 1.0 Introduction

On 5 November 2022, at the end of the 8<sup>th</sup> International CAA conference, research teams from Leiden, Perth and Boston and the DCAA Association met in a public forum with Australian DCAA family members and participants in DCAA research. It was the first time a public forum was part of the program of the conference. Uniquely, it was organised by the patient association together with Australian family representatives, rather than the researchers, which resulted in a community conversation. We estimate there were 60 family members present, some of whom drove over 4 hours from Albany. Those present ranged from known genetic carriers in their 40's and 50's and current participants, to the youngest generation of possible participants for TRACK DCAA and future research in their 20's, none of whom know if they are a genetic carrier.

It was encouraging to discover that the two groups, researchers and family members, had similar discussions to the set questions. Sometimes one group had a specific insight or identified a nuance in a particular problem, but there was no great discrepancy in desired direction or outcomes to the research. Hence, this community conversation is able to spotlight certain areas and issues that can be addressed by both the family members and the researchers. The conversation was able to bring to the fore the burden of disease as an ongoing and lived reality for all family members. One group wrote:

*Current situation affects relationships, thoughts of marriage and kids etc.*

*Be wonderful for this not to be a thing.*

## 2.0 Rationale

This community conversation was based on the World Café model for community conversations as initially developed by Brown and Isaacs (2005). The concept of a community conversation is to pause and develop curiosity, learning from other experiences and perspectives (<https://theworldcafe.com/the-role-of-inquiry-in-world-cafe-conversations/>). We started with the assumption that there are two sets of knowledges in the room: the knowledge of lived experience held by family members and participants and

the scientific knowledge held by the researchers. Both sets of knowledges need each other. The families need the researchers' skills and knowledge in order to proceed towards improving health outcomes. Researchers need the family members to participate, and also their knowledge on what it is like to live with DCAA, the impact it has on their lives, their ideas about ongoing research and their hopes for future outcomes and potential treatments. The community conversation was a place in which these knowledges could be shared and both parties could benefit.

The model of a community conversation necessarily transforms the setting from a unidirectional teaching mode so that the researcher is moved from a position of expert to facilitator and participant. Likewise, family members are moved from passive participant in medical research to co-creators of shared knowledge (Yang et al. 2022). The result is that something changes within the group and the individual participants, something that Brown and Isaacs call 'the magic in the middle' (Brown and Isaacs 2005). As each participant becomes involved in the sharing of knowledge, the goal is that each participant also becomes increasingly invested in the larger research picture.

### 3.0 Our goal

Our goal was to create a space that would:

1. Engage family members and participants in knowledge production;
2. Generate shared knowledge and understanding that would enhance research participation and outcomes.

### 4.0 Method

The public forum was hosted by Sanne van Rijn, patient advocate with 15 years' experience working for the DCAA Patient Association. In her role, Sanne works between patients and research team, boosting recruitment and liaising for participants within the research context. The community conversation, which came as part of this public forum, is a roundtable event where interested parties come together to address particular issues. Prior to the event, the co-host, Dorinda 't Hart, engaged in training with the Consumer and Community Involvement Program at the University of Western Australia<sup>1</sup>. At their advice, we kept family members and researchers in separate groups, answering the same set of questions. By sharing answers at the end of the session we hoped to create a space in which knowledge and new insights could be shared.

Participants could self-select into two types of groups:

- 6 family members and participant groups (6-8 people per group)
- 3 researcher groups (approx. 8 people per group)

The groups were given two questions:

- If you think of a treatment in the future, what does it look like?
- What do you think are obstacles for family members to participate in research?

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<sup>1</sup> See <https://cciprogram.org>

Each group was asked to appoint a facilitator who would ensure that the two questions were discussed and each member of the group had an opportunity to share their thoughts. Notebooks and pens were provided by the Perth research team and one member of the group was also appointed notetaker. These notebooks were later collected for analysis and synthesis. After approximately 40 minutes, the host brought the group together and each group designated a speaker who shared key findings from their group. Maïke Hoek, community representative from the DCAA Association, was appointed notetaker and wrote these comments on slides that were later shared with the whole meeting.

## 5.0 Results

### 5.1 Question 1:

#### **If you think of a treatment in the future, what does it look like?**

In answering this question, it is interesting to note what was not mentioned. Only one of the researcher groups mentioned the possibility of a once-off treatment, 'To turn off the gene.' Two family participant group actively discounted a once-off 'fix' as not realistic. The other family groups did not mention a once-off fix. This once-off solution is not part of the family members' horizon of possibilities, revealing the sense of resignation for the majority of the family participants and acceptance that this genetic condition is simply a part of their life.

