

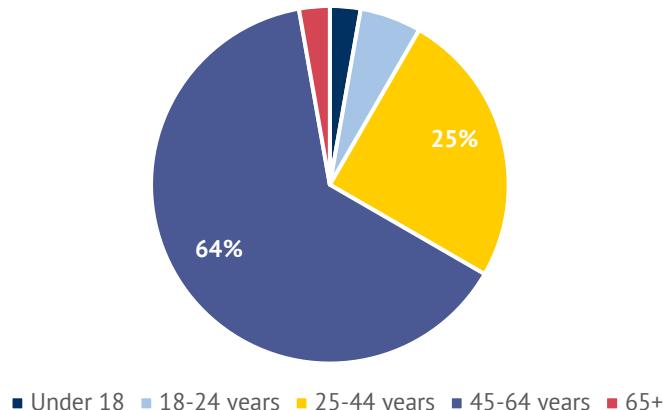
# COMMUNITY WEEKEND 2023

## IMPACT REPORT

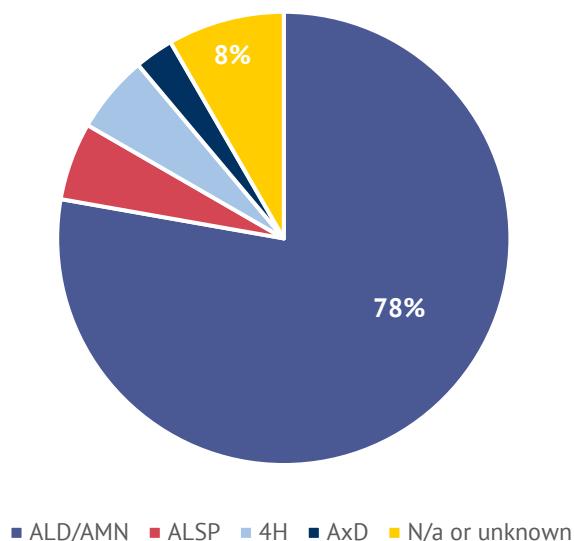
# Demographics

The responses received in this survey came from individuals and their families as well as professionals. Over 60% of respondents were between 45-65 years of age and 25% were 25-44 years of age.

## Which age range best represents you?

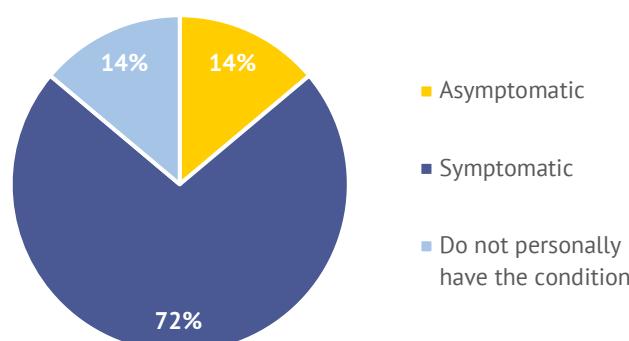


## Type of condition affecting attendees



Most attendees affected by leukodystrophy were symptomatic and the majority of individuals were affected by adrenoleukodystrophy (ALD) and adrenomyeloneuropathy (AMN). This was expected as ALD/AMN are the most common leukodystrophy affecting 1:17,000<sup>1</sup>. There were also people in attendance affected by Adult-onset Leukoencephalopathy with axonal spheroids and pigmented glia (ALSP), Hypomyelination, Hypogonadotropic Hypogonadism and Hypodontia (4H syndrome) and Alexander Disease (AxD) much rarer conditions. For example, Alexander Disease occurs in 1 in 1 million births<sup>2</sup>. 61% of respondents care for someone with a leukodystrophy.

