

# BELIEVE & ACHIEVE



Helping young people to  
**BELIEVE & ACHIEVE**  
FIVE YEAR IMPACT REPORT



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# EXECUTIVE SUMMARY

## Meningitis Now and its Believe & Achieve programme

- Meningitis Now is a charity whose mission is to make sure that no one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.
- In 2017 Meningitis Now, supported by the National Lottery set up a programme, called 'Believe & Achieve'. This programme, recognising the very specific needs and challenges faced by young people, is dedicated to helping 14-25 year-olds whose lives have been affected by meningitis.
- The programme began with a six-month development period. This included recruitment of team members, their training and development of systems and processes.
- Believe & Achieve offers a range of support activities, which young people affected by meningitis can choose to take part in. These include formal and informal needs assessment activities for each young person considering getting involved, various events, different types of mentoring, coaching, counselling, social media activities and one-to-one support from the Programme Coordinator.
- The programme is designed around three outcome areas: **Get stronger, Get together** and **Get ready**.

## The programme reach and its beneficiaries

- In total, 179 young people have been supported by Believe & Achieve since 2018.
  - » Of the 179 young people taking part in Believe & Achieve, around two thirds (63%) have had meningitis themselves as opposed to being indirectly affected by the disease. Most of them (87%) had been affected by bacterial meningitis. Just over a third of Believe & Achieve participants (37%) were indirectly affected by meningitis, including those young people who lost loved ones to the disease.
  - » Young people from all four nations of the UK took part in Believe & Achieve, with approximately 18% of them being from Northern Ireland, Scotland and Wales.
  - » More females than males took part in Believe & Achieve, with a ratio of approximately 2:1.
  - » Believe & Achieve supports young people across a very wide age range. Initially designed for 14-25 year olds, the participation age range has been recently changed to 11-25. Despite this range, older participants took part in the programme during the first five years of its delivery: around two thirds of young people were aged 18 years and over when they first engaged with the programme.
  - » In terms of participants' ethnicities, most (91%) of Believe & Achieve participants come from white UK backgrounds, with the remaining 9% being from minority ethnic groups.

## The Believe & Achieve programme activities: young people's engagement and feedback

- Personalised needs assessment, day events (in person and online), residential weekends and social media were the programme activities for which there was most take-up.
- Though not as frequently accessed by more of the younger age category, activities such as counselling, coaching and next steps and peer mentoring, and one-to-one support from the Programme Coordinator were highlighted as some of the most valuable inputs by those who took part in them.
- Overall, young people's feedback for the different strands of Believe & Achieve activity have been overwhelmingly positive. The vast majority of young people reported that they found the activities very useful, well organised and enjoyable. In addition, their comments often referenced meeting new friends, learning something new, or being afforded a new opportunity.

## Tiered engagement with the programme

- The level of engagement with the programme varied between participants. It also varied for different individuals over time.
- For the purpose of this report, we refer to young people who only had the initial engagement as Tier 1 participants, and those who had a sustained engagement as Tier 2.
- Of the 179 young people involved in the programme, 100 were Tier 1 participants and 79 were Tier 2.
- There were no significant differences between Tier 1 and 2 groups in terms of their: age, ethnicity (whether they belong to any minority ethnic group), when they had meningitis (for those who experienced it directly) and location (whether they live in England or other home nations).
- But there were also some parameters where there were differences:
  - » Female participants were more likely to engage with the programme in depth.
  - » Those who encountered meningitis through their loved one contracting the disease (indirect experience of meningitis) were considerably less likely to engage with the programme in-depth.
- Unsurprisingly, it was the intensity and length of their engagement with the programme where differences between Tier 1 and 2 participants were most noticeable:
  - » For young people whose engagement in Believe & Achieve was categorised as Tier 1, the average number of activities that they took part in was 1.3. For those in Tier 2 this was 5.1.
  - » There were similar differences when looking at the length of their engagement with Believe & Achieve. The average for Tier 1 participants across the entire cohort was 0.4 years whilst for Tier 2 participants it was 2.2 years.

## Programme outcomes and impact

- There was evidence of positive outcomes for around nine in ten young people involved in the programme, virtually all of whom have had deeply traumatic experiences and many also struggle with considerable physical after-effects.
- Where young people engaged with the programme in greater depth and over a longer period of time (Tier 2 participants), the programme has had considerable positive impact and across a wide range of areas.

- » There was evidence of positive outcomes for all young people who engaged with the programme in depth (i.e. categorised as Tier 2 participants).
- » 85% of them made good or excellent progress across all three outcome areas - Get Stronger, Get Together and Get Ready. Not only did taking part in the programme make a considerable difference to their lives at the time of their engagement but many of the positive outcomes achieved for these young people were long-term, sustainable changes.
- » Believe & Achieve has helped young people to better understand after-effects of meningitis and better manage the physical after-effects where this was relevant. Some young people became more adept at pre-empting anxiety, stress and fatigue while others learnt ways to remember things (where they struggled with memory and concentration). Being able to manage their after-effects more successfully also meant seeking ways (treatment or equipment) that would help them better and improve their quality of life.
- » Through their involvement in the programme young people have learnt what they can and cannot control in their lives. They have learnt not to blame themselves, and most importantly learnt to move on and find new positives - things to achieve, feel proud of and happy about. Believe & Achieve has also helped young people to understand how their emotional wellbeing is affected by the physical aspects of meningitis. It has enabled them to improve their emotional resilience and develop coping strategies.
- » An important indicator of mental and emotional wellbeing, feeling supported was the strongest outcome area for Believe & Achieve. Positive changes in this area were visible for all young people who engaged with the programme in depth. For more than two thirds of participants there was evidence of substantial impact. Throughout the entire programme evidence-set there were numerous comments from young people saying that whenever they need help, however small the issue might be, the Believe & Achieve team and programme participants would be there for them. This created a strong sense of emotional security for young people.
- » There was a very strong community feeling among participants engaging in Believe & Achieve, particularly visible in young people's anticipation of seeing each other and enjoyment of each other's company. They felt safe and understood when together. This sense of community was strengthened by the young people's willingness to contribute to support others in the group and their own efforts to keep their relationships active and alive.
- » For some programme participants, their desire to support others was what motivated them to take part in Believe & Achieve. Others gradually discovered the joys of helping others around them and the healing power of such experiences.
- » Improved confidence was consistently cited by young people themselves as a key outcome that they gained through Believe & Achieve. Positive changes were noticeable for the vast majority of the programme participants and for almost two thirds they were substantial.
- » The programme participants developed a range of important and valuable skills as a result of their engagement, including employability and life/essential skills and qualities, career management and study skills, skills linked to interests and passions and independent living skills.
- » Improved aspirations and reaching positive destinations is a highly important outcome area for Believe & Achieve, not least because it considers long term changes for the programme participants. Around two thirds of young people who engaged with the programme in depth showing significant improvements is a remarkable achievement and a clear indication of the programme's effectiveness and impact. In concrete terms, this means that more than sixty young people affected by Meningitis were able to continue and successfully complete their studies, start the next phase of their education or start working. They were able to fulfil their other (non-career related) dreams and ambitions too, including starting a family, travelling or learning to drive. In addition to those sixty young people, there were also many more, whose personal achievements were perhaps smaller at the time of reporting but no less important.

