IMPACT REPORT 2022

Registered charity no. 1106008 (England and Wales) SC051539 (Scotland)

INTRODUCTION

Alex TLC provides invaluable support and information to people affected by a leukodystrophy. Established in 2004 as ALD Life, an internationally recognised centre of excellence for those affected by adrenoleukodystrophy (ALD) and adrenomyeloneuropathy (AMN), we were encouraged by our medical advisors to expand our services. The charity changed its name in 2019 to Alex, The Leukodystrophy Charity or Alex TLC, becoming the only charity in the UK that provides support for all those with a leukodystrophy.

Alex TLC provides direct support to approximately 170 individuals and families annually and has over 900 support conversations each year. To address the multiple, complex issues a leukodystrophy diagnosis can bring, the charity delivers:

- Practical support, advice and information
- A grant programme for beneficiaries
- Development of peer-to-peer networks which empower families and help them realise they are not alone
- Raising awareness of leukodystrophy amongst members of the public and health professionals
- Promoting research and research funding

Collaborating with specialists and stakeholders worldwide, Alex TLC works towards prevention of and best practice in treatments and care for leukodystrophy patients and their families.

The Alex TLC Impact Survey 2022, distributed in February 2022 through to the end of March 2022, gathered the views of those supported by Alex TLC from around the world. Respondents ranged from those who have only accessed our website and online information to those who have attended events or received direct support.

The survey asked for feedback on all elements of our support work, seeking suggestions for improvement and new areas of focus. We also asked questions about respondents' diagnostic journey, their experience of the public and professional knowledge and awareness of leukodystrophy, and feedback on services such as genetic counselling which are not provided by Alex TLC. This will allow us to illustrate areas in need of improvement beyond our own services, helping us to highlight issues and drive change.

Feedback in the survey highlights the many strengths of Alex TLC as a valuable source of support for those coping with leukodystrophy, as well as identifying avenues of further work. We would like to thank all those who took the time to complete it.

METHODOLOGY

The Survey used to gather the opinions of those who have been supported by Alex TLC utilised the 2020 survey as a basis, adjusting or supplementing questions based on beneficiary feedback and staff analysis. The maintained focus on beneficiary viewpoints of our services reflects the positive changes the organisation has made towards a better understanding of the strengths and weaknesses of the charity.

Questions for carers were changed to a simpler format and respondents were asked only to report on the number of people they cared for. This change was made following feedback on the complexity of questions around caring and representation from the previous survey.

35 individuals completed the survey.

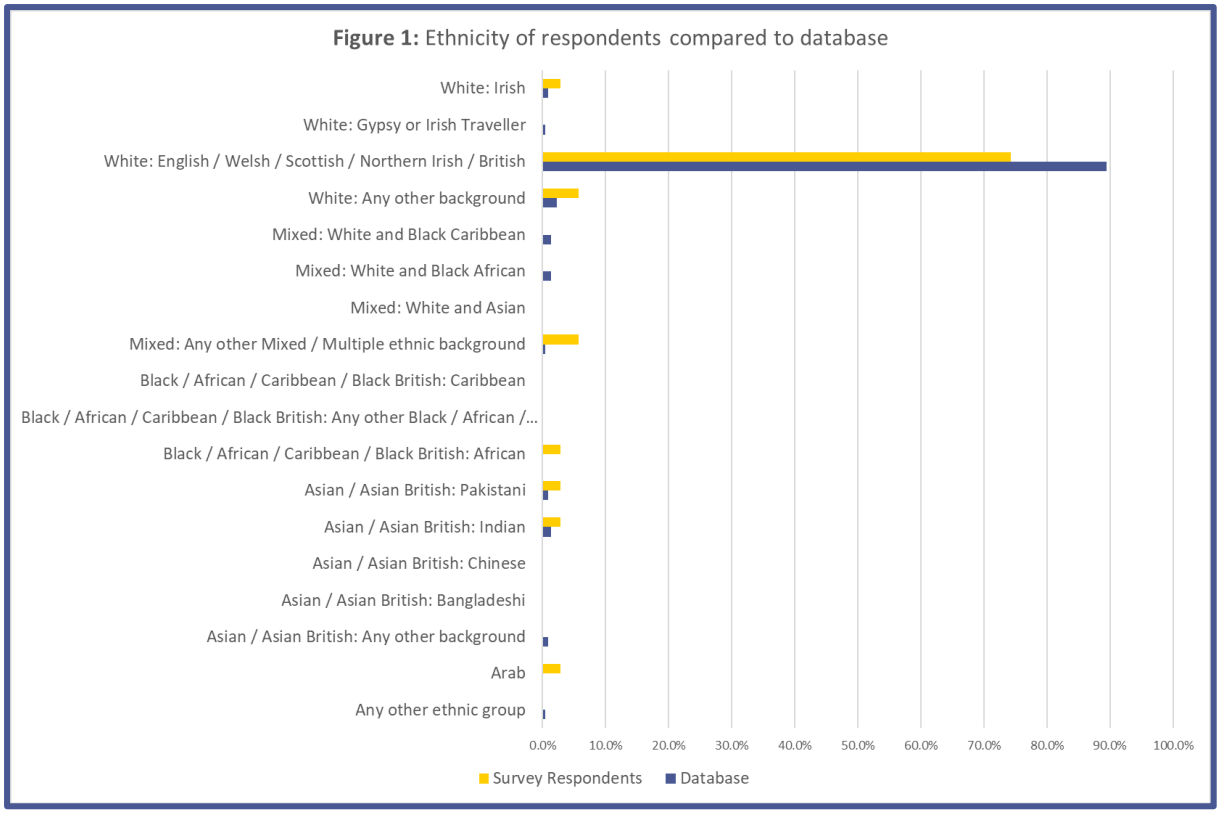
Of these, 24 were carers supporting between 1 and 5 family members.

The total number of views represented is therefore 74.

The survey was distributed to those we have supported via email, as part of our monthly round-up (newsletter) in February and March, shared on social media, our website news and advertised on the Health Unlocked patient forum. Utilising different forms of contact allowed us to reach the maximum number of respondents.

Survey respondents were asked questions about their location, gender, their own condition, and their carer status where applicable. This allowed us to report on feedback responses by a variety of demographics. Respondents were not required to leave their name or email address. An important demographic missed in previous surveys was ethnicity; recognising the value of collecting this data, ethnicity was included for this survey, and is now routinely collected.

Results of the survey as outlined in this report will be used to improve the services and support provided by Alex TLC. The numerous positive responses and comments received will be used for marketing and fundraising purposes, to celebrate our achievements and promote further success. All respondents were asked if comments could be used anonymously for these purposes; all respondents agreed to this and will have their comments featured in this report and used elsewhere.



We asked about the ethnicity of survey respondents (see Figure 1). It can be seen that the highest number of respondents (74.3%) were White British, a lower percentage than held on our database (93.1%). However, the information we hold on our database is limited and does not represent everyone that we support, only those who have completed our registration form. It is important moving forward that we continue to work on projects to increase engagement with ethnic minorities, including collaboration with organisations who can support our efforts such as Breaking Down Barriers, a network of over 50 organisations working together to improve the lives of families from diverse and marginalised communities, so they have equal access to health services.

While our support services and activities are based in the UK, Alex TLC receives and responds to support requests from around the world. In all, since the charity was founded, we have supported people from 52 different countries across six continents, providing direct support interventions in 36 countries. Since our 2020 Impact Report we have not increased our support to any further countries: it will be important to ensure that information on our website is clear that our support is offered to individuals and families globally.

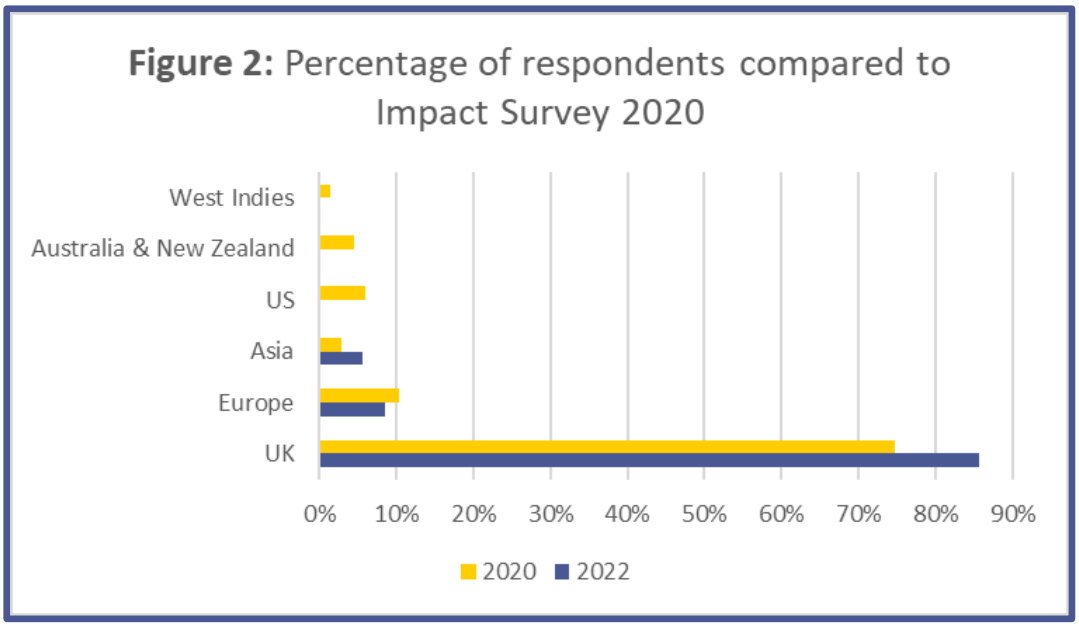
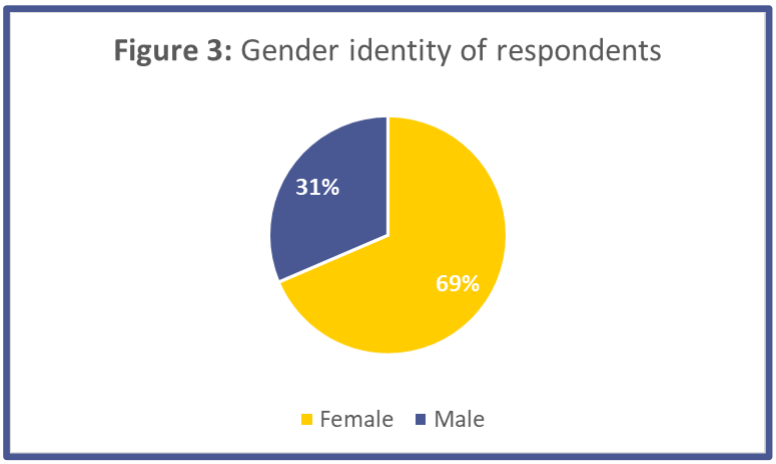
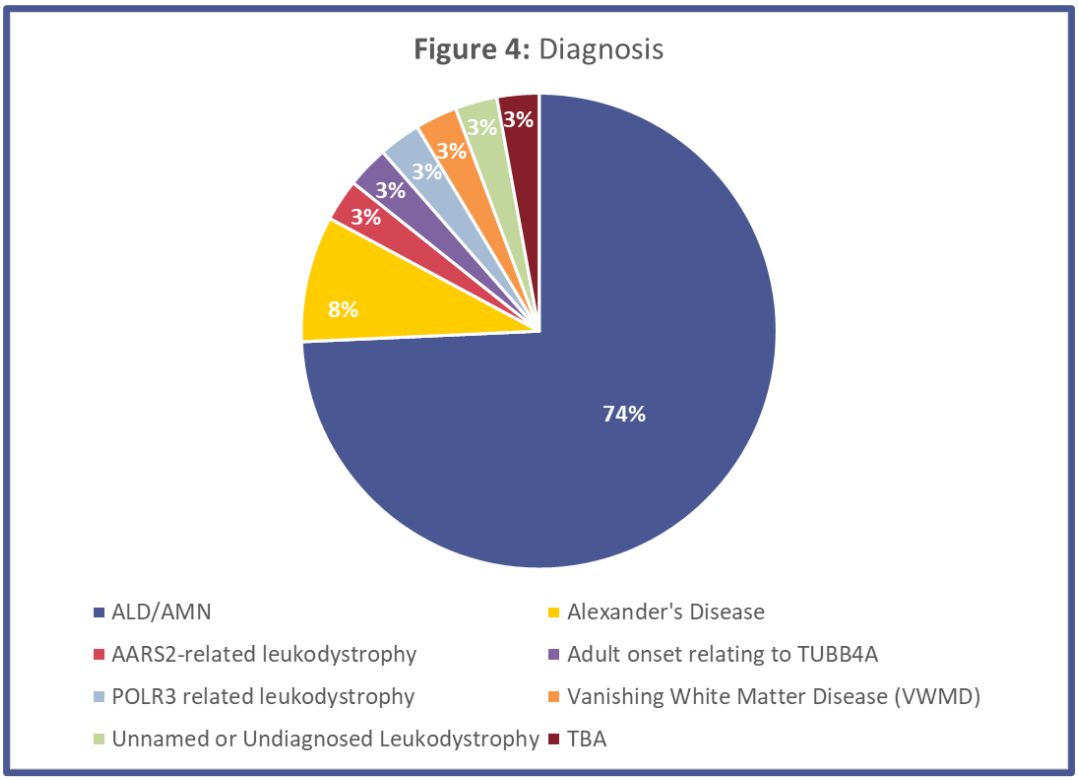