## How are you/the person you represent affected by your condition?



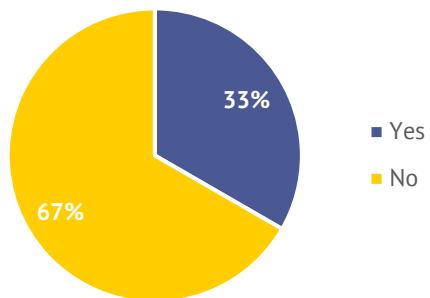
1. Engelen, M., Kemp, S., de Visser, M. et al. X-linked adrenoleukodystrophy (X-ALD): clinical presentation and guidelines for diagnosis, follow-up and management. *Orphanet J Rare Dis* 7, 51 (2012). <https://doi.org/10.1186/1750-1177-7-5>

2. Goldman, MD, PhD, J. E. (2017). Alexander Disease. *Rare Diseases*. Retrieved July 4, 2023, from <https://rarediseases.org/rare-diseases/alexander-disease/>

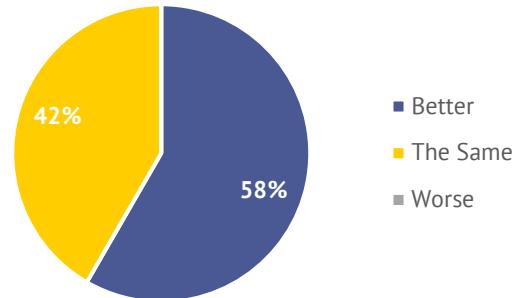
# Overall Experience

Over half of the people had been to an in-person Community Weekend before and all said the 2023 event was better or the same as previous ones. One attendee that had been before said this about the event, *“positive information sharing, updates shared in a client friendly way, opportunity to catch up with and make new friends and share experiences”*. None of the respondents thought the event was worse than those they had previously attended.

## Was this your first time attending an in-person Community Weekend event?

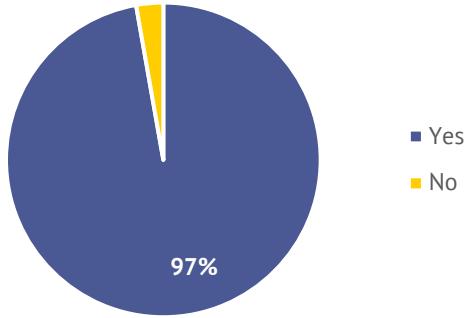


## How do you feel this event compared to previous Community Weekend(s)?



Overall, everyone enjoyed the event, presentations were informative, they appreciated that more leukodystrophies were covered, and it was great to meet up with old friends and make new ones. Some thought previous weekends had better and more interactive entertainment which will be considered for the next event. Feedback from the previous Community Weekend, mentioned wanting more information for women with leukodystrophy and many were very pleased this year with the presentations focused on women with ALD/AMN. This allowed the women to gain important information and research updates about their condition and symptoms which many of them experience.

## Would you attend again?

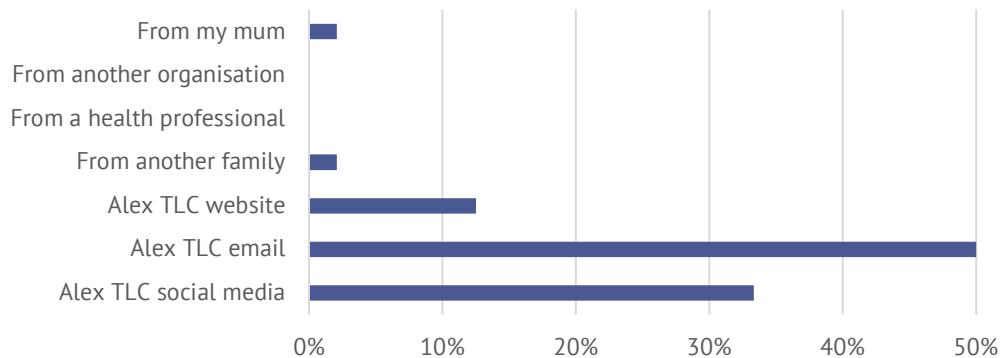


97% stated they would attend again. One attendee explained why they would come again, *“the talks and speakers provided valuable and up to date information on progress in the ALD field as well as sharing information on resources and studies which I could be involved in. Most importantly, I was able to connect with others who are in a very similar position to myself. I feel I have developed a strong support network from the community weekend – thank you!”* Another attendee said, *“we have attended as many community weekends as we could and at every one we have learned something new, met up with longstanding acquaintances and met new patients and their families. We leave the event always feeling a bit less ‘alone’ and reenergised.”*