## Programme learnings: What works in securing engagement and impact

- The programme comprises a large number of activities and forms of support, which has expanded over time and keeps growing. When scrutinised, it became apparent that each of those activities and forms of support has a role to play and is effective in its own right. Our analyses and different sources of evidence highlighted the benefits of all those varied forms of support.
- Having a range of activities on offer means that every participant can (with support) configure their own bespoke and personalised journey through the programme.
- Despite it being excellent, expanding this breadth of activities further is perhaps the only area that merged as a potential programme development opportunity. The available evidence suggests that there is scope to do more in terms of targeting engagement of specific groups of young people. Particularly in relation to their gender and ethnicity.
- Sequencing activities emerged as highly important in the programme evidence, in a number of ways.
  - » Firstly, there were some activities - events and residential in particular - which have a unique and powerful role to play in achieving the programme outcomes. However they can also be difficult for some young people to engage in, so preliminary steps are needed to prepare them.
  - » Secondly, sequencing of activities enables layering of outcomes, from addressing urgent needs to achieving long term impact.
- Apart from the broad patterns suggested above (starting easy and light-touch or focusing on urgent need and then gradually deepening engagement and impact) there were no easy answers of how to sequence the programme activity so that it works for everyone. Going forward, if they are to achieve similar levels of impact, the Believe & Achieve team should avoid looking or applying any ready-made, 'one-size fits all' tactics and continue with its highly personalised approach, supporting everyone to find their path and shape their participation. This should include engaging in the first place, on their own terms. Young people involved in the programme highly valued that they were given the time and space to decide and that they were not rushed or pushed into anything.
- Young people's ownership is visible not only in the choices they make as they take part in Believe & Achieve, it is key to the programme impact too. Whilst the programme creates the environment and conditions in which young people can succeed, every achievement is due to each participant's own hard work, determination and incredible inner strength. Noticing and celebrating their wins, however small, and the level of effort that is required to achieve them, is something that the programme team are so good at. This created a virtuous circle of success, helping participants to move from small achievements to bigger ones.
- Challenge is an important part of the programme. This is most visible in young people being encouraged to try new things.
- The programme tries to be comprehensive for its participants. This involves covering many aspects of their lives, have numerous activities that give their lives meaning, have many people that support them and share experiences with them, have different strategies that help them cope with after-effects of meningitis and counteract its negative impact.
- Believe & Achieve is not simply a sum of its activities and forms of support. It is the people in the team that make it so much more. They shape each young person's journey, ensuring they get exactly what they need and when they need it. They are always there for the young people taking part. So much of the support is delivered through informal keeping in touch and gradually building trust and relationships. Even with the Believe & Achieve community, which is largely self-sustaining because young people support each other, it is the Programme Coordinator and her team that have set it up in the first place, and have been keeping it going ever since, making sure that it remains the safe haven of support and inspiration that the programme participants value so much.

# INTRODUCTION

Meningitis Now is a charity whose mission is to make sure that no one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives. The charity achieves its goals through fundraising, funding research, campaigning, awareness-raising and support activities.

In 2017 Meningitis Now, supported by the National Lottery set up a programme, called 'Believe & Achieve'. This programme, recognising the very specific needs and challenges faced by young people, is dedicated to helping 14-25 year-olds whose lives have been affected by meningitis<sup>1</sup>.

## The programme evaluation and evidence for this report

The principal aim of the evaluation was to identify and assess the key outcomes achieved by the programme for its participants and to demonstrate its impact. In addition, the evaluation sought to surface features that contribute to the effectiveness of the programme and to note any important learnings that would be valuable to Meningitis Now, its funders, and other organisations.

Evidence collection was built into the programme design and delivery from its inception. Over the course of the programme, data collection was carried out by the programme team at Meningitis Now. Chrysalis Research offered advice around tool and analysis framework design.

The Believe & Achieve team carried out a wide range of data collection activities in accordance with two main priorities:

- Capturing participating individuals' starting points and changes to their knowledge, skills, attributes, behaviours and state of wellbeing as they engaged with the programme. Evidence was captured at multiple points in time and included participant feedback and reflections, observations of their family members, staff observations, feedback from counsellors, coaches and mentors where this was relevant.
- Monitoring effectiveness of the programme activities, such as events or mentoring, by seeking participant feedback about it.

<sup>1</sup>Throughout the report, the term 'meningitis' is used to describe meningitis and meningococcal septicaemia



To prepare this report, Chrysalis Research performed an **independent analysis of a wide range of documentary evidence shared by Meningitis Now** including:

- Previous programme reports and similar outputs.
- Information about the background characteristics of the programme participants and details of their engagement.
- Feedback and evaluation forms, related to specific programme activities.
- Social media records and poll results.
- Individual records of participants' development for 79 young people who had engaged with the programme in greater depth.

Within these individual records, evidence of participants' behaviour, learning and development at different stages of their engagement was mapped against the programme outcomes. These were grouped under three core areas - Get Stronger, Get Together and Get Ready. For each outcome, a score indicating the level of progress and development from baseline (or lack of it) was calculated by the Believe & Achieve team. The scores were independently validated by the evaluation team, using all the evidence presented in the individual records. An additional round of moderation was subsequently carried out by Chrysalis Research, to check and resolve any discrepancies between the programme team's and researcher scores. Next, mean scores were calculated for each individual to determine the level of their progress and development. Mean scores across the entire cohort were also calculated for each outcome and impact area.