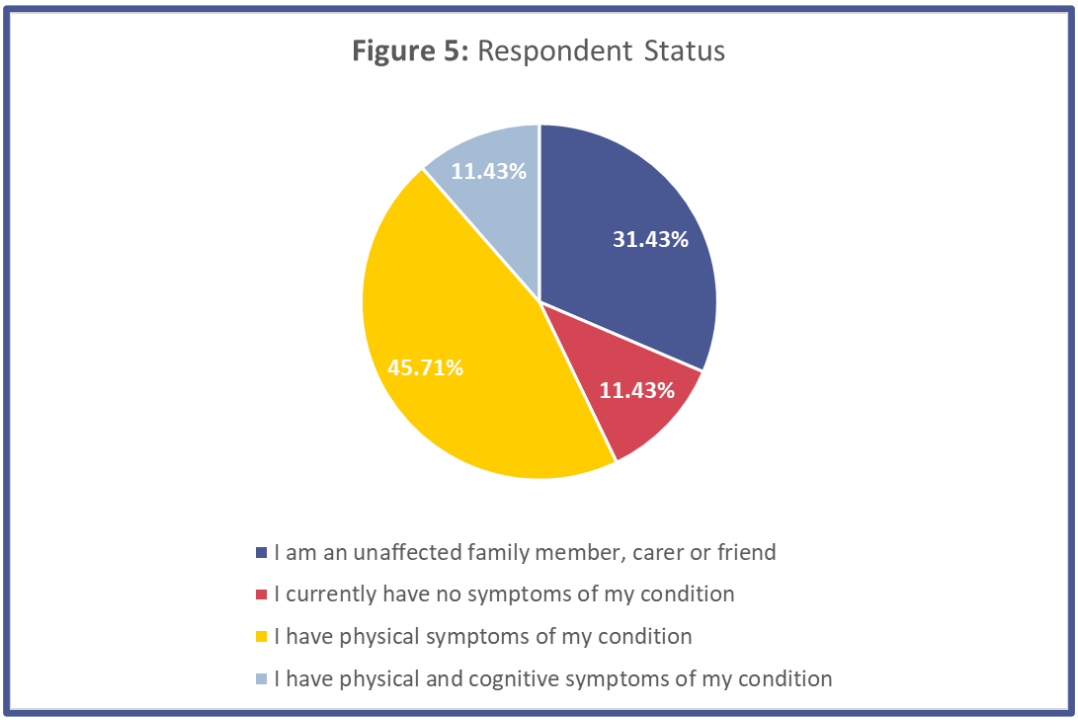
Figure 2 shows the location of respondents of this survey compared to the Impact Survey 2020. The diversity of respondent location is less, with respondents only being from the UK, Europe, and Asia. As expected, UK beneficiaries make up the highest percentage, both on our database and as respondents to our surveys. Although a quarter (25.17%) of our database lives in the US, no-one from this country completed the survey. We would assume this is due to the high levels of support available from US-based support groups. Overall, we have seen less overseas engagement in comparison to our 2020 survey, which received engagement from respondents in the US, Australia, New Zealand and the West Indies. This reduction does not mirror the diversity of our database as our support is requested from numerous countries and regions across the world.

Figure 3 demonstrates that the majority of survey respondents were female. This matches the experience of many of the rare disease charities Alex TLC has encountered, acknowledging that females seem more likely to engage with support organisations.



Following our expansion to support all leukodystrophies, we were encouraged to see some representation of this change in survey responses (Figure 4). Although the majority of respondents (74%) had an ALD or AMN diagnosis, this was expected as it reflects the relative prevalence of these disorders compared to other, rarer, leukodystrophies (1:15,000 compared to 1;50,000). There has been an increase in the proportion of individuals affected by leukodystrophies other than ALD or AMN, with five types of leukodystrophy being represented in the survey. We hope in the future to see a higher representation of other leukodystrophies to reflect our increased reach.





We asked respondents about their relationship to leukodystrophy; whether they were directed affected by a condition, or an unaffected family member or carer (Figure 5). Most respondents (68%) were affected by a leukodystrophy with over half experiencing symptoms, either physical (45%) or both physical and cognitive (11%). Of these respondents over a third (37%) were also a carer of someone affected by a leukodystrophy. This highlights that the genetic nature of these disorders means there is a high probability that those caring for the most severely affected patients are often also coping with their own symptoms. It is important to note that carers will often also have additional children or family members to care for. The impact of caring, particularly on mental health, will be explored later in this report.

Leukodystrophies affect people of all ages and backgrounds

CONTACTING ALEX TLC

Following on from our 2020 survey, we considered when the individual or family received a diagnosis, and when they first contacted Alex TLC (Figure 6). It is clear that we have maintained engagement with beneficiaries over all time periods, including those that only use our website for informational purposes, indicating confidence in our services.

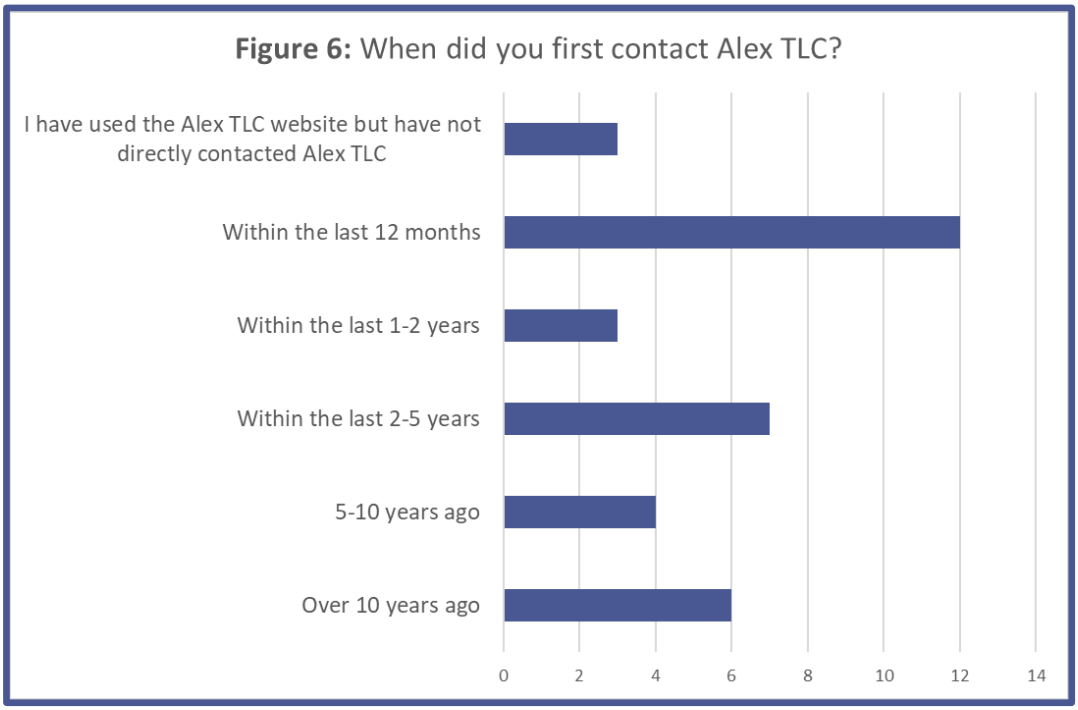
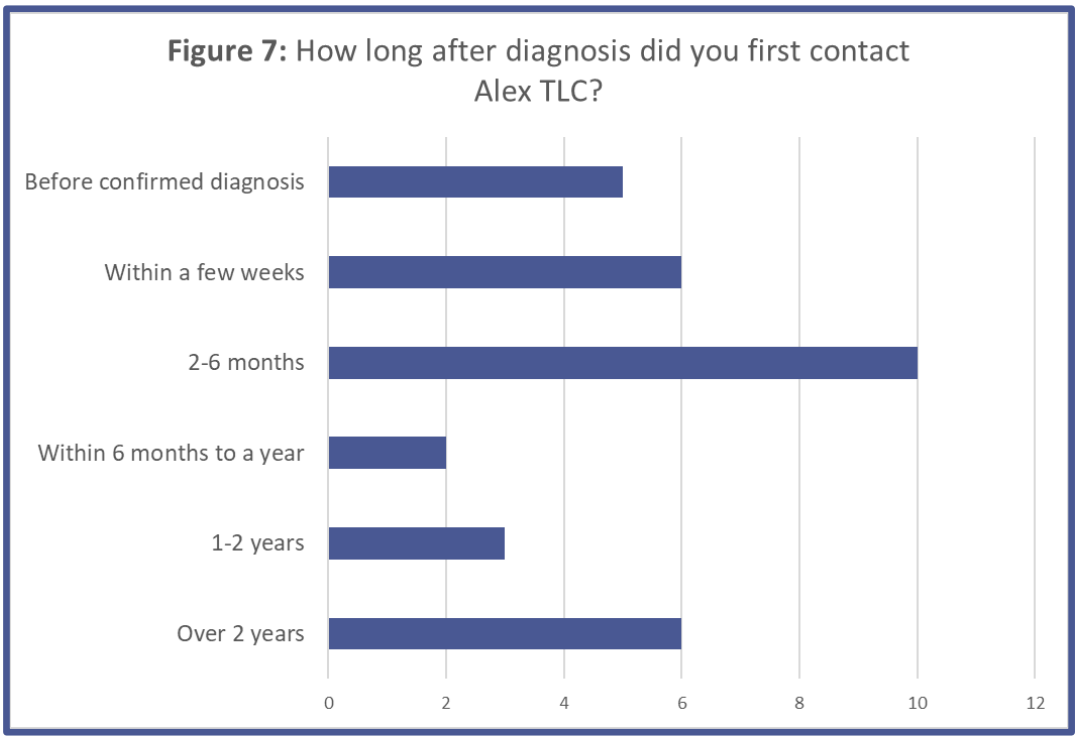
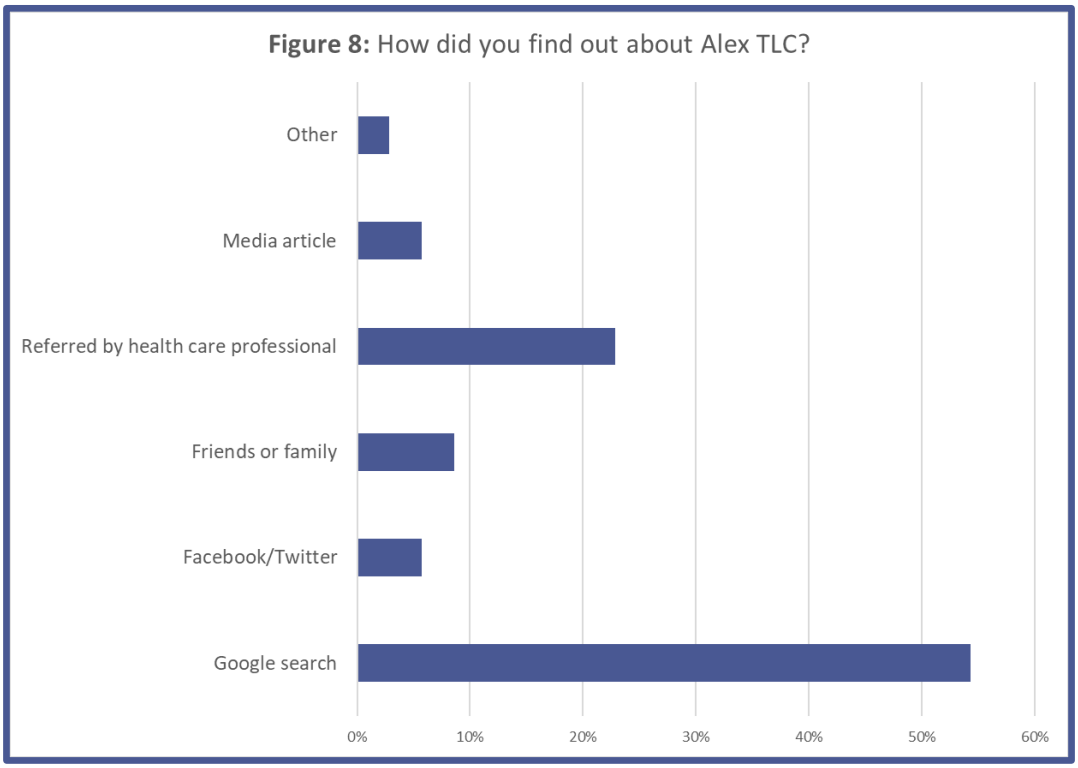


Figure 6: When did you first contact Alex TLC?

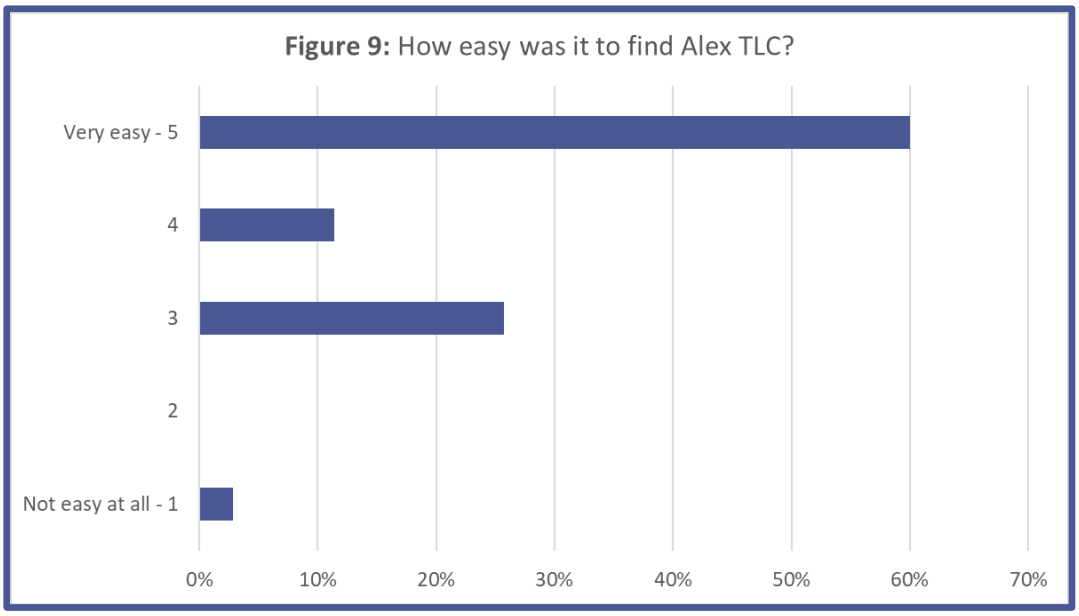
As shown in Figure 7, the time at which respondents contacted us was varied. This was different in comparison to the 2020 survey where respondents either contacted us within a few weeks of diagnosis or waited a significant length of time before seeking our support. From our experience we know beneficiaries react differently to a diagnosis, with some wanting to know everything about their or their loved one's condition from the start, while others are wary of what the future may hold. This is reflected in the varying answers to this question. It is important for support staff to be sensitive to these differences and to ensure families and individuals feel able to approach us when they are ready.