# Attendance

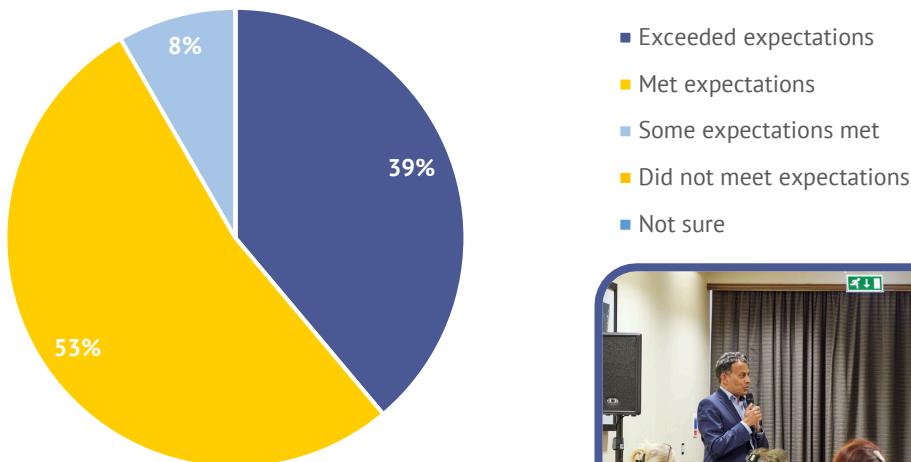
Almost everyone who attended the Community Weekend either due to their own condition or that of a loved one heard about the event from Alex TLC communications, mainly email and social media but also from our website. Other attendees were told about the event from a family member.

## How did you hear about our event?



The main reasons for attending the Community Weekend 2023 were to learn more information about leukodystrophy, *“to meet other families who understand, listen to doctors discussing progress with research and to be able to spend time together as a family”* and overall to connect with the Alex TLC community. The majority of respondents had their expectations met and exceeded, only 8.3% (3 people) had some expectations met, one hoped for information on their specific condition.. As there are over 50 leukodystrophies, unfortunately it is not possible to include information on all conditions, we tried to accommodate all attendees but could not due to the unavailability of a presenter. We will communicate our limitations on condition related content next time.

## Did the event meet your expectations?



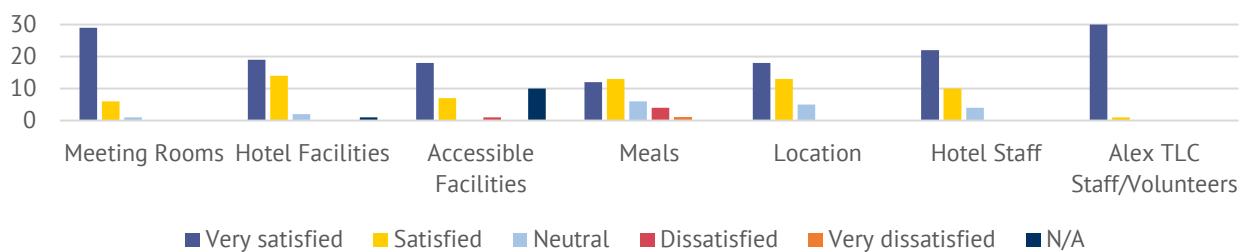
# Location and Venue

Overall, all were very satisfied with the venue, but there were some mixed comments on the meals. Many commented that *"Birmingham was a great choice to bring everyone together regardless of their home location. The NEC was also good for transport links"*. Regarding the meals, everyone enjoyed the breakfast buffet but said lunch and dinner *"was all very much the same"* and *"meal choices could have been better to cater for everyone's tastes"*.



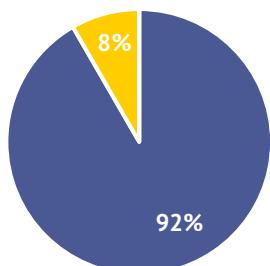
Buffet style was chosen as a result of previous event comments, though some comments suggested this made it more difficult for those with mobility issues to plate their own food. There were lowered tables for this cohort but unfortunately food was not replenished once it had run out which we raised as an issue with the hotel. In future events, the meal options will be further discussed to include more variety and child friendly options, as well as more aid for those who need it.

## How satisfied were you with the venue?

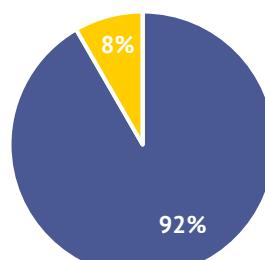


One of the most important outcomes from the Community Weekend we hope attendees experienced was meeting new people and making connections which may help them feel less alone. Over 90% said the event helped them connect with others and feel less alone in their situations. One attendee said, *"we met some amazing families and really enjoyed the socialising aspect of the weekend"*, another said, *"I met people from previous weekends and made some new connections"*. Attendees appreciated the event bringing together people that truly understand what they are going through, as shown by the positive feedback saying, *"we felt truly understood and never judged"*.