In addition, the research team carried out some primary data collection, including:

- Observations of one of the events (the Ultimate Day in July 2022), during which informal interviews were held with most of the attending young people and Meningitis Now staff.
- Further six depth interviews with the programme participants.

## Reporting notes

Throughout this report we present percentages rounded to the nearest whole number. This sometimes means that totals can appear to be one or two percentage points out.

## Acknowledgements

Chrysalis Research would like to thank the Programme Coordinator and other staff at Meningitis Now for their support during the data collection and analysis and for opening up their data to external scrutiny. We are also grateful to all programme participants involved in our research, for their time and sharing their thoughts and experiences with us.



# THE BELIEVE & ACHIEVE PROGRAMME

## Background

The impact of meningitis can be devastating, leaving people bereaved or facing a future with lifelong disabilities such as limb loss, hearing loss and acquired brain injury. Even if there are no visible after-effects, meningitis can lead to memory loss, behaviour changes and mental health issues such as anxiety and depression. For young people, meningitis can disrupt education, putting them at a significant disadvantage compared to their peers.

Without help, young people whose lives have been affected by meningitis could be denied the opportunity to achieve their full potential and have a successful future. Funding from The National Lottery Community Fund allowed Meningitis Now to launch Believe & Achieve. This is a five-year programme of support specifically dedicated to helping young people aged 14-25 to take their next step towards rebuilding a positive future after meningitis.

The title of the programme was inspired by Alex Williams, a founding Young Ambassador who sadly died in 2012. 'Believe and Achieve' was his motto in life and encapsulates the programme's aim of helping young people to take stock of where they are currently and where they want to be in the future. During this journey they will overcome challenges, make new friends, learn new skills, celebrate successes and importantly, give young people the confidence to believe in themselves.

The programme is designed around three outcome areas:

- **Get stronger:** offering emotional support to young people through professional counselling and peer support.
- **Get together:** forming friendships through social events, residential weekends and Believe & Achieve's digital community.
- **Get ready:** Developing young people's skills and confidence through workshops, coaching and mentoring.

The programme began with a six-month development period. This included recruitment of team members, training (on safeguarding, evaluation and first aid as examples), and developing systems and processes. A Programme Coordinator with extensive experience in youth work was appointed to shape and deliver the programme during the set-up stage and has acted as the driving force behind it ever since.



In January 2018, a project advisory group was set up to work out the key dimensions of the programme development and communications. It comprised three young people, two external professionals with experience of working with young people, the CEO of Meningitis Now, one of its trustees and three members of staff.

Believe & Achieve branding was also created to establish a distinct identity for the programme. Firstly, it communicated the existence of an engaging youth initiative to a core audience of 14-25 year-olds. This encouraged take up. It also raised the profile of Believe & Achieve within the organisation. This resulted in a higher number of internal referrals.



For five years, between 2018 and 2022, Believe & Achieve supported young people affected by meningitis across the UK.

Meningitis Now has recently been successful in securing continuation funding from the National Lottery Community Fund. This allows the delivery of the Believe & Achieve programme to continue for a further five years.

### **Programme overview, effects of Covid-19 and development over time**

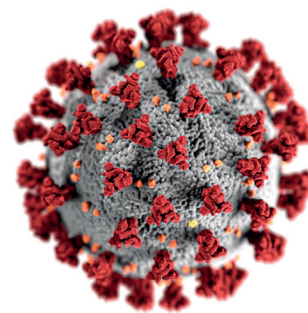
Believe & Achieve offers a range of support activities, which young people affected by meningitis can choose to take part in. These include formal and informal needs assessment activities for each young person considering getting involved, various events, different types of mentoring, coaching, counselling, social media activities and one-to-one support from the Programme Coordinator.

The programme also allows different entry points, catering to the needs and preferences of each individual young person.

The programme activities have evolved over time, with changes made to both the content and format of the support on offer. Believe & Achieve actively consults young people (via feedback forms, online polls, conversations and the advisory group) on what they would prefer and value in the way of support. This approach enables the team to deliver services that meet the most pressing areas of need and achieve the greatest impact.

## Impact of Covid-19 on programme delivery

As with most organisations, from March 2020 onwards, the Covid-19 pandemic fundamentally altered the nature and quantity of activities delivered as part of the programme. Lockdown resulted in the cancellation of a residential, several face-to-face social events and peer mentoring. The economic repercussions of the pandemic meant that two support roles within the Believe & Achieve team could no longer be sustained. These roles were set up to assist with tasks such as event planning, administration and in-person assessments to accommodate the significant growth in young people being supported by the programme over the first two years of its delivery. These responsibilities now fall to the Programme Coordinator, supported by staff from other parts of the organisation.



However, there were some lasting positive effects of the pandemic as well; lockdown stimulated the trialling of digital channels for the delivery of activities. With careers provision on hold in schools and a depressed job market, Believe & Achieve saw a surge in demand for coaching and Next Step mentoring. Once set up online, these services became easier to organise than they had previously been face-to-face.

Counselling sessions were also delivered remotely, giving much needed support to young people who battled increased anxiety as a result of the pandemic. The Believe & Achieve team also began to offer regular one-to-one check-in calls for young people who did not want to engage with professional counselling but simply needed somebody to talk to. This individualised support activity continues to be offered to this day.

Believe & Achieve events were migrated online as a result of the pandemic. Though they do not quite match the social experience of face-to-face events, the removal of geographical and mobility barriers made online events a more inclusive format. Once social restrictions were lifted, Believe & Achieve delivered a blended approach of online and face-to-face events to capitalise on the advantages that both formats have to offer.

Believe & Achieve's social media community also came to the fore during lockdown. This brought young people together, providing mutual support and encouragement during a period of acute isolation. Whilst it could be argued that young people at that time were to some extent a captive audience in need of social connection, the quality of the facilitation and interactions were such that new participants were recruited to the programme via this channel. It is worth noting that 35 out of the 179 programme participants have only ever engaged remotely - either via online events, one-to-one calls or on social media.