We also asked survey participants how they initially found out about Alex TLC, with the majority responding that this was a result of a Google search (Figure 8). Following this, the greatest proportion were referred to us by a healthcare professional.



There was mixed feedback regarding how easy respondents found it to find Alex TLC (Figure 9). Although a majority of respondents reported that Alex TLC was very easy to find (60%), over a quarter (26%) chose the middle response indicating there were some difficulties and one individual remarking that finding us was not easy at all.



As discussed in the previous report, continued self-publicisation in patient support groups, among healthcare professionals with expertise in rare and neurological diseases and in online support group forums will help to ensure that a maximum number of individuals will be able to find us. Since the previous report we have invested in an SEO expert to ensure maximum search engine optimisation. This means that a search for any leukodystrophy will feature our webpage as a result. We are also involved in a new NHS England Inherited White Matter Disorders Service (NHSE IWMD Service*) and Registry (Inherited White Matter Disorders is an alternative term for Leukodystrophy). We are the lead patient representative organisation, alongside Metabolic Support UK, on the Development Committees for both the Service and Registry. As such staff have:

- helped develop the patient literature for both the Service and Registry
- ensured patients can input their own data into the Registry, including psychosocial impact data for both patients and those that care for them.
- arranged with Service clinicians to attend Service clinics and offer in person support for patients and their families.

**NHSE IWMD Service: https://www.england.nhs.uk/publication/inherited-white-matter-disorders-diagnostic-and-management-service-iwmd-all-ages/*

DIAGNOSIS AND GENETIC TESTING

We asked about the amount of time that elapsed between first experiencing symptoms and receiving a diagnosis for their or their loved ones' condition (Figure 10). We have found that this varies widely, with some people waiting just weeks or days to have an accurate explanation of the cause of their symptoms, and some people remaining undiagnosed for many years. It was most common for a respondent to receive a diagnosis within 2 to 5 years (20%) or for it to be a pre-existing condition (17%). A pre-existing condition was the result of, for example, being the child of an affected individual or carrier, or receiving genetic testing following the diagnosis of a relative. Following not far behind were either waiting 15 or more years for a diagnosis (14%) or within 0 to 6 months (14%). This is concerning as it suggests that respondents may have gone through a lengthy diagnostic odyssey while enduring symptoms; with many types of leukodystrophy, once symptoms are noticeable it is often too late for treatment.

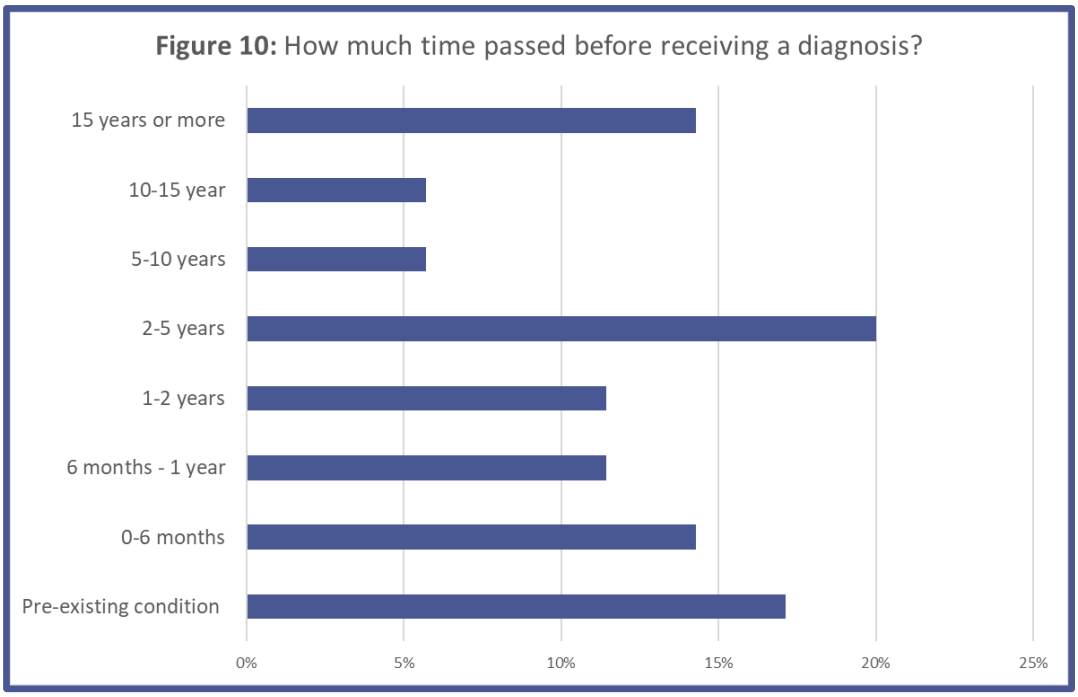


Figure 10: How much time passed before receiving a diagnosis?

We asked survey participants to comment on their experiences of receiving a diagnosis. As shown above many had to wait a period of time before being given a diagnosis, meaning symptoms were often already present:

"My son was 11 years old and was suffering from some vision problems and fatigue so after a year with different glasses an MRI confirmed ALD"

"His walking and balance started to go in the summer of 2020. Brain scan in Nov 2020. Gene testing started in Feb 2021."

Other individuals expressed their frustration at the time it took to receive a diagnosis, with several respondents having multiple tests before a diagnosis was confirmed:

"It was made in the UK [in 2005] after several incorrect diagnoses in India starting in 1991"

"No diagnosis given on visiting specialist several times from July 1999. Asked for 2nd opinion in 2003. Several blood tests taken in March 2003 and one showed AMN positive. 2nd taken in June 2003 and showed negative. 3rd taken in Sept 2003 and showed positive."

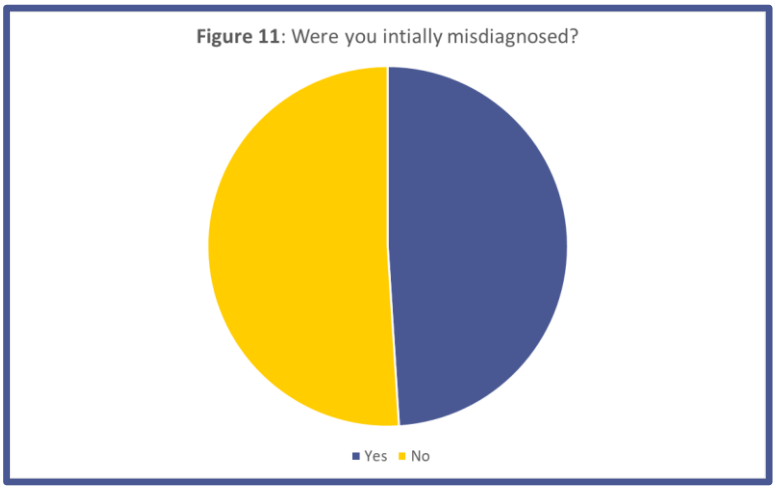
"We had to wait from May 2015 till November 2015 for genetic confirmation of mutations in ABCD1 gene."

Among respondents to this survey, the average time between first identification of symptoms and diagnosis was around 5 years. The longest amount of time that an individual waited to receive a diagnosis was over 26 years. Unfortunately, this figure for the diagnostic odyssey has increased from 4 ½ years since our 2020 Impact Report. This could be due to larger numbers of individuals with rarer leukodystrophies accessing our support, where correct diagnosis can take longer.

As discussed earlier in the report, we are currently working with NHS England as the patient representative organisation on the development committee of a newly commissioned NHSE IWMD Service and Registry. We hope this service will help to reduce the time it takes to receive an accurate diagnosis, especially for those with rarer types of leukodystrophy.

We are continuing to proactively work to get the most common leukodystrophy, adrenoleukodystrophy (ALD) added to the UK newborn screening programme. We ran a government petition in 2021, receiving over 10,000 signatures and our campaign was discussed in Parliament. Unfortunately, our application to the National Screening Committee was unsuccessful but we have commissioned projects to gather the evidence needed to optimise our next application. This includes a research project in collaboration with Sheffield Hallam University to understand parents' experiences of having a child diagnosed with childhood cerebral ALD. There are significant gaps in the availability of literature evidencing the impact of rare disease as a whole, and we hope to use this evidence not only for ALD newborn screening but also as a basis with which to improve access to new treatments and research. We are also working in collaboration with Genetic Alliance to capture attitudes and opinions of whether ALD should be included as part of the newborn screening programme from adults who are affected by, or those who support an adult affected by, the condition. The results of this project will be used to commission further research on the adult perspective of the benefits of newborn screening for ALD.

Figure 11 shows that a large proportion of survey respondents initially faced misdiagnosis (44%). Among survey participants, a misdiagnosis of multiple sclerosis (MS) was most common. However, the list of suggested conditions is very diverse, and includes autism, a stroke, low grade glioma, fibromyalgia, encephalitis and ACTH receptor defect. In comparison to the 2020 survey there is more variety in the conditions respondents were misdiagnosed with, which could reflect the higher number of respondents with rarer types of leukodystrophy which are more difficult to diagnose.



The stress of a protracted diagnostic odyssey and living with unexplained symptoms cannot be underestimated with respondents reporting a range of first symptoms:

"Seizure high temperature select on feeding sensory to food smells & tastes"

"Gait, falling over, odd sensations in legs, inability to sleep"

"Incontinence, Wandering, Memory Loss, Cognitive Decline, Confusion, Swallowing Difficulties"

For individuals who had a pre-existing diagnosis, several individuals commented that they were tested for a leukodystrophy following a close relative either beginning to experience symptoms or being diagnosed.

"My son was diagnosed first, them myself and then my daughter"

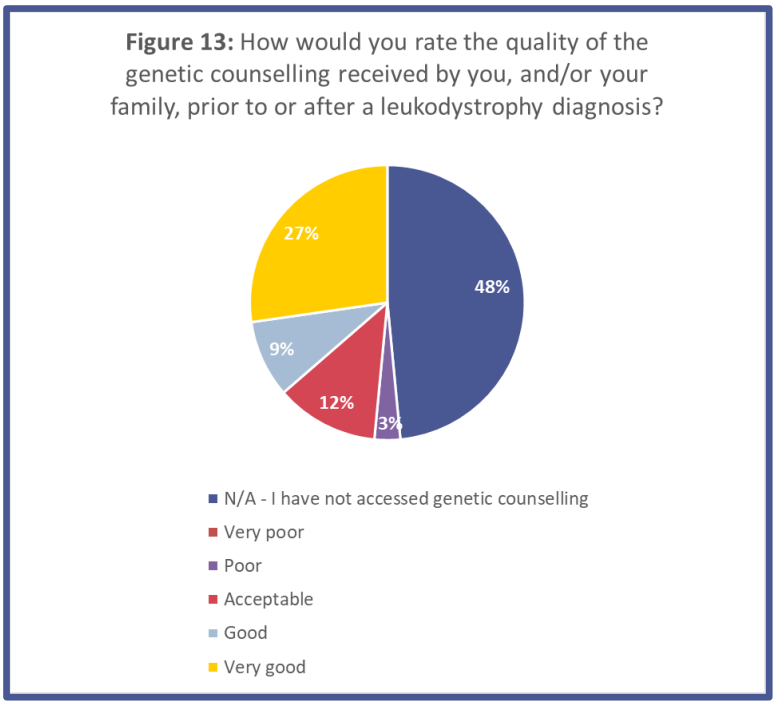
"Discovered through a family member whereby my Mum got tested - had a positive result, so both me and my brother got tested and both got a positive result. As a result my niece (brother's daughter) will also be positive."

"My nephew was diagnosed with it and our whole family was tested"

Prompt genetic testing is of utmost importance in regard to managing a hereditary condition such as leukodystrophy for a number of reasons. Firstly, receiving an accurate explanation for why an individual or their loved one is experiencing worrying symptoms can be a relief in itself. Secondly, an early diagnosis means that life-saving treatment can begin as soon as possible. Thirdly, it means that relatives of an affected individual can be contacted quickly and also tested to see if they too are affected. It is crucial that wider family are contacted following a diagnosis so that the gene is not unwittingly passed on.

We asked survey participants whether they had ever been offered and/or received genetic counselling (Figure 12). The majority (51%) responded positively, having been both offered and received genetic counselling. It was concerning that over a quarter (29%) of respondents had not been offered genetic counselling and that several respondents (14%) did not know what genetic counselling was.

Among those who had received genetic counselling, the majority (48%) reported that the quality of the counselling they received was very good (Figure 12). 12% reported that they found the genetic counselling to be acceptable, 9% that it was good, 3% that it was poor, with no-one reporting the counselling to be very poor. Of concern, is that 48% of respondents reported that they had not accessed genetic counselling. The importance of genetic counselling cannot be ignored when managing a hereditary condition such as leukodystrophy.



We asked survey participants to comment on their experience of genetic counselling. In line with the results shown in Figure 13, experiences varied widely, with some reporting positive experiences, whilst others either endured negative experiences or were simply not offered the service.

"It was simply superb. The geneticist was knowledgeable and compassionate

"Information given about condition, blood tests done, forms given to give to relatives, follow up appointment and telephone calls to check on how we were doing"

"I was not offered any, my daughter was offered brutal advice that really upset her"

"Wider family was ignored"

"Never heard of it or been mentioned to me by a professional"

Some considered genetic counselling unnecessary given their personal situations:

"I have very few relatives, and I am an only child. I only have one cousin, who was informed about X-ALD. Genetic counselling is not as relevant to my family as it will be to many others. I have no other children other than my affected adult son."

"Nothing really as we have no family"

"I have very few relatives, and genetic counselling cannot offer me anything."

A majority (83%) of survey respondents said that the need to contact their relatives in genetic counselling conversations was discussed (Figure 14). However, it is concerning that 17% of respondents had received genetic counselling but had not discussed the importance of contacting relatives in these sessions.