## Did the event activities help you to connect with others?

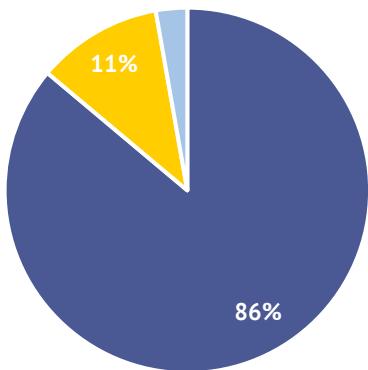


## Did meeting other people with a leukodystrophy at the event help you to feel less alone in your/their situation?



# Presentations and Workshops

Another important aim of the event is to help attendee's increase their understanding of their or their loved one's condition, ongoing research, and treatment options. This should be accomplished by the various presentations and workshops provided throughout the weekend. Positive feedback suggest this was achieved as 86.1% said the information shared did increase their understanding in these areas, *"the perfect mix between accurate terminology and easy to understand concepts"*. One person did not find the information increased their understanding of their condition as unfortunately there was no information specific to their condition, in future we hope to have some information for each condition represented at the Community Weekend.

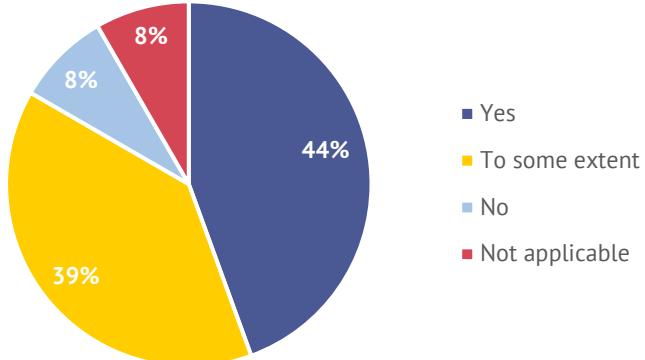


**Did you find the information shared during the event increased understanding about your/loved one's condition, research, and treatment options?**

- Yes
- To some extent
- No

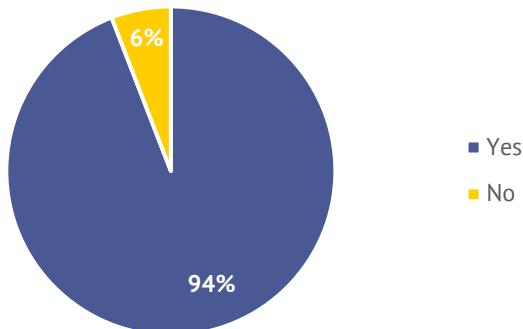
Guidance provided through the presentations and workshops were aimed to help improve management of their or their loved one's condition. Results were a bit split between 44.4% of those saying yes, they do feel it will help and 38.9% saying they feel it will help to some extent. From the three people that said no, only one provided comments, they felt there was not much discussion on how to actually get help to manage their symptoms. Others that said to some extent, also wished for more information on symptom management and aids. This helps us to better understand what information and guidance attendees want and will be taken into consideration for future events, so they get more aid in managing their condition. This comment from one of the attendees nicely captures the positive feelings of most attendees, *"everything from shared information between participants, workshops and talks, could be put to use to better manage our conditions"*.