#### **Theme 1:**

- Oral treatment, especially pills. This was the most popular solution, mentioned by all family groups.
- Needles/injections/spinal tap were also considered by family groups although there was variation as to how often intervention could be a reasonable requirement. Suggested reasonable requirements ranged from every 6 months to 5 years.

#### **Theme 2:**

Strengthening blood vessels and thus delaying the onset of the disease.

This was an important outcome for both researcher and family groups.

#### **Theme 3:**

Lifestyle

Family participants were open to adjusting their lifestyle to both prevent the development of the disease as well as to allow ongoing treatment. However, impingement on lifestyle (e.g. where one could live) was factored into the kind of treatment that would be seen to be acceptable.

#### **Theme 4:**

Non-invasive

This was important for most of the groups, which speaks to the preference for oral treatments rather than spinal taps.

#### **Theme 5:**

One family participant group mentioned the intervention of technologies and machines such as a 'tunnel or bed that does calculations.' One researcher group also mentioned

imaging and eye scans, but overall technologies were not forefront in the answers of either of the groups.

**Theme 6:**

Accessibility, such as affordability.

This was important for all three researcher groups but absent from the family participant groups. Perhaps this is a tacit expectation.

5.2 Question 2:

**What do you think are obstacles for family members to participate in research?**

**Theme 1:**

Fear and anxiety

Fear was expressed about the procedures themselves, such as needles and spinal taps. There was the presence of fear of hospitals, anxiety around the risks of some procedures, particularly around the potential side effects of some of the treatments (eg. radiation)

**Theme 2:**

Commitment

This included time commitment during participation. Some participants may need to take time off work or may only be able to participate during their holidays. Both require a form of sacrifice. Some family groups were concerned about the two year commitment of being part of the study.

Another element of commitment can be measured in the distance and potential cost of travel to Perth in order to participate.

The burden of this commitment increases when the participant will not necessarily see the benefit him/herself.

**Theme 3:**

Family planning

Not being able to have children for the two years while participating in the study was noted as a barrier for some, especially as the ideal age for participation is within the prime childbearing years.

**Theme 4:**

Confronting.

While the researchers assessed the participation in the study and medical tests to be confronting, the family participant groups noted that participation meant being confronted with the lived reality of the condition. Non-participation offered perceived 'ignorance is bliss'. This appeared to be especially true for the younger generation in Australia who have not yet been confronted with the full effects of the disease. Here in Australia, the visible effects of the disease are only just being felt the next generation, so not many of the younger generation have witnessed the passing of a family member due to DCAA.

**Theme 5:**

Privacy.

Participation may mean you need to explain to people why you need the tests done (eg. work). This can be awkward when there is no visible signs of illness and the participant is unwilling to discuss his/her genetic status.

Privacy around genetic status was also identified as important. There was a concern that participation could mean finding out your genetic status before you are ready. There was also a concern that others may learn your genetic status before you are ready to share that information.

## **Theme 6:**

### **Religion**

This is seen as an obstacle in that some people may take it to mean that some family members see the condition as 'God's will'. It is also seen as an enabling factor that family members can enjoy 'God's provision' of researchers and potential cures and/or treatments.

## **5.3 Solutions**

While not specifically asked, most of the groups offered solutions of how to overcome these barriers to participation.

1. More information especially for the younger generation;
2. Information needs to be accessible in layman's language where possible;
3. Communicating the importance of participation;
4. Promote the benefit of participation, such as regular health checks;
5. Normalise research participation more generally.

## **6.0 Limitations**

1. We had limited time to hold this community conversation. Hence, we limited the discussion to two questions.
2. The participation of Australian DCAA family members was limited. Non-participants in the community conversation may also be non-participants in the research, but this could not be verified. Due to their non-participation, their specific concerns could not be recorded and/or addressed.

## **7.0 References**

- Brown, Juanita, and David Isaacs. 2005. *The World Café: Shaping our futures through conversations that matter*. 1st ed. San Francisco, California: Berrett-Koehler Publishers.
- Yang, Chieh-Ling, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers, and Marie-Louise Bird. 2022. "World Café - a community conversation: A Canadian perspective on stroke survivors needs for community integration." *Topics in Stroke Rehabilitation* 29 (5):392-400. doi: 10.1080/10749357.2021.1928839.