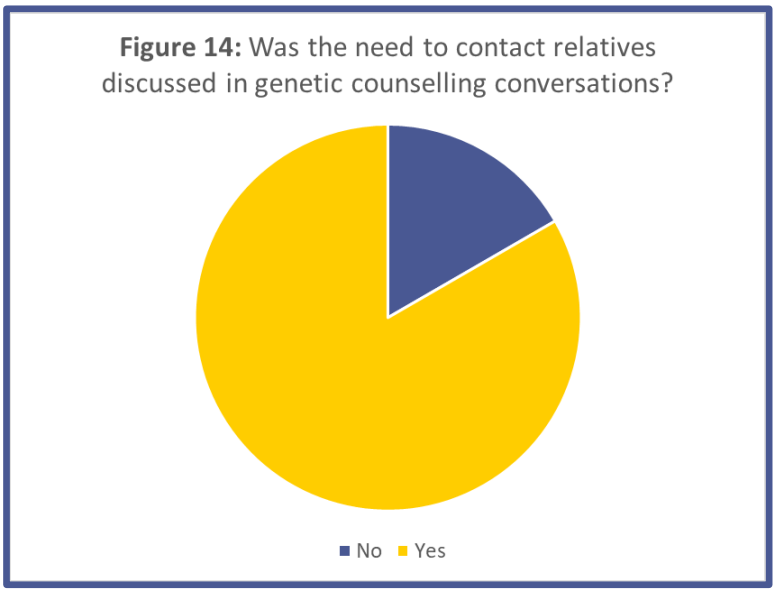
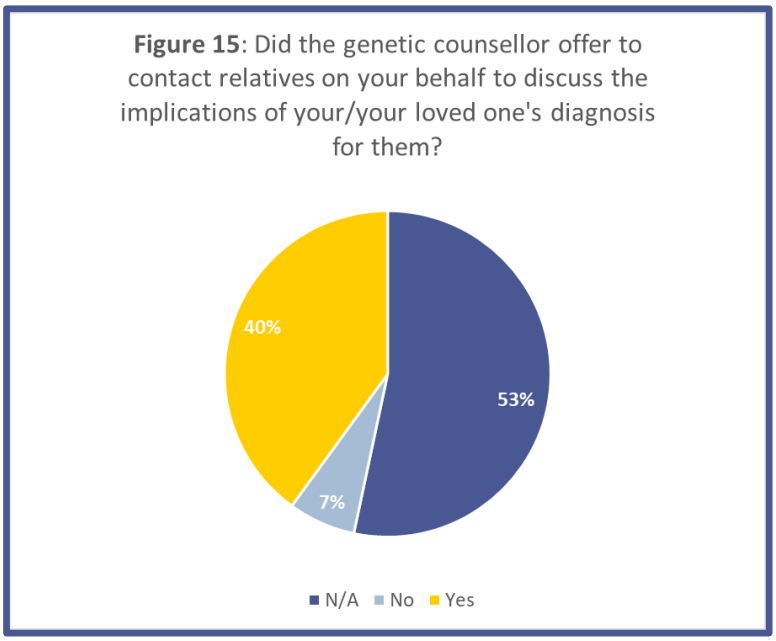


Figure 14: Was the need to contact relatives discussed in genetic counselling conversations?

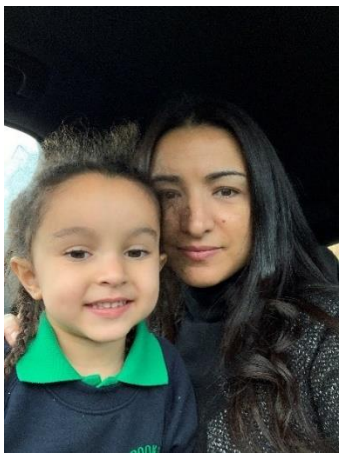
We included a question enquiring as to whether the genetic counsellor offered to contact relatives on respondent's behalf to discuss the implications of a genetic diagnosis (Figure 15). The majority (53%) said that this wasn't applicable to their situation perhaps because they were able to contact their relatives themselves. A large percentage (40%) of respondents said the genetic counsellor had offered, although one person did respond they had to ask them, and several respondents (7%) reported that they did not offer at all.



We can conclude from this part of the survey that genetic counselling both across the UK and the world is not consistently high quality, and individuals receiving genetic counselling are not always informed of the need to inform relatives that they should also be tested. It would be interesting to explore why a number weren't offered genetic counselling and whether health care professionals need a better understanding of how genetic counselling can benefit families when sharing the diagnosis with the rest of the family.

We will continue to work to improve this and collaborated with a Genetic Counselling MSc student at Cardiff University on a project entitled 'A qualitative study exploring family communication following a diagnosis of adrenoleukodystrophy in the UK'. The study aimed to explore psychosocial impacts of receiving an ALD diagnosis for families using in-depth interviews. There were three overarching themes which were identified in the data (1) The change of circumstances of a diagnosis (2) Negotiating new roles and responsibilities and (3) Changing relationships. As a result, we added information to the website to help with understanding genetic counselling and the role Alex TLC can have in supporting conversations with wider family and engaging with genetic counsellors.



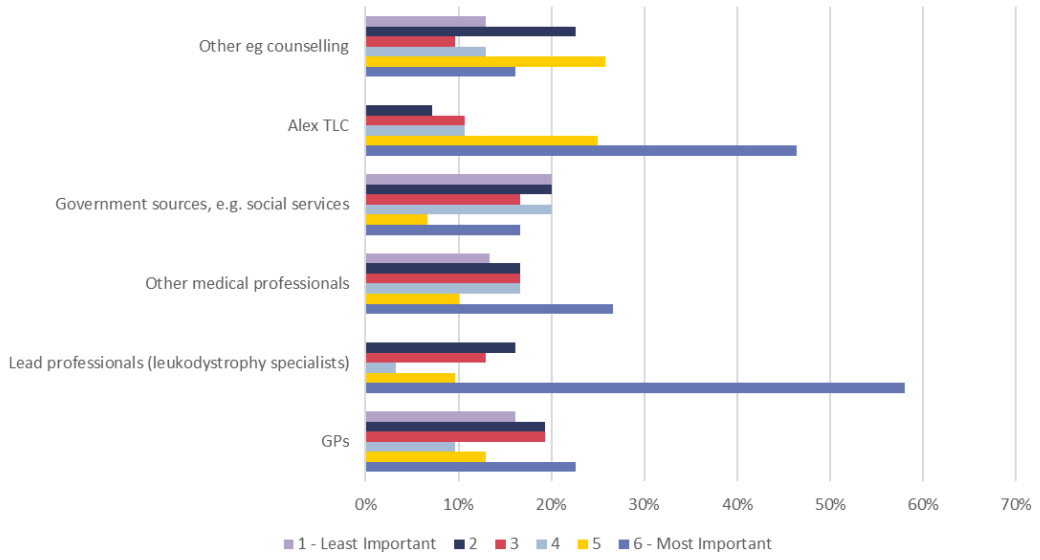


Leukodystrophy can have wide ranging implications within families

SOURCES OF SUPPORT

We asked survey respondents to rate the importance of various services in supporting management of their or their loved ones' condition (Figure 16). Alex TLC was rated the highest (71% either scored 5 or 6), followed by Lead professionals (leukodystrophy specialists (68%). Other forms of support received similar but less high ratings: Other, e.g. counselling (42%), Other Medical Professionals (37%), GPs (36%) and Government sources (24%). This is consistent with findings from both our 2018 and 2020 Impact Reports, where other forms of support other than GPs, Lead professionals and Alex TLC, were rated as less important.

Figure 16: How important are the following as a source of support?



We asked respondents to remark on their answer to this question and found that the support needs, and desires of individuals varies widely. A number of respondents remarked on their positive experience of the support they received from Alex TLC.

"Karen of Alex TLC has been a lifesaver helping me care for my wife with AARS2 leukodystrophy."

"Alex foundation spoken once with one mum straight away got some strength & answers"

"It is early days for my wife and me. When we came back home after a bombshell diagnosis we did not know who to turn to. A GP at our surgery offered to vet any organisations we found on the web. So we got to Alex. It was wonderful. Now I have been allocated to a different consultant in Sheffield who seems accustomed to working with Queens Square and I also have an appointment ...in a couple of month's time. Wow!"

"Found ALEX support excellent"

Several respondents remarked on how other specific services that had been a source of support for them.

"Helen Douglas House have been amazing support for us, Sebastian's trust also great"

"Lanarkshire Carers in Hamilton, South Lanarkshire have been excellent, and only 11 miles from home."

Other medical professionals were also praised within comments.

"Lots of NHS people have been splendid, including physiotherapists and occupational therapists."

"Helpful input from physiotherapist and OT"

One respondent said how their 'wife and immediate family around me' were their source of support. Consistent with our findings from previous years, several respondents concerningly felt they'd had difficulties accessing any form of support.

"We have not had any help from social services, they have not been in touch. PIP was denied as [he] is not poorly enough. Letter diagnosis sent from the neurology department was not great. Genetics have been good. We have not been offered counselling."

"I have not received any support, neither has my son or my daughter."

"Not being able to get proper answers from anyone"

"Rare so unknown where support available, limited social media and only CLIMB"

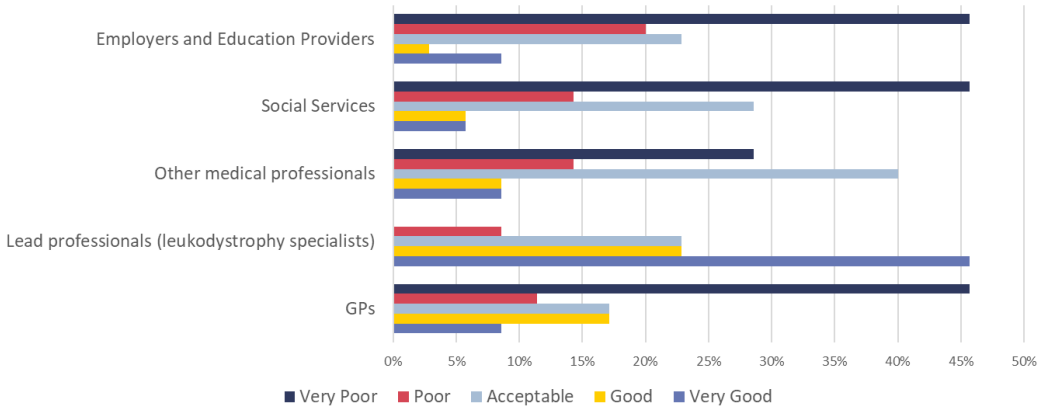
Feedback indicated that several respondents feel unsupported with lack of support from any or limited services, indicating we have a role in raising awareness of how and where to access support, including Alex TLC services. This was a finding consistent with the previous Impact Report, and resulted in a new member of staff, an Engagement and Communications Officer, joining the Support Services Team. This finding demonstrates that, although improvements have been made, there is still work to do, as well as the importance of highlighting both the support available from Alex TLC and health care professionals, and ways to find relevant services for support.

SERVICES' LEVEL OF KNOWLEDGE

We asked respondents to rate the knowledge of non-specialist doctors, GPs, lead professionals (leukodystrophy specialists), other medical professionals, social services, and education providers and employers regarding their or their loved ones' condition (Figure 17). Leukodystrophy specialists were rated highest with nearly half of respondents (46%) rating them 'Very Good'. The majority of other respondents (46%) rated them either 'Good' or 'Acceptable' with only a small proportion (9%) rating them poor and no respondents rating them 'Very Poor'.

This feedback is consistent with our 2018 Impact Report, where no one reported leukodystrophy specialists as having 'very poor' levels of knowledge and a slight improvement from our 2020 report with only 42% of survey participants giving a rating of either 'good' or 'very good' and a high number of respondents rating the knowledge levels of leukodystrophy experts as 'poor' or 'very poor'.

Figure 17: How highly do you rate the following on their levels of knowledge regarding you/your loved ones' condition?



As with findings from the 2020 Impact Report the knowledge levels of GPs and other medical professionals were not highly rated, with 57% and 43% of survey participants giving a score of 'poor' or 'very poor' for these groups, respectively. Although this was an improvement from the ratings of 83% and 63% received in the previous survey. This improvement may be due to an increased awareness of rare diseases in the medical field with more focus on increasing the education of rare diseases during initial GP training and further medical research into this area.

Social Services received a poor rating too, with 60% of respondents rating their knowledge either poor or very poor, however employers and education providers were given the poorest rating of all services, with 66% rating their knowledge as either poor or very poor. These figures were similar to the 2020 survey.

We work to improve knowledge and awareness of leukodystrophies both among the public and healthcare professionals. We hope the recent increase in awareness, knowledge and research within the rare disease field will lead to an improvement for leukodystrophy too. Over the coming years, we will continue to work to make connections with leukodystrophy specialists and raise awareness of all leukodystrophies. We will continue to ensure that we share the highest quality condition information and research updates, in our community and with our professionals, through distribution of our monthly research summaries. We will continue to help connect affected individuals with relevant specialists including our involvement with the new NHSE IWMD Service and Patient Registry.

A lack of knowledge of leukodystrophies among educators, employers, and social services, as found in both our 2018 and 2020 reports, continues to be an issue. Since the previous report we have been working with Genetic Alliance to support their campaigns to help raise awareness of rare diseases. We will be contacting individual councils to ask them include Alex TLC as a support organisation in their local authority resources. This will help to increase awareness within groups utilising this facility and may increase referrals to our charity.

MENTAL HEALTH

Living with a leukodystrophy, either as a patient or a carer, can have a detrimental effect on mental health. There are a number of factors that contribute to this, including the 'diagnostic odyssey', coping with the physical and cognitive symptoms of the disorder, or watching a loved one endure neurodegeneration, and coming to terms with the genetic implications for wider family. It is important as a support organisation that we are aware of the mental health issues that may affect members of our community. We continue to help improve emotional well-being by providing compassionate, professional, and practical advice and support.

This section of the survey was essential in finding out the experience of those living with or supporting someone with a leukodystrophy. When asked what is seen as the most significant challenge facing a respondent in relation to either their or their loved one's leukodystrophy, several respondents identified it as being their loved one's mental health. Many respondents reported that leukodystrophy had negatively impacted their own mental health, with many stating it has caused depression, anxiety and stress. There was also an emphasis on the struggle to stay positive and a feeling of being broken.

"Very stressful"

"Depression, anxiety"

"Severe anxiety, panic attacks"

"It is hard to stay positive all the time"

"It has had a negative impact on my mental health"

"I try to keep as positive as possible but its not always easy. I find myself worrying about the future and how things will end up."

"I'm broken and exhausted"

When asked what effect leukodystrophy has had on their own mental health, there were similar responses, with many reporting anxiety.