**Do you feel the guidance during the event will help to improve management of your/a loved one's condition?**



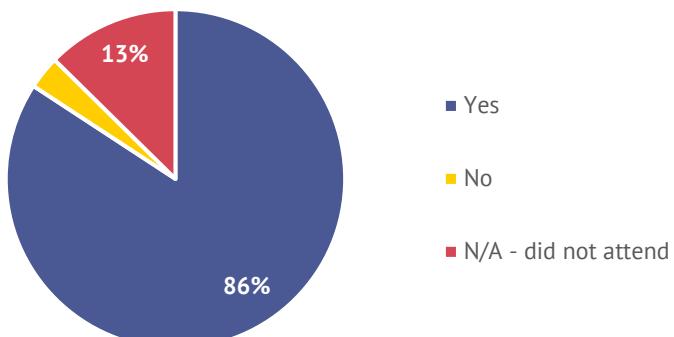
The feedback was very positive regarding the usefulness of the content of the presentations and workshops, 94.4% and 86.1% respectively, found the content useful. Those that answered no to these questions provided no feedback regarding the presentations but for the workshops they simply stated they were tired and needed a break to rest. For future events we will consider how we can minimise the fatigue reported by some attendees. Presentations were overall found to be informative, interesting, and easily understood. News of the NHS England Inherited White Matter Disorder Service and Registry resulted in excitement from the community on these developments, “*huge progress in creating clinical platform and registry for all leukodystrophies*”.

### Overall, did you find the presentation content useful?



The additional focus on women with ALD was especially appreciated, “*very interesting and hopeful again, feel like women’s voices were heard and understood*”. As stated previously, this was important for the women to gain valuable information regarding their condition. The workshops were “*useful and easily understandable*”. Through our new collaboration with Leukolabs who work with zebrafish models to study leukodystrophies, there was a display of live zebrafish and embryos to view under a microscope. This activity was popular and fun for all to see and learn more about them and their role in research. The Mindfulness workshop received great feedback, “*thoroughly enjoyed the practice. Very useful and encouraging. Pujit is a real inspiration!*”.

### Overall, did you find the workshop content useful?

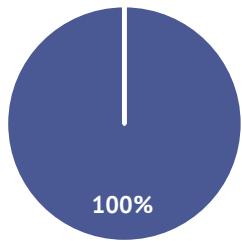


# Children's Activities

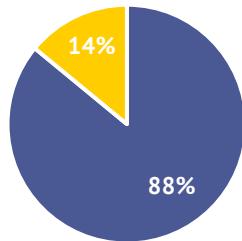
There were children's activities provided throughout the Community Weekend, which were very popular and thoroughly enjoyed by the children as depicted by the feedback that 100% of them that attended enjoyed them. The majority said the activities helped their children make connections with other children, only one said no as there were none their age this year but have made friends in previous years that they are still in contact with.



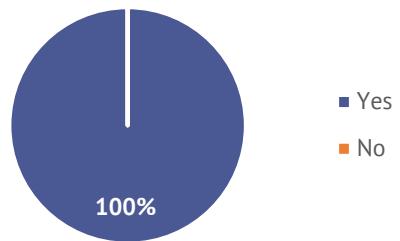
**Did the child/children enjoy the activities provided?**



**Did you feel the activities helped them make connections with other children at the event?**



**Did you feel they were welcomed, included and safe in all activities supervised by the Alex TLC team?**



All respondents said they felt their children were welcomed, included and safe in all activities supervised by the Alex TLC team. One quote from a parent summarizes all of these sentiments nicely:

*"this was unbelievable the staff and the activities were just the best, the children all loved attending these, the staff were so lovely kind and had empathy for every child, the children loved the activities and the staff."*

Parents appreciated that the children's activities gave them the opportunity to focus on the presentations, while their children were taken care of and having fun.

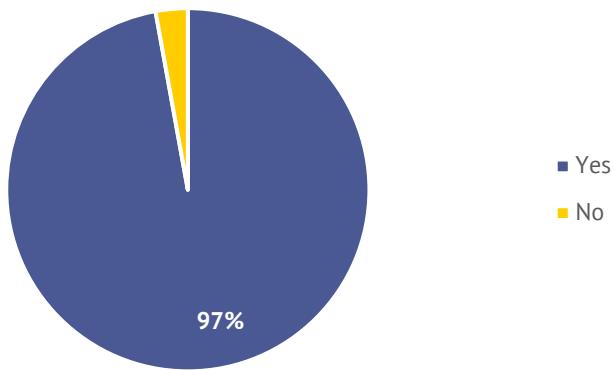
# Final Comments

Further topics attendees would have liked included are, sexual health and well-being for young people (16-25), family planning for women, information on how clinical trials are run and what it is like actually being a participant, alleviation and management of symptoms, talks from physiotherapists about practical suggestions, mobility aids, etc, nutrition and fitness workshops.