# THE PROGRAMME REACH AND ITS BENEFICIARIES

Access to the Believe & Achieve programme and its support services is free. Young people can be referred by Meningitis Now staff (e.g. Community Support Officers or the helpline), or they can self-refer using a form on the Meningitis Now website, or contact the Believe & Achieve team directly. Eligibility criteria for the programme are:

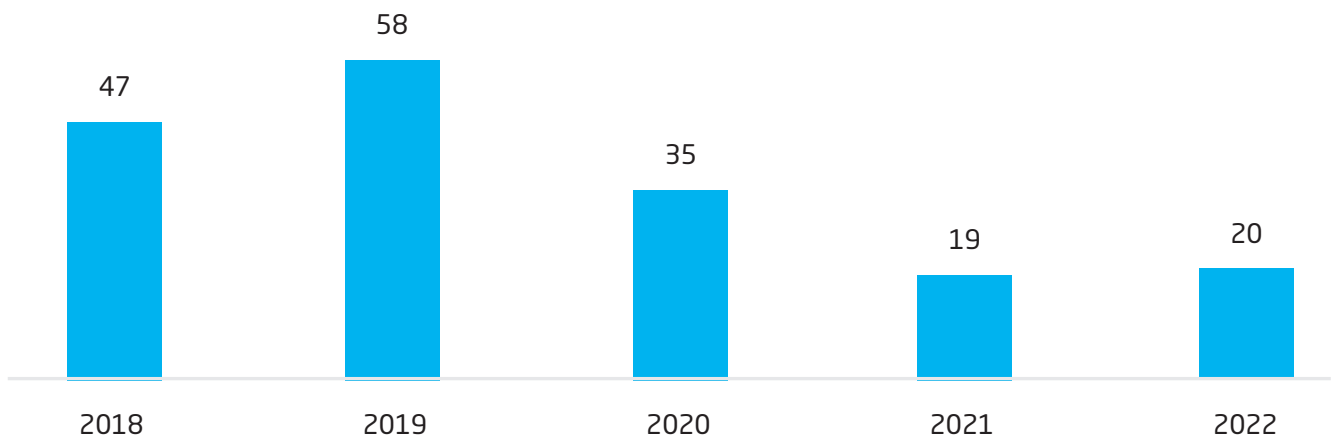
- Aged 14-25 (this age range was extended to 11-25 from September 2022)
- Based in the UK
- Affected by meningitis, whether directly or indirectly - for instance, when a family member, girlfriend/boyfriend or close friend contracted meningitis.



In total, 179 young people have been supported by Believe & Achieve since 2018.

Figure 1 shows that the programme has successfully engaged new participants every year throughout the five-year period. There was a peak in 2019, coinciding with having three dedicated Believe & Achieve staff. 2020 saw the rapid transition to online support as the coronavirus pandemic unfolded.

**Figure 1: number of new participants engaging with Believe & Achieve each year**



Of the 179 young people taking part in Believe & Achieve, around two thirds (63%) had **had meningitis themselves** as opposed to being indirectly affected by the disease. Most of them (87%) had been affected by the bacterial rather than viral form of the illness. The latter is usually less serious but can still leave people with significant after-effects.

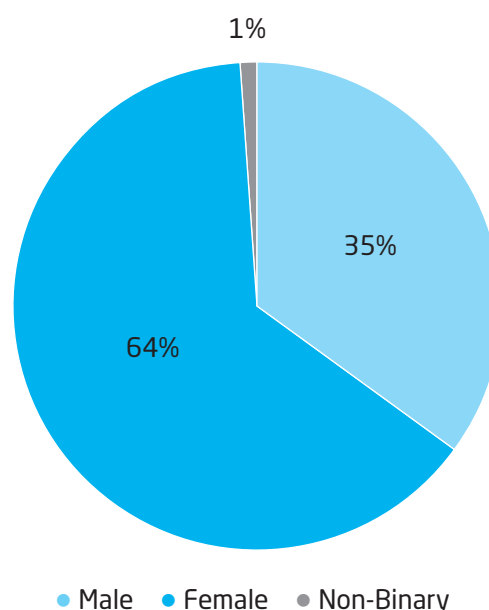
The programme has succeeded in engaging equally those young people who had contracted meningitis as a young child or baby (54%) and those who had experienced it in later childhood, as a teenager or young adult (46%).

Just over a third of Believe & Achieve participants (37%) were **indirectly affected** by meningitis. Most of these young people had a sibling or friend who had been impacted by the illness. For a small number, it was a parent or a partner who had had meningitis. Importantly, Believe & Achieve also engaged young people who lost loved ones to the disease. One in three of those indirectly affected by meningitis had suffered bereavement.

Young people from **all four nations of the UK** took part in Believe & Achieve, with approximately 18% of them being from Northern Ireland, Scotland and Wales. This closely reflects the general population patterns in this country. The latest (2021) census found that 84% of the population in the UK live in England and the remaining 16% are in the other home nations. Given the small size of the Believe & Achieve team, the geographical reach of the programme has been impressive. This was partly achieved through online events and social media, but staff also travelled extensively to meet young people in their own homes and made a point of hosting in-person events in different home nations. It is also worth acknowledging the long journeys made by some young people to attend Believe & Achieve events in person (despite fatigue symptoms). This demonstrates their high level of commitment to the programme.

In terms of the **programme participants' gender**, more females than males took part in Believe & Achieve, with a ratio of approximately 2:1. Some of this might be explained by gender differences recorded in wider research and evidence<sup>2</sup>, that suggests males tend to be less inclined than females to seek help for emotional and mental health difficulties. These issues often present in people who have experienced a disease as serious and potentially deadly as meningitis.

It could also be that the social support element of Believe & Achieve encourages more girls than boys to take part. Studies have shown that girls are more likely to rely on coping strategies that involve interpersonal relationships, whereas boys are more likely to use other approaches such as distraction<sup>3</sup>. It is also possible that having a high number of female staff may have unintentionally encouraged the gender imbalance. The peer mentoring scheme involving boys may be helping to mitigate this. Importantly, gender preference is recorded, and non-binary individuals are represented within this programme.



<sup>2</sup>Liddon, L., Kingerlee, R. and Barry, J.A. Gender differences in preferences for psychological treatment, coping strategies, and triggers to help-seeking. In: *British Journal of Clinical Psychology*, 2018, Mar; 57(1):42-58; Raviv A, Sills R, Raviv A, Wilansky P. Adolescents' help-seeking behaviour: the difference between self- and other-referral. In: *Journal of Adolescence*, 2000, Dec; 23(6):721-40.