"…Think my four children and their families are being brave and hiding feelings about the genetic issue"

"Sadness, a daily burden"

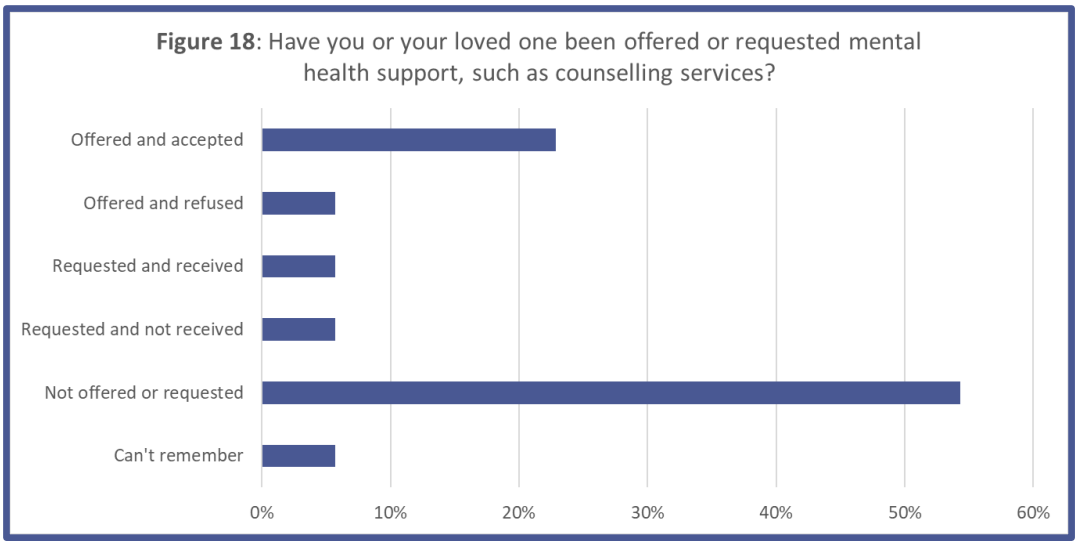
"Depression & stress"

"It causes a great deal of anxiety and worry about what is going to happen in the future"

"It has an effect in that there is a always a worry with respect to my brother"

We asked survey participants about their experience accessing mental health support (Figure 18). The majority (54%) of respondents reported they had not been offered or requested mental health support, which does not reflect the noticeable need in the feedback given above. This could

suggest that respondents are unaware that mental health support is available or how they are able to access this support. This is a larger percentage than in both the 2020 Impact Report (33%) and 2018 Impact Report (44%). This could be reflective of the demand on mental health services following the impact of the Covid-19 pandemic or the fact secondary carer's may prioritise the wellbeing of the person they are supporting over their own wellbeing. Taken together (including those who had requested and been offered mental health support), only 29% of survey participants had received support. A minority of participants (6%) had requested support and not received it.



When asked to comment on the quality of the mental health support that they had received, many individuals gave positive feedback about their experiences.

"Local NHS mental health support was excellent."

"My support has been VERY helpful"

"Excellent"

There were several respondents who were critical, with a common theme being that the support was ineffective as the counsellor did not understand the nature or severity of the condition.

"Son who died had support before death which was not very helpful as they did not know what they were dealing with."

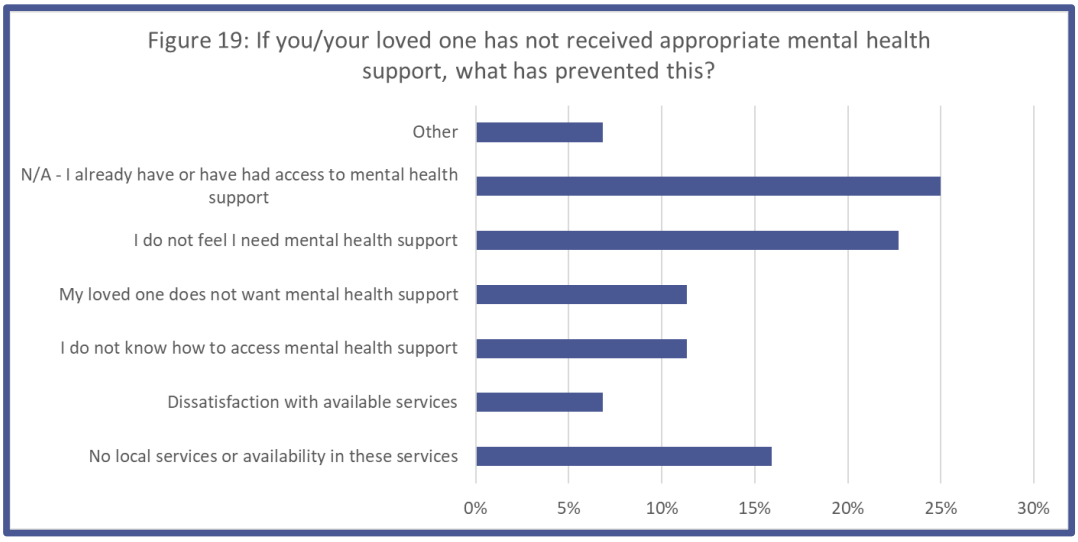
"Not enough understanding of ald"

Of those respondents who hadn't received mental health support, one respondent reported this was because there wasn't a need for mental health support as it wouldn't help.

"Our family are in the mindset that we just have to 'get on with it'. No amount of talking takes the problem away."

Whereas another respondent spoke of how they utilised other forms of support to help them with their mental health, including support from Alex TLC.

"I have excellent support from Karen Harrison by phone."



When asked about what factors had prevented them or their loved one from accessing mental health support (Figure 19) other than the respondents to whom this question wasn't applicable, the majority of respondents (23%) reported that they felt that they did not require such support, with a further 11% of survey participants responding that their loved one did not want it either. In comparison to the previous report there was an increase from 4% to 11%, in those that did not know how to access mental health support. There was only 7% who reported that the main barrier was dissatisfaction with current services and 11% who said it was because there were no local services or availability in these services.

We wanted to find out about perceptions of mental health and support. Many respondents didn't know how mental health support could be helpful to them or their loved one in supporting their mental health. A lack of understanding of what mental health support was available could explain why several respondents said that it wasn't needed. However, given the high number of respondents who reported depression and anxiety, poor mental health amongst our survey demographic is clearly an issue.

"Really don't know"

"I have no idea because it simply does not seem to exist"

Positive feedback demonstrating how respondents felt mental health services could support them included:

"It would give me an outlet for my anxiety so that I can be more present for my kids"

"Being able to talk to someone that isn't family"

"I think it is important that there is support out there if its needed"

"An outlet for feelings, help with coping"

"It would be useful for my wife, as it will give her an opportunity to share how she feels and be able to access support."

"It may help him to come to terms with what is happening to his body."

We asked respondents about what we, or other services, could do to improve the management of their or their loved one's mental health. Several respondents suggested an increased awareness and more information. This reflects a similar finding to the previous impact report which highlights the importance of better awareness and increased levels of education about leukodystrophies. Better awareness and education could help patients and their families know that they are not alone, help them understand how to better manage their condition, and help local authorities provide appropriate support.

"Increase awareness, support specialist mental health services for sufferers, provide advice on where this kind of support can be accessed."

"Any suggestions for support is welcome"

"More information on how to access counselling, financial support"

Many survey respondents took the opportunity to comment on how the current support offered by Alex TLC has been beneficial to them and one respondent described it as a 'lifeline'. There were other more specific suggestions of things Alex TLC could do to help, including more online support meetings, database of counsellors, services in local areas, a sounding board and financial support.

"Sounding board, answer questions"

"An accessible of database of counsellors who have worked with previous ALD carers"

"More online support"

"More zoom calls :D"

"Financial support"

"Check in with Asymptomatic boys and mothers AMN parents of boys"

"Mapping exercise of what is happening in your area"

The request for more zoom calls is positive feedback for our online community calls. These are currently being offered monthly and will be reviewed regularly to ensure they meet the needs of the community. We have been attempting to increase the awareness of Alex TLC's grant programme through regular correspondence, via email, socials and our monthly news-round up. We will also be providing in house counselling which will allow direct access to free counselling

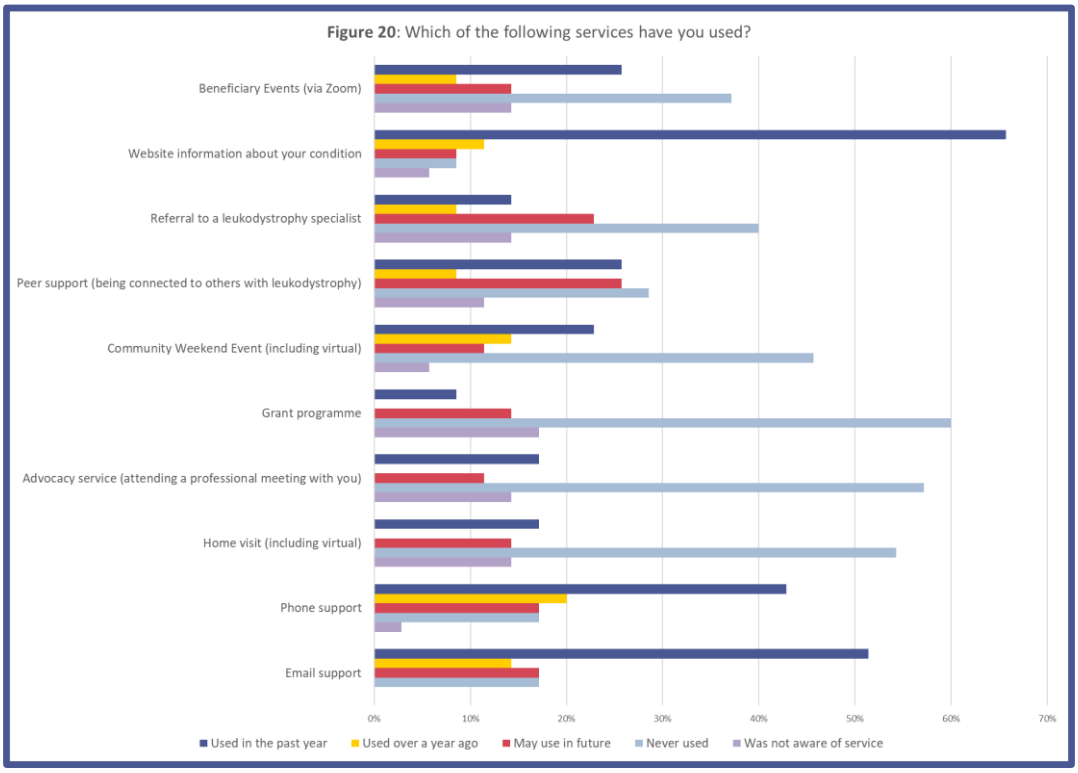
sessions for our community. The further ideas of sounding board, database of counsellor and mapping exercise will be explored as future possibilities by the Support Services Team.

We will continue to proactively support and provide mental health support to our community, following these set actions:

- Share information about organisations which provide mental health information and support on our website
- Continue to organise ongoing community events, including monthly virtual meetings and the introduction of face-to-face local community events, to provide an opportunity for peer support
- Ensure that our in person Community Weekend in 2023 can be accessed virtually for individuals who feel unable to attend due to their mental wellbeing
- Provide in house counselling to allow direct access to specialised psychological support

ALEX TLC SERVICES

Accessing our website to obtain information about leukodystrophies was the most common way for survey participants to interact with Alex TLC with 66% of respondents reporting that they had accessed the website in the past year (Figure 20). This is consistent with the findings of our previous report which found utilising our website the most frequently used service (53%).

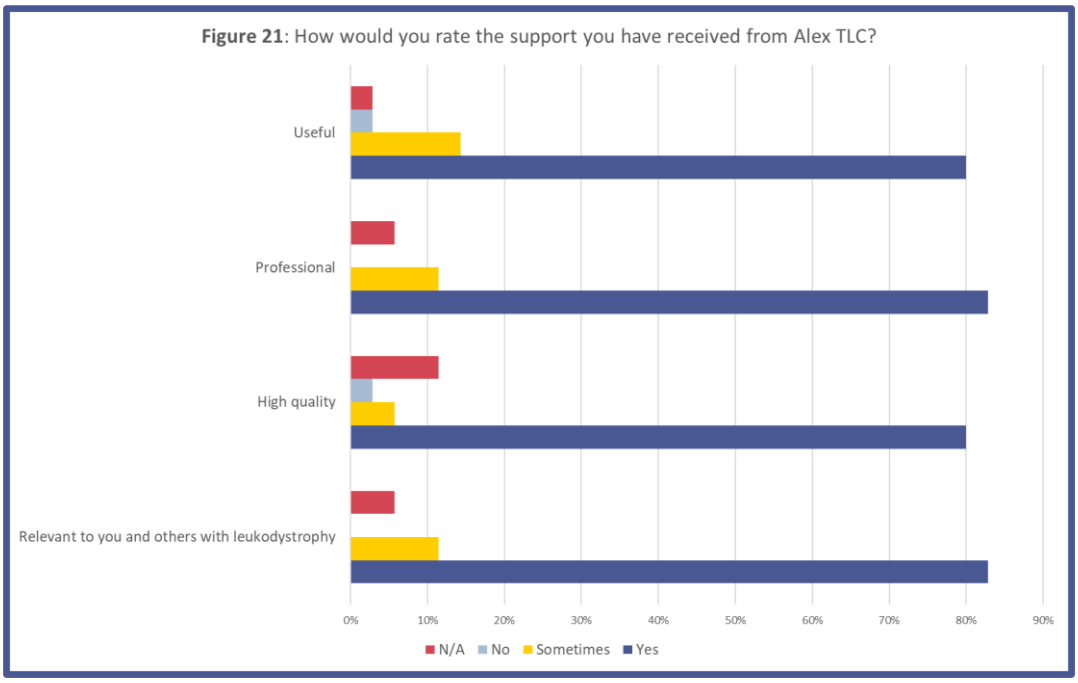


Support by email and phone had been used by 51% and 42% of respondents, respectively. Of the other services available, many had not been frequently utilised (both used in the last year or used over a year ago) only 17% of respondents had utilised a home visit (including virtual), 17% advocacy and 9% grant programme. These figures seem low in comparison to the number of people who have actually used these service within our last reporting year: 118 home visits, fulfilled 32 advocacy requests, and provided 8 grants.