Overall, over 97% of attendees felt the Community Weekend was useful for those affected by leukodystrophy:

*"I thought the event was brilliant. It was great to see so many individuals and families having the time to talk to others and learn from different professionals. Despite the challenges faced by many there, there was a real sense of positivity as people made connections and shared their stories."*

## Overall, did you feel the event was useful for those affected by leukodystrophy?



Some final comments about the Community Weekend

*"This is a fantastic event and I feel vital to the leukodystrophy community".*

*"It really couldn't of been any better. An awful lot of work must of went into making everything perfect. Great team".*

The presentations were livestreamed for people to join virtually, on Saturday there were **100** attendees and on Sunday there were **64** attendees.

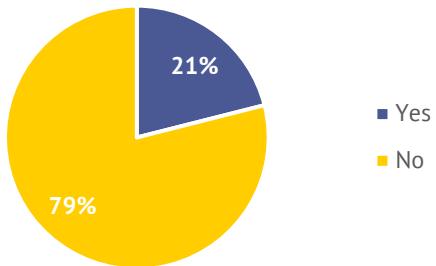
Regarding our [YouTube](#) channel, across all the videos uploaded from the Community Weekend, there have been **751** views since May 12<sup>th</sup>. These have been the top viewed videos:

- Adrenomyeloneuropathy AMN, Symptoms and treatments for men - Dr Robin Lachman = **88** times
- Transplant for Advanced Cerebral ALD, Risk-Benefit - Dr Troy Lund = **42** times
- Symptoms and Treatments in Women with Adrenoleukodystrophy (ALD) - Dr Florian Eichler = **41** times
- Mental Health for Patients, Carriers and Carers - Dr Pujit Gandhi = **38** times

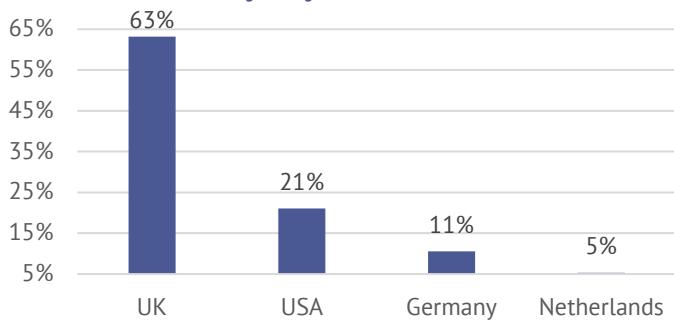
# Professionals

There were 31 leukodystrophy professionals who attended the Community Weekend, with 21% representing a pharmaceutical company. The professionals who attended have their work based in different countries, over 63% of them were based in the United Kingdom while 21% were United States based, 11% based in Germany, and 5% based in the Netherlands.

## Did you attend the event as a pharmaceutical representative?

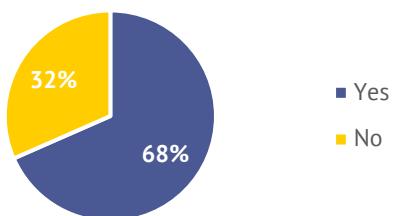


## In which country is your work based?

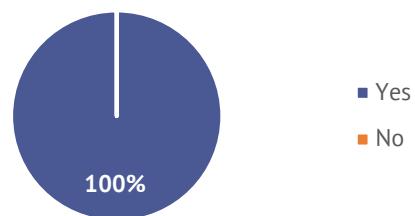


They all really enjoyed the event and networking opportunities it provided with a broad range of different professionals, patients and families *“the networking with families and other professionals was the best I have had”*. This was the first in person Community Weekend for over 68% of the professionals and 100% of them said they would attend again. *“I loved this event; it was my first time attending such event and it was great time to meet with professionals as well as the family and the people who work for the Alex charity. I will definitely attend again.”*