Believe & Achieve supports young people across a **very wide age range**. Initially designed for 14-25 year olds, the participation age range has been recently amended to 11-25. This is based on feedback from parents and young people to enable an easier transition from Meningitis Now family initiatives. The profile of participants is slightly skewed towards older age groups, with around two thirds of young people being aged 18 years and over when they first engaged with the programme. Older individuals might be more willing to engage in Believe & Achieve because it is something they choose to do themselves, instead of being persuaded by parents to take part. The ability to connect with others on social media and share their experience particularly appeals to older participants. They are also more likely to take up the offer of counselling compared to their younger counterparts.

Programme data on **ethnicity** shows that most (91%) of Believe & Achieve participants come from white UK backgrounds, with the remaining 9% being from minority ethnic groups. According to the latest (2021) census data, approximately 13% of the UK population aged 16 and over was from a minority ethnic background. This ranged from 3% in Northern Ireland to 15% in England. Therefore, involvement in the programme of young people from minority ethnic groups is only slightly lower than the national average and may be natural variation occurring in a relatively small sample of 179 young people.

In conclusion, the Believe & Achieve programme is supporting a diverse set of participants, both in terms of their background characteristics, geographical location and the nature of their meningitis experience. To further support inclusivity within the programme, we would recommend further subdividing 'minority ethnic' into more specific categories and systematically recording any disability data where relevant. This will allow an examination of whether these groupings influence the types of activities engaged with, and impacts achieved.




<sup>3</sup>E.g. Camara, M., Bacigalupe, G. and Padilla, P. The role of social support in adolescents: are you helping me or stressing me out? In: *International Journal of Adolescence and Youth*, 2014, 22(2), pp.123-136.

# THE BELIEVE & ACHIEVE PROGRAMME ACTIVITIES: YOUNG PEOPLE'S ENGAGEMENT AND FEEDBACK

The Believe & Achieve programme has comprised the following activities:

- Support needs assessment with individuals
- Events - both in-person and online
- Residential weekends
- Social media
- Counselling
- Coaching
- Business/Next Step mentoring
- Peer Mentoring
- Regular one-to-one support with the Programme Coordinator
- Other forms of support



Activities were  
very useful,  
well organised  
and enjoyable

Overall, feedback forms for the different strands of activity have been overwhelmingly positive. The vast majority of young people reported that they found the sessions very useful, well organised and enjoyable. In addition, their comments often referenced meeting new friends, learning something new, or being afforded a new opportunity.

## Personalised support needs assessment

In the early stages of programme delivery, the Outcome Star assessment (designed specifically for children and young people who are facing or have experienced serious illness<sup>4</sup>) was originally intended to be carried out at the start of a young person's involvement with Believe & Achieve, to help them identify their own needs and priorities in life, education and work, as they first engaged with a programme.

However, it became apparent that this was neither feasible nor necessarily desirable. For example, the depth of this initial assessment using Outcome Star could deter some individuals from engaging further. For this reason, other - less formal - means of capturing starting points were introduced. This meant that every young person wishing to take part in Believe & Achieve could do so, with or without a needs assessment. The team have also made adaptations to their assessment approach so that it can be used to support Believe & Achieve participants more effectively. Where appropriate, some assessments are now conducted online, and face-to-face sessions may be embedded within a crafts-based activity to put young people at ease. The assessment format depends on where the young person is based, and what type of contact they would like from the Believe & Achieve team.

<sup>4</sup><https://www.outcomesstar.org.uk/using-the-star/see-the-stars/support-stars/>



The available evidence suggests that in many cases, these in-depth conversations with individual participants are an important first step for young people in identifying their needs, priorities and goals. They also have value over and above their needs assessment function. They provided an opportunity for the Believe & Achieve team to:

- Start building relationships and rapport with the young people affected by meningitis.
- Explore any individual issues negatively affecting young people's wellbeing and quality of life, irrespective of whether they were viewed as directly linked to meningitis or not.
- Recommend activities and aspects of the programme that were not only directly relevant to each individual's needs but also most appealing to them as a way in.
- Offer bespoke and individually tailored advice, information and, where relevant start referral processes (e.g. for counselling).
- Verify that the programme continues to deliver the support most needed by the young people it is designed to help.

In total, nearly two thirds of participants (63%) took part in a Believe & Achieve assessment, making this the number one activity strand that young people engaged with. The gender and age profile of those who received an assessment is broadly in line with profile of Believe & Achieve participants as a whole.

## Day events (in person and online) and residential weekends

### In person events

Events initially took the form of in-person workshops designed to help participants develop transferrable skills and coping strategies, such as 'Dealing with stress and coping with change'. However, feedback from young people revealed they were less interested in workshops focusing on specific skills and more attracted to hands-on practical activities, challenge tasks or trying to understand themselves better. Consequently, events became more activity-based but had an element of skills training embedded within. Young people also suggested including more active or sports-based activities. This led to several Health & Fitness, Challenge and Outdoors Days being organised (left, indoor skiing, April 2022).



As the programme evolved, it became clear that the social element of getting together with other young people living through similar experiences was highly valued. For this reason, in-person social events were also introduced into the programme. These events encouraged young people to meet to simply spend time with each other without a specific skills-based activity. Four face-to-face social events took place before lockdown, in locations throughout the UK (Bristol, Manchester, London and Belfast). There was also one post-lockdown event in London (May 2022).



As the five-year programme funding drew to a close, the Believe & Achieve team organised a special celebration event called the Ultimate Day. Exciting activities included circus skills workshop, a treasure hunt and crafts. The day culminated in a Graduation ceremony. This joyful occasion brought together young people, their families and friends from across the UK to formally recognise their incredible achievements over the past five years. Each young person was awarded a certificate which detailed their involvement in the programme and highlighted their accomplishments. Participants visibly enjoyed the day, meeting old friends, making new ones, and setting up WhatsApp groups so that they could all stay in touch with one another. On the day we observed a strong sense of unity, collective pride and shared purpose amongst young people, family and staff.

In total, 93 young people (52%) participated in at least one face-to-face Believe & Achieve workshop or social event over the last five years. This made this strand of activity the second most popular means of engaging with the programme. Considering that social restrictions were in place for much of 2020 and 2021, and that some young people had social anxiety, restricted mobility or lived in remote areas, this is quite an accomplishment. It is testament to the exciting and varied activities on offer; circus skills, Escape Rooms, Go Ape, working with animals and rock-climbing to name but a few. The face-to-face events were very well received with four out of five participants rating them as very good (Figure 2). All but five young people across all events said they had fun which is an impressive achievement. Of those 93 young people, 83 reported they had met new people who had been impacted by meningitis and 66 said they had supported others as a result of attending.