There are several services focusing on peer support (Peer Support and Beneficiary Events) which had been used in the past by 35% of respondents. Our Community Weekend was held in 2018 with two virtual weekends being held in 2020 and 2021, over a third (37%) of respondents had attended the weekend. There were only 6% of respondents who weren't aware of the community weekend which could account for new beneficiaries who have joined recently.

Over 83% of survey participants were aware of the existence of all of our services, this is a slight reduction since 2020 (85%) and may be due to the number of new beneficiaries who have joined us since then. Moving forward, it will be important to ensure new beneficiaries are given detailed information about our services which continue to be shared on a regular basis through our website, social media and monthly News Round-Ups.

We wanted to find out what the respondents thought of the support they had received from Alex TLC (Figure 21). The support provided by Alex TLC was mostly reported (over 80% for all categories) to be relevant, professional, high quality and useful. There was only one person who thought it wasn't high quality and another thought it wasn't useful. Otherwise, all other respondents thought it was sometimes helpful or felt this aspect wasn't relevant to them, maybe as they hadn't received direct support from our charity.



We asked survey participants how the support offered by Alex TLC had helped either them or their loved one. Many commented on how our services have allowed people affected to know that they were not alone, this was a theme that was found in the previous survey.

"I'm not alone"

"Just knowing we are not alone helps to cope."

"Knowing someone understood"

"It's made me feel like I'm not alone"

"Help my social because I have one kids and only my wife is working"

Many described how support offered by Alex TLC helped them as they were able to have questions answered and source valuable information.

"Knowing you are there. Answering questions. Helping locate ALD medical professionals"

"Lots of useful information in general, but Alex TLC was specifically helpful in providing a steroid card"

"I always have a place to bring my questions, no matter how silly those questions are!"

For others it was having someone who understood their journey and who they could talk to.

"Have always been at the end of the phone in the early days"

"It has been great to speak to Karen when I felt my life was falling apart."

"Being able to talk to someone who knows how I am feeling and offering advice"

"Karen and Sara have always been there from good times to bad times, meetings, phone calls, emails, support. They need more than a medal"

Others highlighted how receiving support had offered opportunities to hear from and be in contact with professionals in the field.

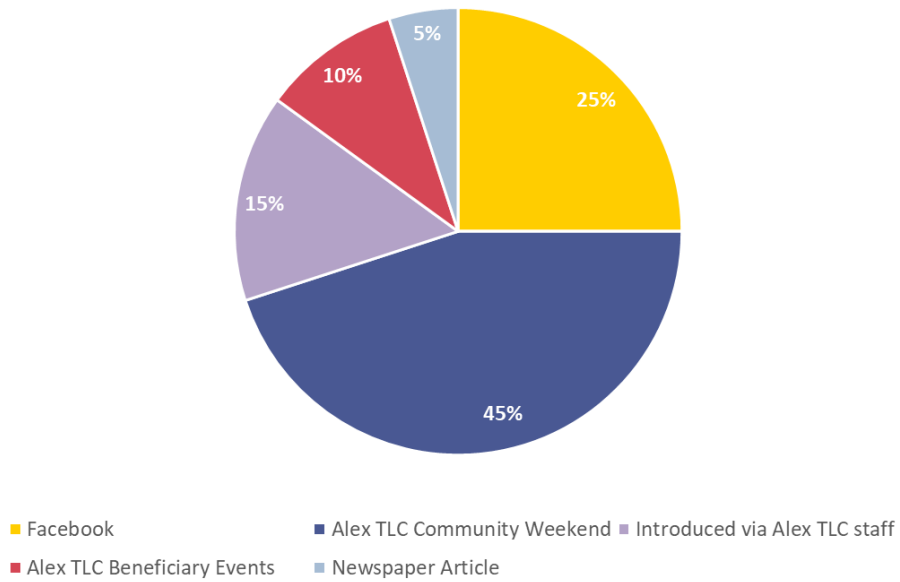
"I have had the opportunity to meet and hear from adrenoleukodystrophy experts at the community events - both in person and virtual events. This is a tremendous support when you live far away from leukodystrophy specialists."

"Contact with professionals from USA, Germany, France, Netherlands. Alex TLC has given our family all the information available from every part of the world."

"Provided information (knowledge is power), helped get in touch with world experts and other patients"

Many individuals and families within the community find a positive benefit from connecting with others with the condition who are going through similar experiences, including challenges. Being in contact with others allows them to share experiences and gain mutual support from each other. We also directly link individuals and families through our Peer Support Programme. We wanted to find out whether respondents were in contact with other families and how this contact came about. Since the previous Impact Report we have increased our presence on social media and started offering regular beneficiary events within the charity, we were keen to see if either of these had had an impact. Over half of respondents (57%) had been in contact with others affected by Leukodystrophy (see Figure 22). We asked respondents how they came into contact with others, with the Community Weekend (45%) and Facebook (25%) being the main methods of contact.

Figure 22: How did you come in to contact with other individuals and families within the charity?



We started our online community meetings in 2020 due to the Covid pandemic and for those who had attended, we wanted to find out more about their experience. Only 26% of respondents had an attended an online event but many reported a positive experience.

"Symptomatic females and symptomatic adults. I enjoy having just a female chat."

"I met other families dealing with adult children with the same condition."

"Lots of advice given and reassurance"

"I love the fact that this can bring other sufferers together"

There were several respondents who suggested improvements for the online events and one respondent reported that the beneficiary event they attended 'didn't help me' but didn't give any further feedback to why they gave this answer.

"I like events with a topic to give attendees more in common"

"A few topics of conversation before the event would be useful to promote discussion, a general discussion about topics outside our conditions, funny stories, film/book reviews etc.."

Finally, we asked those participating in the impact survey about what Alex TLC could do to improve our support services. A majority of respondents (77%) said there wasn't anything we could do to improve our support services. For those who thought improvements could be made the several suggestions were given.

"Anything that can improve support for families"

“Keep in touch, if doing online info sessions do plan in advance”

“Make them easier to access, push information, those with ALD don't have the energy to search”

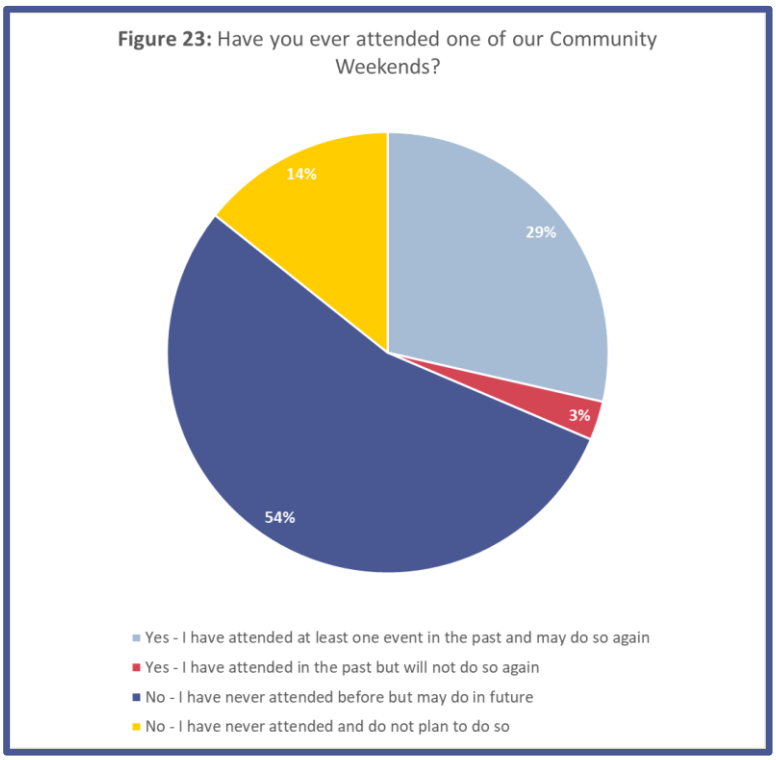
“More contact with families”

“Make more use of people who have been dealing with ALD/AMN for a long time, e.g. as mentors”

It is important that we utilise this feedback to make improvements in our peer support program, including our monthly online meetings. We will ensure clearer communication of upcoming meetings, sending information via email, our monthly Round-Up newsletters and sharing activities on our social media channels. It is important to raise awareness of our peer support network, an important form of support for our community to utilise. We will introduce ‘Ask Our Community’ enabling individuals to ask questions or seek information from the rest of the community. These direct asks will be sent on a monthly basis via email to our community and shared on our social media channels.

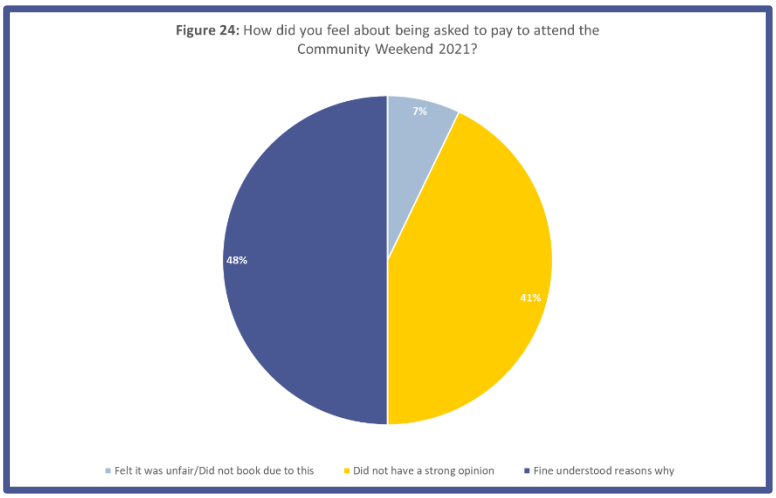
COMMUNITY WEEKEND EVENT

The Alex TLC Community Weekend is an opportunity to bring families together to provide a space in which they can meet, talk freely, and support one another. It also provides a chance for families to hear from leukodystrophy specialists and get research updates. Due to the COVID-19 pandemic, our 2020 Community Weekend converted to a digital event in 2020 and 2021, with a return to face-to-face events confirmed for 2023.



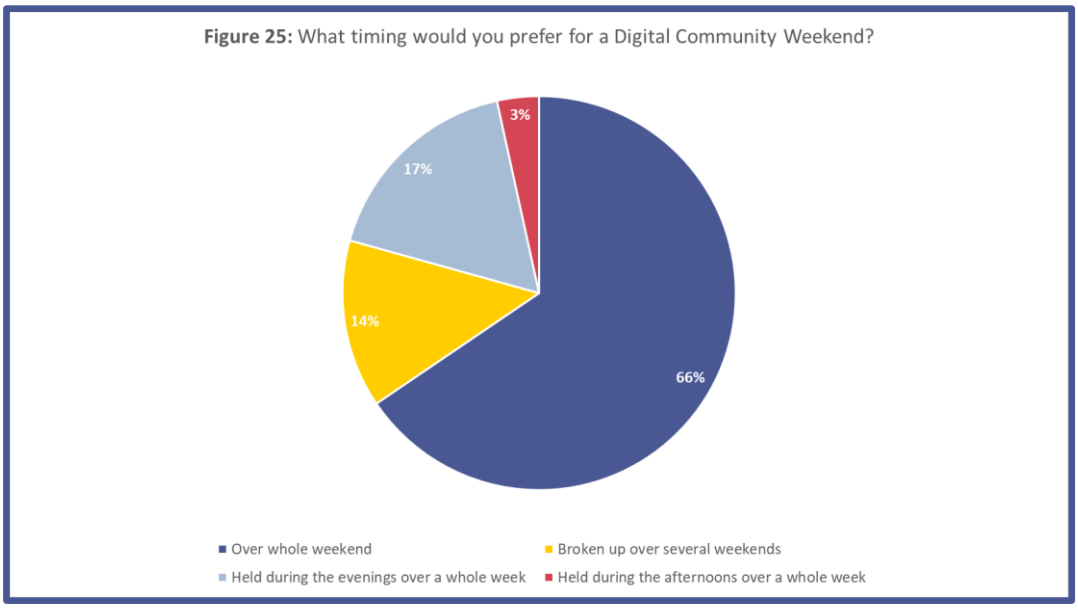
Almost a third (29%) of survey participants had previously attended a Community Weekend, and regardless of whether or not they had previously attended an event, 83% of respondents reported that they would potentially attend in the future (Figure 23). 3% of participants reported that they had attended but would not do so again, and 14% that they had not attended in the past and would not do so in the future.

Only one respondent said they have attended and would not again, reporting this was because they would 'find it too difficult to come again'. For those who haven't attended a weekend previously, they reported the reason they cannot attend was either they are not based in the UK, find it too difficult to attend the event or these kinds of events are not for them. For those who have not attended and do not plan to attend, they reported they cannot attend as they are not based in the UK, find it too difficult to attend the event and do not want to meet others with a more progressed leukodystrophy. We had one respondent who said they 'did not like the event' which seemed strange as they had not attended a community weekend event previously.



For our Digital Community Weekend 2021 we asked for a small payment from attendees to access the event, including watching recorded videos afterwards. When asked about paying for the event (see Figure 24), just under half (48%) were 'Fine and understood the reasons why' and a majority of the rest (45%) 'Did not have a strong opinion'. However, 7% felt that was unfair or did not book due to this. Although we did offer financial support to those who did could not afford the fee, it could be they weren't aware or did not feel able to utilise this support.

Our priority is to ensure Community Weekends can be attended by all in our community, and we would not want an attendance fee to restrict this. We offered 'an early bird ticket' giving a reduced ticket rate when booking early, 76% of respondents thought we should offer this again. We offered free places for those experiencing financial hardship, 86% of respondents thought we should offer this again.



The digital community event was held over a weekend from 10:00-17:00 on both Saturday and Sunday. This was to ensure that it did not interfere with morning or evening family commitments. We were interested if we were to hold a digital event again what timing would be preferred (see Figure 25). A majority of respondents (66%) agreed that holding it over a whole weekend was their preference, although others favoured it being held during evenings over a whole week (17%) or being broken up over several weekends (14%). The least favourable option (3%) was being

held during the afternoons over a whole week, which may be due to priorities such as work or family commitments.