## Was this your first time attending an in-person Community Weekend event?

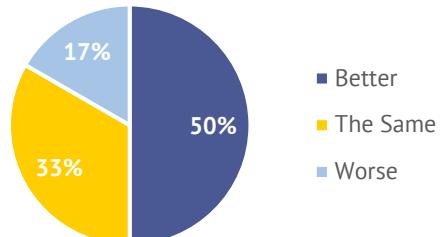


## Would you attend again?



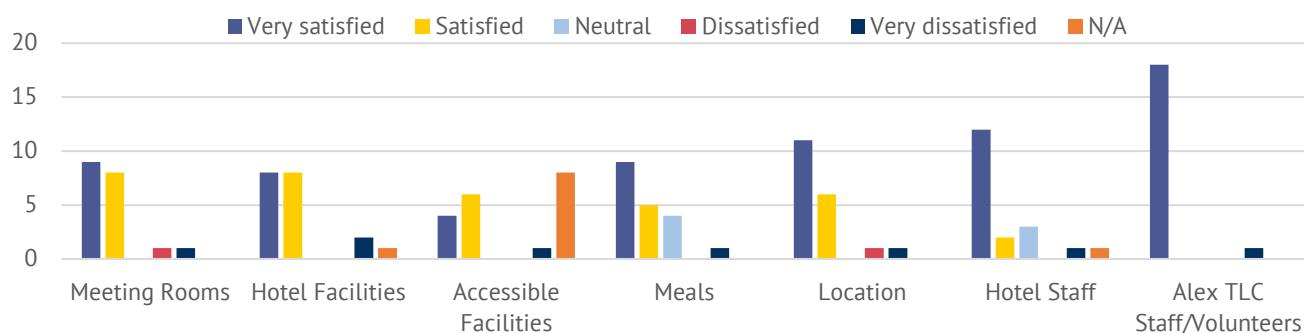
Those that have attended before thought the 2023 Community Weekend was better (50%) or the same (33.3%) as previous events, *“The previous ones were great but this one surpassed them”*. Only one person said the event was worse which was due to them feeling there were not enough professionals who attended in person and that those presenting should only be remotely if they are from abroad. Unfortunately, due to conflicting priorities and the bank holiday that weekend, some professionals were unable to attend in person. Future events we will do our best to ensure more professionals are able to attend in person as it is beneficial to themselves and attendees to have the opportunity to meet and interact.

## How do you feel this event compared to previous Community Weekend(s)?



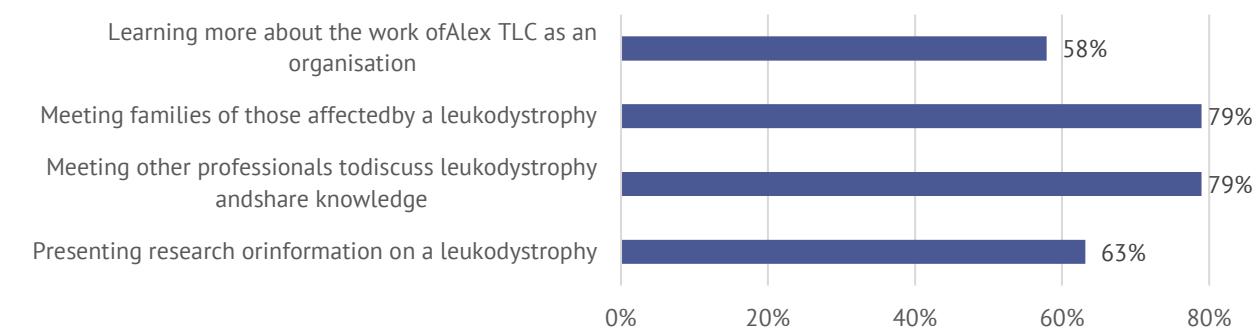
Overall, all were very satisfied with the venue though there was also some feedback about areas for improvement, “*The organisation and location was excellent and easy to travel to. The size of the main room was maybe a little too large for the number of people and now half the room was empty. The location where the speakers were standing was somewhat odd. A large part of the screen was hidden for the audience behind the speakers and hence much of the content on the slides behind the speakers.*” Due to an upgrade from the hotel, the presentation room was larger than planned for our number of attendees. We will be sure to check how presentations will be viewed by the audience more thoroughly for the next event. There were some mixed reviews on the meals which has been commented on by attendees as well and some mixed reviews on the hotel staff though this was due to a misunderstanding around table set up for lunch.