## Figure 2: Ratings for in-person Believe & Achieve events

Base: 148 evaluation forms for 14 face-to-face Believe & Achieve events



● Very good ● Good ● Average ● Poor ● Very poor

The proportion of girls on the programme who attended a face-to-face event was slightly higher than the proportion of boys (55% vs 45% respectively). This suggests that in-person socialising may be a format that female participants are more naturally drawn to than male participants. A similar pattern was visible for the residential weekends (see below).

Older participants aged 18 and over are also slightly less likely to attend than their younger counterparts (48 vs 58%). This could be because they have more commitments as they move into adulthood.

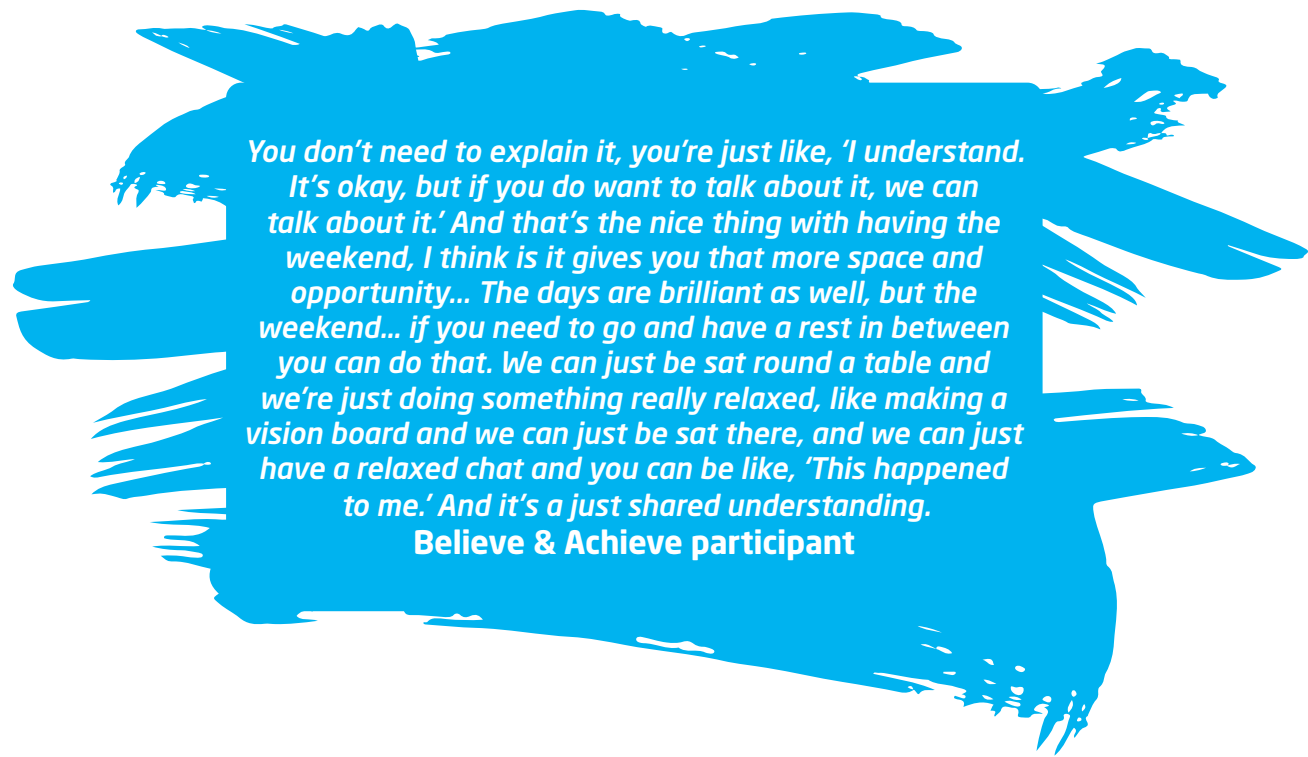
## Residential weekends

Residential weekends played an important role for the programme's 'Get Together' strand. They enabled young people to not only meet others affected by meningitis but also to genuinely get to know each other and develop friendships, while undertaking challenging activities together. Over the course of the programme, four weekends for 18-25 year olds, three weekends for under 18s and one weekend for Young Ambassadors were delivered in venues such as Centre Parks and the Calvert Trust.

Data on engagement was only available for 18+ residential weekends, so no meaningful analysis by age for older and younger programme participants was possible. In terms of gender, the data showed that proportionately, more young women of that age group were likely to take part in residential weekends (36%) than young men (21%). This is consistent with the pattern shown for in-person events we observed earlier in the report.

The residential weekends for 18-25 year olds were extremely well received. Of the 43 feedback forms returned, 42 rated their experience as 'very good', and one person as 'good'. All participants indicated that they had had fun on the residential and all but one reported learning something new and meeting new people affected by meningitis. Once again, a safe environment was created for them to just be themselves. As with the social events, young people valued the opportunity to meet and form lasting bonds with others who had been through similar experiences. Some young people realised they lived within travelling distance of one another and planned to meet up subsequently.

In some cases, the weekends were transformational for young people; new skills and aptitudes emerged, and big gains were made in terms of achieving in the different outcome areas.



*You don't need to explain it, you're just like, 'I understand. It's okay, but if you do want to talk about it, we can talk about it.' And that's the nice thing with having the weekend, I think is it gives you that more space and opportunity... The days are brilliant as well, but the weekend... if you need to go and have a rest in between you can do that. We can just be sat round a table and we're just doing something really relaxed, like making a vision board and we can just be sat there, and we can just have a relaxed chat and you can be like, 'This happened to me.' And it's a just shared understanding.*

**Believe & Achieve participant**

## Online events

Online events were initially introduced during the pandemic. This was a time when the Believe & Achieve team was required to pivot the programme delivery very rapidly in order to support young people at a time of huge uncertainty and isolation. Adapting a Believe & Achieve event to work online demanded considerable ingenuity. The team successfully engaged young people by splitting the age groups to keep the dynamics working well. This meant different age-appropriate activities within each session and sending out kits to be used in the sessions (e.g. baking ingredients) beforehand.