We are planning to hold an in-person community weekend in 2023 and were interested in people's views of paying for the event, and whether these views would be different to those for a digital event. Interestingly 69% would be willing to pay for the event, in comparison to the 48% for the digital event. It will be important for us to explore a suitable costing scheme for the event to make it accessible for the whole community. However, we also need to consider balancing this against the overall cost of putting on the event. We should also consider a support scheme for those experiencing financial hardship, as several respondents said money would be a factor in allowing them to attend an in-person event.

"I couldn't afford it"

"'It's ok for people that live near the resource but people who live faraway cost of travel to expensive"

We asked respondents to comment on their experience of attending a Community Weekend. As in the 2020 Impact Report, we received overwhelmingly positive feedback with no issues or negative feedback.

"It was a privilege to meet all the experts from around the world, and every effort was made by Alex TLC to make it informal and fun."

"Good get together"

"Amazing opportunity to network and hear about the scientific developments"

"I liked the accommodation - first class. I liked the speakers - experts in their field. They were all informative and approachable. I met others with ALD and AMN, which was an invaluable experience.

"Loved the research updates. Great to meet others who know what you are dealing with. Small group sessions of similarly affected people particularly useful."

"Fun, informative and very supportive"

"Fantastic great to chat to professionals and meet new people"

Banner advertising Digital Community Weekend 2021

GRANTS AND PERCEPTIONS OF ALEX TLC

Alex TLC provides small financial grants for families and individuals affected by leukodystrophy. We provide financial support to patients and families for access to equipment, care, treatment, those undergoing Bone Marrow Transplant (BMT)/Gene Therapy or for families in financial hardship or going through bereavement. In our reporting year, 2021 to 2022, we gave eight grants to families affected by leukodystrophy for BMT, bereavement and equipment.

Alex TLC grant programme helped purchase an adapted bike for a young man affected by ALD

There were only two respondents who had previously received a grant from us which were both a financial hardship grant. They both thought our grant policy was fair and one respondent said that the grant provided financial support for their family.

We were interested to find out why other respondents hadn't accessed our grant programme. Over a third of respondents (38%) said that it was because they didn't need to access a grant.

"Not needed thank you"

"Haven't needed one"

However, there was an equal number (38%) of respondents who weren't aware of the grant programme or what the process was. It will be important that we continue to include information about the grant programme in regular communication channels and in support conversations.

"Never heard of it"

"Did not know you could get a grant? and what for?"

"Not sure of process"

There were several respondents that didn't believe they would meet the criteria to be able to access the grant programme, so it will be important to important to clarify the criteria for our grants.

"I don't believe it applies to me"

"I did not know they were available. I assume because we are both working we would not be eligible."

Alex TLC aims to deliver high quality support, advice, knowledge, and care for those affected by a leukodystrophy. It's important for us to know how respondents feel about our charity, so we understand what we are doing well and areas where improvements are needed. We asked how far respondents agreed with several statements about their perceptions of Alex TLC as shown in Figure 26.

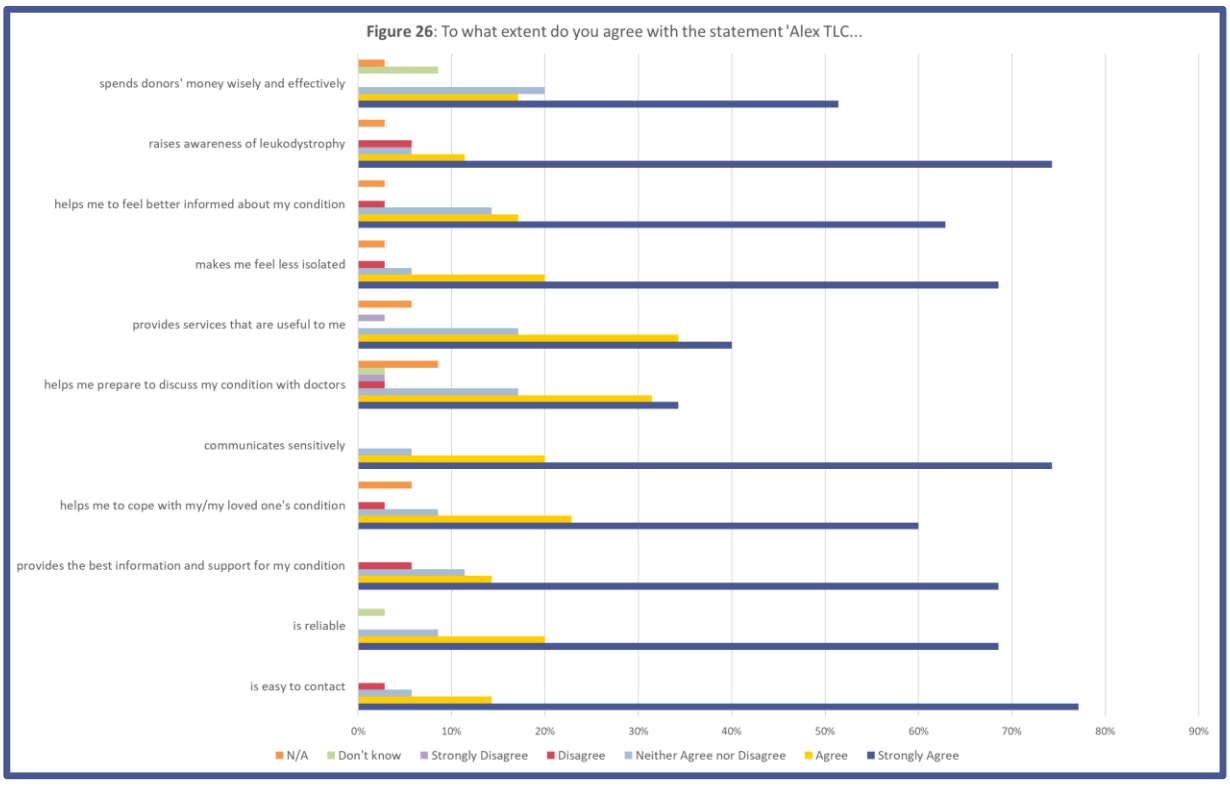


Figure 26: To what extent do you agree with the statement 'Alex TLC...

For each individual statement at least two thirds (66%) of respondents strongly agreed or agreed. The top four statements were 'communicates sensitively' (94%), 'is easy to contact' (91%), 'is reliable' (89%) and 'makes me feel less isolated' (89%). This is encouraging feedback and provides an understanding of our role as a supportive and caring organisation for families affected by leukodystrophy.

However, there was quite a decrease in those agreeing with 'helps me prepare to discuss my condition with doctors' (66%) and 'spends donors' money wisely and effectively' (69%). These were the only two statements were several respondents chose the answer 'Don't know', it could be that not as many people agreed with these answers as there isn't enough information about the charity's role in these areas of work. It will be important that we share information about the support that is available to help families prior to medical appointments and provides regular updates about the work of the charity, including campaigns, research, and projects.

We asked respondents about the overall support given by Alex TLC, the average score was 4 out of 5, with 83% of respondents either being happy or very happy with the support they'd received. When asked to comment on their impressions of Alex TLC, there were a number of positive remarks, including praise for our phone support and research information.

"Very organized, empathetic and ready to help"

"Excellent phone service with sound support. Always feel better after speaking"

"We would have been lost without (Alex TLC) especially in the beginning"

"For a small charity, the support is excellent."

"Alex TLC do a splendid job in supporting patients and families whilst providing a platform for specialists and researchers to come and talk to us"

"Everyone was happy and lovely. really understanding and supportive throughout the diagnosis, and told us the time line of treatment and investigations"

"A life line for our family"

"Up-to-date, and adapts to change. Gives full information on clinical trials, and important developments in science"

Although a charity supporting individuals and families worldwide, one respondent felt it was only good for patients in the UK. It will be important for us to ensure we consider everyone within our community when sharing information, including research, so that we cater for those in the UK and globally. One respondent said that they 'hadn't really found the charity supportive', which mirrored their answers of disagree or neither agree or disagree, for all of the statements. It is important to review all aspects of the charity regularly, reflecting on where improvements can be made. There was some feedback suggesting the charity had become too big and that our work was dependent on a small team. It will be important to communicate the advantages of expansion to our community clearly so the benefits can be understood.

"As I said when Sara first started it I found it great. But now it is to big and I am lost in the system with you. Bring back the old days. Go back to the start when it was friendly."

"Too dependant on a small number of people"

We are now supporting individuals affected by all leukodystrophies, expanding our support from primarily ALD and AMN in 2018. Understandably, as we support more individuals and families with a wider range of conditions we will continue to grow. It will be important for us to review how the experience is for those accessing support and to consider what factors have contributed to the feeling of Alex TLC being too big and unfriendly. Although a majority of respondents were either happy or very happy with the expansion (71%), there were several respondents (9%) who were very unhappy. One respondent discussed a concern about catering for a larger audience possibly limiting the information available about ALD or AMN at community weekends.

"I worry if when it comes to meeting up at the annual weekend people won't come because there are too many other talks although I understand why it possibly had to be done."

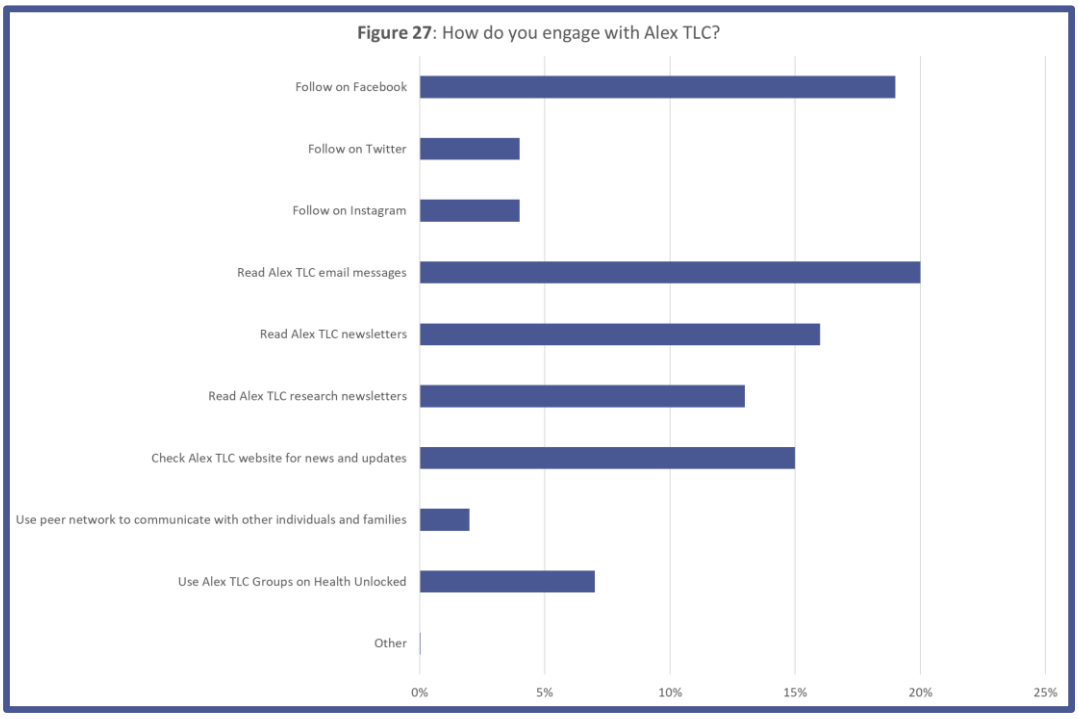
Although several respondents supported the need for the charity to diversify and the positive outcomes it may lead to for families and also how it will help to increase awareness of the charity.

"It make Alex TLC relevant to more families - bigger and louder voice"

"Incorporating other leukodystrophies is diversifying to keep being relevant to many more families. It's been a necessary expansion. If the charity remained too small and specific it may not attract enough attention"

ENGAGEMENT

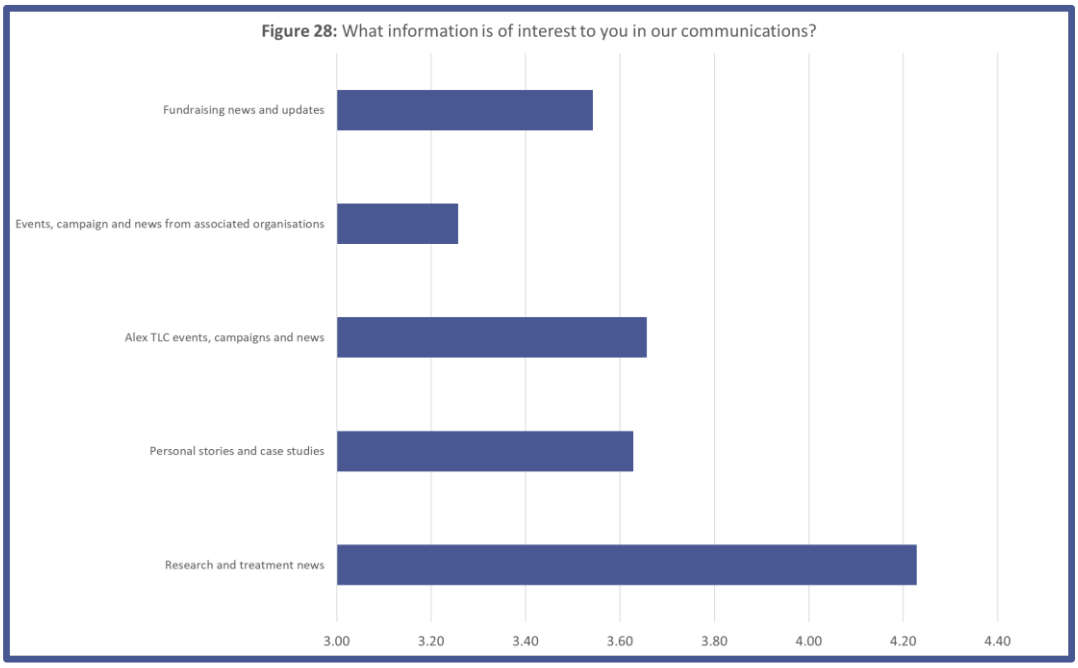
We asked survey participants about how they engage with Alex TLC (Figure 27). A majority (89%) of respondents chose multiple methods of engaging with the charity. The most popular form of engagement was reading Alex TLC email messages, suggesting this is a good form of communication for us to use. The charity sends out monthly news-round ups (formerly known as newsletters) and research summaries, but these were less engaged with than email messages as a whole with engagements rates being 16% and 13% respectively. However, these figures are not representative of the engagement from the community. Over a 5-month period the open rates of news-round-ups and research summaries were both 36%. It is important that we continue to use emails as a means of communication for other forms of contact other than the monthly round-up and research summaries, but also distinguish between the two types of engagement, from people accessing our information and those directly engaging with our work.