## How satisfied were you with the venue?

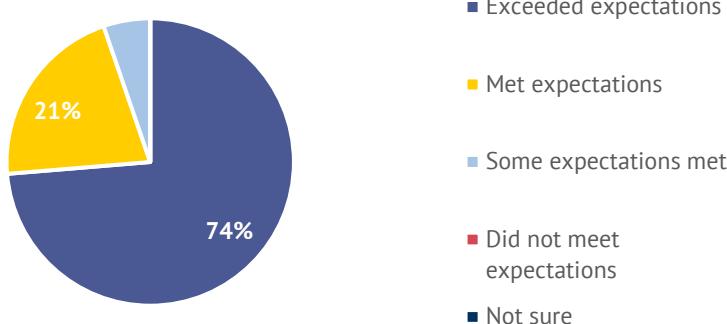


Professionals attended for several different reasons, including presenting research or information, meeting other professionals, meeting families affected by a leukodystrophy, and to learn more about the work that Alex TLC do. Based on their reasons for attending, over 73% had their expectations exceeded and 21% had them met.

## What were your main reasons for attending the Alex TLC Community Weekend?

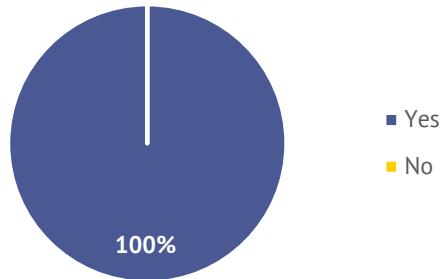


## Based on your reasons for attending, did the event meet your expectations?

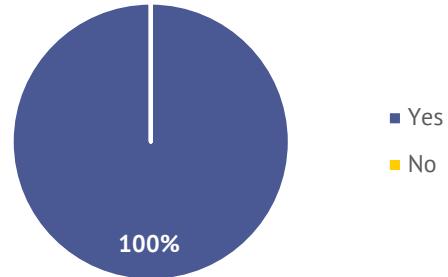


There were two roundtable sessions held: a Research session focused on the rarer conditions as ALD and AMN were covered in the main sessions and a Newborn Screening session. These sessions were recorded and shared on our [YouTube](#) channel. Of those that participated in the professional roundtable talks, they all found these useful, saying “*The presentations and discussions amongst the health care professionals were very informative*”. Following presentations in the main rooms, Q&A sessions were held and all professionals who participated found them useful.

### If you participated in a Roundtable, did you find these sessions useful?



### If you participated in a Q&A, did you find these sessions useful?



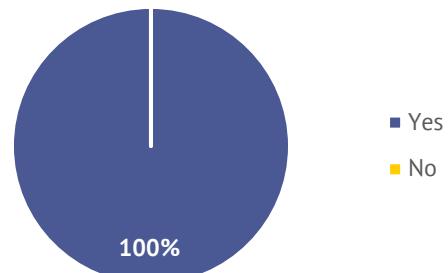
All professionals found the presentation content throughout the Community Weekend useful.

*“The presentations were relevant and highly informative. It’s a difficult ask for the presenters to pitch something to the level of experts and laypersons at the same time and most of them achieved that feat”.*

*“Only comment would be that the sessions were quite ALD heavy - this is obviously where the majority of expertise is but would be good to have a bit more breadth in future. I.e., what’s happening on a research/treatment front for rare LDs now worldwide/in the UK.”*

The rarer conditions were presented and discussed during the round table session and then the discussions were summarised in the main room.

### Overall, did you find the presentation content useful?





# Lessons Learnt for Future Events

Through the feedback gained in these surveys from our attendees, we are able to learn from and improve on different aspects of the event so future events are even better.

- We will work on having even more interactive and fun entertainment in the evenings, keeping activities attendees enjoyed and incorporating new ones.
- We hope to have some information included for each condition represented during the Community Weekend.
- Buffet style was chosen as a result of previous event comments, though comments suggested this made it more difficult for those with mobility issues. In future events, the meal options will be further discussed to include more variety and child friendly options, as well as more aid for those who need it.
- Feedback about having more information on symptom management and aids will be taken into account and we will consider how we can incorporate this in future event.
- The event schedule was quite packed as it was the first in-person event since 2018 and there were lots of presentations over 2 days. The schedule will be reconsidered to provide attendees ample time to rest in between attending presentations and workshops.
- Unfortunately, due to conflicting priorities and the bank holiday that weekend, some professionals were unable to attend in person. Future events we will do our best to ensure more professionals are able to attend in person as it is beneficial to them and attendees to have the opportunity to meet and interact.
- We will be sure to check how presentations will be viewed by the audience more thoroughly for the next event.
- Professionals would like more time for strategy planning for future research and clinical efforts as well as more dedicated time to the other and rarer leukodystrophies. This will be taken into consideration for following events.