In total, the programme delivered eleven online events, nine of which occurred during periods of social restriction and the remaining two in 2022. As with in-person events, online sessions offered a variety of themes. Some themes were skills- or knowledge-based (for instance, dealing with anxiety, meningitis after-effects, peer mentoring) and others were purely social. The Believe & Achieve team learnt that certain topics were in fact better suited to shorter online sessions than face-to-face events, so these will continue to be delivered remotely. However, young people voted to retain at least some in-person social events.

Online events were the fourth-most popular means of engaging with the Believe & Achieve programme, with 24% of young people taking part in at least one online event. Evaluation forms completed by participants showed that these were rated almost as highly as in-person events (albeit within the limited context of the pandemic). The social events occurring during lockdown were particularly appreciated, with a great many young people reporting that they had had fun and felt supported.

*I thought the format would change the atmosphere of the event but I got the same run of emotions I get at in-person events. We got to talk through issues, be motivational and have fun without worry, all in an hour!*

**Young person attending an online social event, Xmas 2020**

### Figure 3: Ratings for online Believe & Achieve events

Base: 68 evaluation forms for 8 online Believe & Achieve events



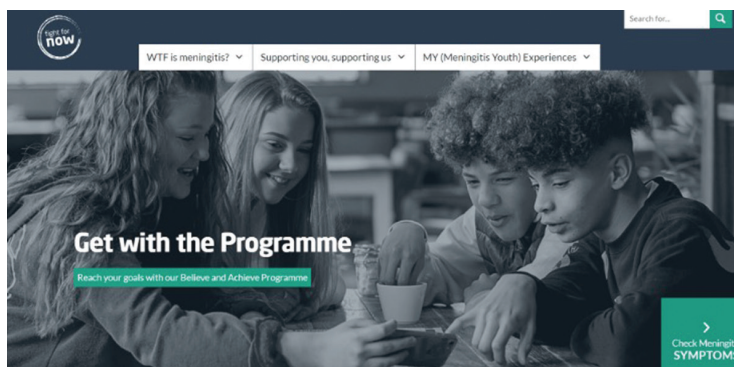
● Very good ● Good ● Average ● Poor ● Very poor

In contrast to in-person events or residential weekends, there were no notable differences in online event participation between the different genders and age groups. With this in mind, this particular activity can be viewed as one of the most inclusive, even though it is not as popular (nor indeed as impactful) as some other programme activities.

In conclusion, in-person and online events and weekend residential play a key role in the programme provision. They enable young people affected by meningitis to connect with each other and form a mutually supportive community of 'Believe & Achievers' and form longstanding friendships. They provide a **safe environment** where participants can have **fun, share their story and listen to the experiences of others**. Events are effective entry point into the programme. For instance, they are sufficiently 'light touch' to appeal to newcomers before they go on to discover the more involved support strands, such as counselling or mentoring. Significantly, events also attract friends and partners of those directly affected by meningitis, who would perhaps not have accessed support for themselves otherwise.

## Social media

One of the original aims for the Believe & Achieve programme was to create a **dynamic community of mutual support** for young people affected by meningitis. A critical part of this has been to establish a social media community for Believe & Achieve and a youth-targeted microsite, 'Fight For Now'.



Over the past five years, Believe & Achieve has succeeded in widening its online reach. The number of followers on its Facebook, Twitter and Instagram pages grew year on year. Social media played a particularly important role during the pandemic: offering practical and emotional support with posts on a range of subjects, such as dealing with anxiety, and exam cancellations. It also provided a means of connecting with peers at a time of increased social isolation.

Just under half of all programme participants (86 young people) have engaged with Believe & Achieve through social media, with further similar numbers of young people following the programme's social media. This is therefore the third most popular means of engaging with the programme. Girls are significantly more likely to sign up to Believe & Achieve social media channels (56%) than boys (34%). This strand engages more participants aged 18+ (54% of these signed up) than their younger counterparts (38%).

Young people who first met each other at events and residential weekends have even created their own social media groups independently of Believe & Achieve. This has allowed them to build their own self-sustaining support networks for the future.

The Believe & Achieve online community continues to serve many purposes. It allows young people to access advice and support, but crucially, also provides them with the opportunity to reach out and **share their meningitis story** with others.

42 young people chose to do this, covering topics as diverse as fatigue, professional coaching and losing a loved one to meningitis. Responses from members show that they drew great comfort from reading these posts and being able to support each other. As above, there were proportionately more girls contributing, and this was more likely amongst 18+ years.

Social media is also used by the team as a tool for canvassing the views of Believe & Achieve participants. This enables the programme to be continually shaped and adapted to the needs of its participants. Many young people have also posted comments in response to events or residential weekends they have attended. One young man even created a series of video blogs about them.