Of the social media platforms, Facebook was the most commonly used (19%), with Twitter and Instagram receiving far less engagement, both only 4%. There were a number of respondents (15%) who utilise the Alex TLC website for news and updates. We keep our community informed by regularly posting in the news section on the website. This is important for those who do not engage with the charity via email or the social media platforms. We run several groups on Health Unlocked, a social network for health, which several respondents (7%) use to keep engaged with the charity. The least utilised form of contact was using the peer network to communicate with other individuals and families (2%). This is either indicative the peer network is not often utilised or that we are not communicating well enough that we have a peer support network. As discussed in the 'Alex TLC Services' section one of our main priorities moving forward will be to make improvements in our peer support programme which include clearer communication of upcoming

meetings, raising awareness of our peer support network, and introducing regular 'Ask Our Community' communications.

We also asked respondents what information was of interest to them in our communications (Figure 28). An average score has been taken for each of the types of information, from their scores of 1 (not interesting) to 5 (very interesting). The highest rated information was the research and treatment news (4.23). This indicates the importance of this information within the community for keeping up to date with recent leukodystrophy research and clinical trials. Personal stories and case studies (3.63) scored similarly with Alex TLC events, campaigns, and news (3.66). This shows the importance of keeping up with regular community communications and ensuring our "Alex TLC family" feeling is maintained. Fundraising news and updates were rated slightly lower 3.54, however community fundraising is a priority for 2022/23 with new fundraising staff and a proactive strategy now in place. Hopefully as the community becomes more engaged with fundraising these updates will have more importance. Finally, with the lowest average rating was events, campaigns, and news from associated organisations (3.26) demonstrating that respondents put more importance on the news of the charity than other organisations. Although we include an 'Other News' section in the monthly Round-Up, we do not tend to send direct correspondence about the work of other organisations so as not to dilute our own communications.



Finally, we wanted feedback about respondents' experiences completing the survey. This included any difficulties completing the survey, opinion about the length of the survey, any other comments, or suggestions for improvements. With regards to the length of the survey, a majority (54%) thought it was long but were happy to complete it. Although 40% said it was about right, there were several respondents who said it was too long and it put them off completing it. It's important to consider that there were several people who started the survey and didn't finish it. Unfortunately, we cannot find out how much of the survey they completed but it could suggest the reason they didn't finish the survey was due it's length.

"It's a bit long and feels as though its focused on pushing the weekend event"

"No advance warning of length. kept been sent round in circles"

"It states at the beginning of the survey it would take 7 minutes. After 50 odd questions I nearly gave up!! It took me 55 minutes. Q42 You can't tick more than one. Sorry but some questions I didn't answer as it probably would have taken me another 20 minutes."

It will be important when designing the next Impact Survey that the survey length is taken into consideration and that any estimate of time taken is more accurate. Although we were mindful to give clear detailed explanations with each question, one respondent said that we should include an 'explanation box after each question to explain certain answers'. This suggests that options should be mindfully chosen to reduce any ambiguity. Another respondent reported 'finding the date first diagnosis' was difficult to answer as they couldn't remember and the answer must be in the form of a calendar date. For future surveys we may consider a free text field for this question.

CONCLUSIONS

The Impact Survey 2022 was completed by a small number of individuals from our community. They represent a number of different leukodystrophies and are at different stages of their leukodystrophy journeys. Individual survey respondents utilised our services differently and included both individuals who first contacted Alex TLC many years ago, and those who first contacted the organisation recently. Respondents were affected individuals, carers, and those caring for loved ones whilst also managing their own symptoms.

There was positive feedback about the support and services offered by Alex TLC with a majority of survey participants finding our support to be relevant, professional, high quality and useful. However, some respondents didn't know what support there was available for them to access. This suggests we have a role in educating affected individuals about how and where to access support; highlighting both the support available from Alex TLC and other health and care organisations, and ways to find relevant support services.

When we asked respondents of how we could improve as a charity, the following suggestions were made:

- Improve support for families, including introducing more online community meetings
- Keep in touch regularly
- Ensure information about online meetings is available in advance
- Make more use of people who have been living with conditions as mentor

This feedback supports workstreams we have already put in place and can implement as part of our future pipeline:

- New Research Analyst and Counsellor posts will directly translate into improved support for our community
- Community check-ins (individual "How are you, do you need any support?" emails) to all on our database twice a year have already been implemented as a response to similar feedback in our 2020 Impact Survey
- Our digital support activities will be communicated earlier with more reminders
- We will explore viability of additional online community meetings
- A priority for 2022/23 is more proactive use of our Peer Support Network and encouraging users to build supportive long term peer relationships

It will also be important to consider when designing future impact surveys, what improvements can be made. We include a few modifications based on feedback and our own experience of analysing the data:

- Allow a wider time frame for completing the survey
- Make sure the survey is shorter
- Ensure that any estimate of time for completion is accurate
- Make sure answers for questions are clear and understandable, if not provide further information
- When asking for dates ensure that it is possible for respondents to give an estimate opposed to an exact date

Below are tables summarising the main survey findings, actions and future concepts for each section.

Section	Demographics and Diagnosis
Survey Findings	• A majority of survey respondents were female • Most respondents were White British • Less diversity in global location of respondents • The majority of respondents had an ALD or AMN diagnosis
Actions	○ Aim to engage with males impacted by these conditions and explore different approaches to encourage engagement ○ Continue to work on projects to increase engagement from ethnic minorities, including collaboration with organisations who can support our efforts such as Breaking Down Barriers ○ Ensure that information on our website is clear that our support is offered to individuals and families globally
Future Concepts	➢ Create a support group specifically for men with regular meetings

Section	Contacting Alex TLC
Survey Findings	• The time at which respondents first contacted us was varied • Most respondents found the charity because of a Google search or were referred by a healthcare professional • There was mixed feedback regarding how easy respondents found it to find Alex TLC
Actions	○ It is important for support staff to be sensitive to these differences and to allow families and individuals to approach us when they are ready ○ Ensure our SEO expert continues to achieve maximum search engine optimisation for when people search for leukodystrophy ○ Promote our charity and role as patient representative organisation within the NHSE IWMD Service and Patient Registry
Future Concepts	➢ Develop a project looking at other possible engagement opportunities with other rare disease and support organisations

Section	Diagnosis and Genetic Testing
Survey Findings	• The amount of time that elapsed between first experiencing symptoms and receiving a diagnosis for their or their loved ones' condition varies widely • A large proportion of survey respondents initially faced misdiagnosis • Over half of respondents had been offered and received genetic counselling but over a quarter of respondents had not been offered genetic counselling and several respondents did not know what genetic counselling was • Of those who had genetic counselling, the ratings were mixed with several individuals reporting the quality of the service was 'poor' or 'very poor'

Actions	○ Ensure we support the development of the NHSE IWMD Service as the Patient Representative Organisation, promoting its role to diagnose rarer leukodystrophies ○ Continue our campaign to get ALD added to the newborn screening programme, utilising results from our CCALD Sheffield Hallam Project as evidence ○ We will continue to work on improving the knowledge and understanding of our community by raising awareness and ensuring accurate information is available
Future Concepts	➢ Once there is official publication of the study, "Communicating the genetic implications of adrenoleukodystrophy", we will share it more widely as a resource to use as guidance when supporting families requiring or going through the process of receiving genetic counselling

Section	Sources of Support
Survey Findings	• Alex TLC and Lead professionals were rated as the most important services in supporting management of their or their loved ones' condition • Several respondents concerningly felt they'd had difficulties accessing any form of support
Actions	○ We have a role in raising awareness of ways to find and access relevant services for support, including the services we provide
Future Concepts	➢ We hope having a presence at NHSE IWMD Clinics will help new beneficiaries feel able to engage with the charity and approach us for support

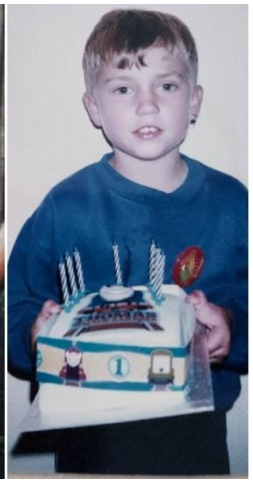
Section	Services Level of Knowledge
Survey Findings	• A lack of knowledge of leukodystrophies continues to be an issue; the knowledge levels of GPs, other medical professionals and social services were rated poorly, with employers and education providers rated the poorest
Actions	○ We will continue to work to improve knowledge and awareness of leukodystrophies both among the public and healthcare professionals ○ Share the highest quality condition information and research updates, with our community
Future Concepts	➢ We will continue to develop connections with leukodystrophy specialists through our role with the NHSE IWMD Clinics ➢ We will raise awareness of all leukodystrophies, through collaborative relationships and new research projects ➢ Undertake project involving contacting councils to ask they include our information as a support organisation in their local authority resource

Section	Mental Health
Survey Findings	• Many respondents reported leukodystrophy had negatively impacted their own mental health, with many stating it has caused depression, anxiety and stress • A majority of respondents reported they had not been offered or requested mental health support as many didn't know how mental health support could be helpful to them or their loved one • Respondents who had access to mental health support gave positive feedback about their experience, but several reported the support received as being ineffective due to lack of knowledge about leukodystrophy
Actions	○ Continue to offer one to one support to beneficiaries, where mental health difficulties are noticed, we will signpost to appropriate mental health information and suggest speaking to their GPs for support ○ We encouraged the inclusion of questions around mental health, both for patients and carers, in the newly created NHSE IWMD patient registry
Future Concepts	➢ Utilise information gathered through the NHSE IWMD patient registry to address mental health issues that arise more comprehensively by creating further information and signposting materials ➢ Share information about how to access counselling sessions through the new counsellor role

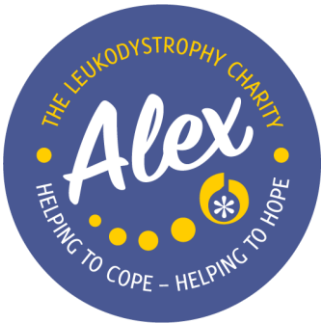
Section	Alex TLC Services and Engagement
Survey Findings	• Accessing our website to obtain information about leukodystrophies was the most common way for survey participants to interact with Alex TLC • The number of respondents who utilised our other services, including one to one support, peer support and advocacy, were not reflective of how highly support services are accessed in the charity each year • Some respondents weren't aware of all our services • Most respondents engaged with the charity using multiple methods, the most popular form of communication was reading our email messages • Respondents were most interested in research and treatment news
Actions	○ Ensure information about our services is regularly shared on our website, social media and monthly news round-ups, this is particularly important for those who have only recently joined the community ○ Ensure clearer communication of upcoming meetings, sending information via email, our monthly round-ups and sharing on our social media channels ○ Introduce an 'Ask Our Community' enabling individuals to ask questions or seek information from the rest of the community ○ Continue to use emails as a form of communication for other forms of contact other than the monthly round-up and research summaries ○ Continue to send out monthly research summaries and share information on socials and our website
Future Concepts	➢ Use our new Research Assistant role to support the expansion of research avenues, including sharing of information and future research projects

Section	Community Weekend Event
Survey Findings	• Almost a third of survey participants had previously attended a Community Weekend and we received positive feedback about their experience • The reasons given for not attending a community weekend previously included geographical distance / travel and not wanting to meet others with their conditions more advanced than their own • A majority of respondents agreed with and understood the reasons why we charged for our last digital event in 2021
Actions	○ Ensure that the community weekends we offer can be attended by all our community continues to be a priority ○ Advertise in advance and provide clear information about what's involved; share ways we can help attendees overcome barriers that may prevent them from attending, e.g. travel, childcare, worries about what event involves ○ Explore a suitable costing scheme for our Community Weekend 2023 event to make it accessible for the whole community ○ Ensure that any financial support is clearly and regularly advertised as we would not want an attendance fee to restrict anyone from attending
Future Concepts	➢ When planning future weekends speak to previous attendees to gain their opinions and thoughts on concepts

Section	Grants and Perceptions of Alex TLC
Survey Findings	• Only two respondents had previously received a grant from us. Other respondents hadn't accessed a grant because they didn't need to, or they weren't aware of the grant programme or what the process was • Several respondents didn't believe they would meet the criteria to be able to access the grant programme • Respondents had a positive perception of the charity, the statements which were most agreed with were 'communicates sensitively', 'is easy to contact', 'is reliable' and 'makes me feel less isolated' • Fewer respondents agreed the charity 'helps me prepare to discuss my condition with doctors' and 'spends donors' money wisely and effectively' • Majority of respondents were either happy or very happy with the support they'd received from us
Actions	○ Continue to include information about the grant programme in our regular communication channels and in support conversations ○ Ensure we clarify criteria for grants so that beneficiaires feel able to utilise our grant programme ○ Share information about the support that is available to help families prior to medical appointments and provides regular updates about the work of the charity, including campaigns, research, and projects ○ Ensure we consider all within our community when sharing information, including research, so that they cater for those in the UK and globally
Future Concepts	➢ Review how the experience is for those accessing support and to consider what factors have contributed to the feeling of it being too big and unfriendly

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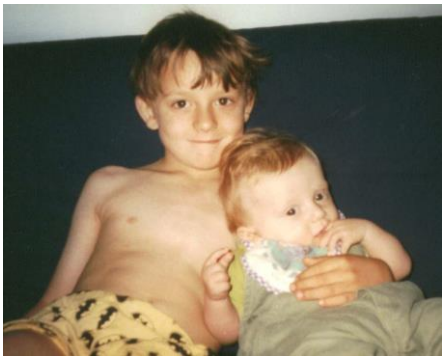


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