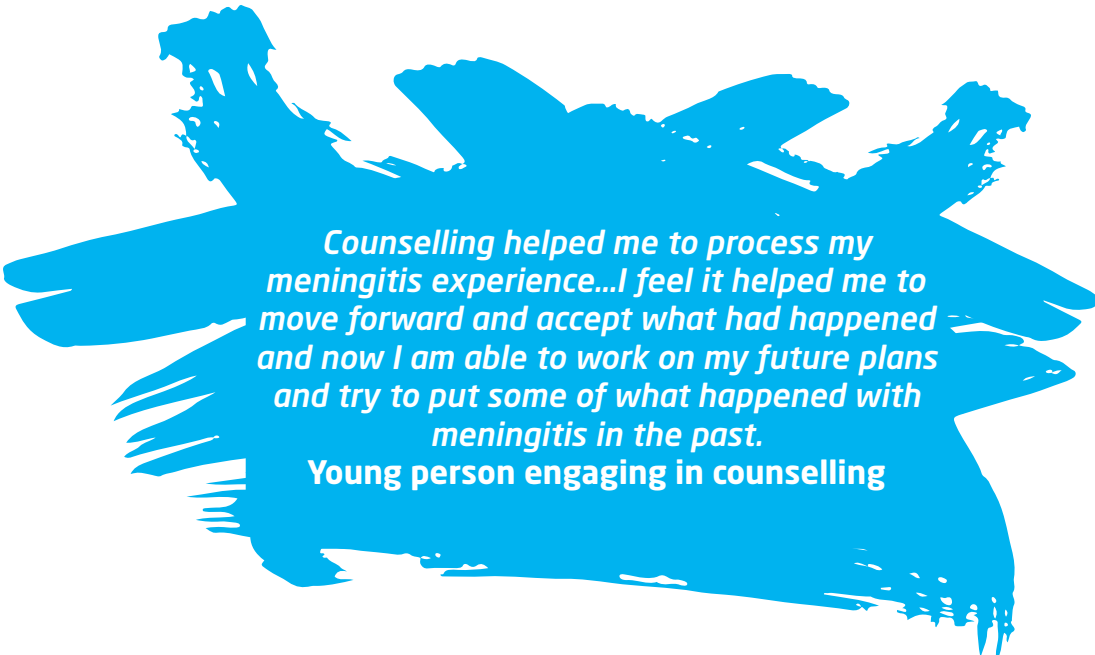


## Counselling

Initial assessments carried out with young people showed that many could benefit from counselling sessions. These could help with coming to terms with their after-effects of meningitis, boost their confidence and improve their mental and emotional wellbeing. In some cases overcoming the trauma caused by their experience of meningitis. Though only accessed by **36 young people** (20%), this strand of support is an important part of the Believe & Achieve offering. Those who underwent counselling felt they gained a lot from it. Of the 27 feedback forms returned, 24 rated the counselling they had received as very good, two rated it as good, and only one had a mixed experience of it. There was ample evidence of counselling being one of the factors that triggered and supported many positive outcomes for the participating individuals. One of the key aspects young people valued was the ability to talk about issues that they would not feel comfortable broaching with anyone else, even their own family or close friends.

The participant profile indicates that older participants aged 18 years+ were more likely to access counselling (24%) than those aged under 18 (13%). There were no significant differences between female and male programme participants.

Though counselling still remains a vital strand of support for Believe & Achievers, participants will need to apply for funding through Meningitis Now's Rebuilding Futures Fund going forwards, rather than being referred to a counsellor directly. It will be important to observe whether this has any impact on young people's take up of counselling in the coming years.



*Counselling helped me to process my meningitis experience...I feel it helped me to move forward and accept what had happened and now I am able to work on my future plans and try to put some of what happened with meningitis in the past.*

**Young person engaging in counselling**


## Coaching and mentoring

### Coaching

Over the course of the programme, 22 young people engaged with individual life coaching sessions. There were virtually no differences between younger and older programme participants (under and over 18 respectively) in terms of how likely they were to access coaching. There were however significant gender differences: 16% of participating female programme participants took part in coaching compared to only 6% of males.

Of the twelve feedback forms returned, ten rated their coaching session as very good, one as good and one as average. The coaching was particularly useful in helping young people to identify their own strengths, set goals for themselves and perhaps most significantly, increase their self-confidence and motivation. Coaching also indicated to young people how they might achieve their career or education goals in practical terms, for instance through volunteering, fundraising or writing a blog about their meningitis experience. As with the counselling sessions, Believe & Achieve participants will need to apply for individual coaching sessions via the Rebuilding Futures Fund going forward, so this may affect take up.

The programme has also evolved to incorporate group coaching within other Believe & Achieve events, including residential. In this way, the concept of coaching has been introduced to young people in a less formal environment. It is hoped this will make it seem less daunting. This form of delivery has proven to be far more popular, successfully engaging **39 young people**.



*It was really helpful having a professional who could help me navigate how to grow and achieve my goals after illness. Figuring out how to deal with people in your life and build a positive network helped me in my personal and professional life.*

**Young person engaging in individual coaching**

### Next Step Mentoring

Under the 'Get Ready' outcome area, Believe & Achieve initially recruited and trained 15 business mentors to provide ongoing professional development support to young people. Feedback from these mentors showed that the training was well-organised and easy to follow. Acquiring a good understanding of active listening and boundary-setting meant they felt confident working with young people.

However, this particular strand had a very low uptake in the first year of the programme. In consultation with the Advisory Board, Business mentoring was reconfigured into Next Step mentoring. This is a one-off meeting with a professional for advice on a particular topic such as CV writing. This has proven to be more popular with young people, particularly when offered in conjunction with a social event or workshop. Since then, a small number have progressed onto more regular meetings with their Next Step mentor.

In total, **21 young people** have engaged with Next Step mentoring. Numbers are too small to comment on participant profile in a meaningful way, but it appears that this type of support was accessed fairly evenly by all age groups and genders.

Three young people completed evaluation forms on their regular Next Step mentoring sessions. They all found the experience to be helpful, instilling them with confidence and practical tips.

## Peer mentoring

Peer mentors were recruited from the young people who had already benefitted from Believe & Achieve activities during the early years of the programme. 14 young people have acted as peer mentors and 17 Believe & Achieve participants have been successfully paired up with a peer mentor.

The Believe & Achieve team also carefully select a peer mentor to attend each event (in person or online). They take into account whether that person is comfortable to talk in a group situation or not, the age range they prefer to work with and any areas of expertise they may have (e.g. Health & Fitness). Whilst it is impossible to draw firm conclusions from the small numbers involved, it appears that both female and male participants are equally likely to act as peer mentors. Young people's age was not a relevant parameter to consider for this activity because only those who are over 18 can be Believe & Achieve peer mentors.


Feedback from peer mentor training indicated that the sessions had been well-organised and very useful in providing information on active listening, safeguarding and boundaries. As a result, all felt confident in their ability to mentor a young person.

As for peer mentees, all age groups and genders were equally inclined to sign up for this type of support. Feedback from those who had received mentoring indicated that they valued this type of support. It helped to build up their confidence, made them realise they were not alone in their struggles and gave them encouragement.



*Next Step mentoring has inspired me to advance my career in a number of ways and left me feeling a lot more confident about the future...we have discussed opportunities, taken steps to help me progress my career, talked about any worries I'm having and made future plans.*

**Young person engaging in Next Step mentoring**



*It has been a while since I have done peer mentoring, so felt a bit nervous to go back to it! Hearing other people talk about their experiences [of peer mentoring] refreshed my memory of how it works, what to do, and made me feel a LOT more comfortable and confident going back to it.*

**Peer mentor, commenting about their training**



## Regular one-to-one support

This strand of support began during the pandemic, when young people faced increased social isolation and anxiety. Believe & Achieve's Programme Coordinator identified that some young people simply wanted someone to talk to without necessarily having to go to a counsellor. As a result they started offering regular online or phone support to those young people who needed it. This support is very much tailored to the needs of the individual in terms of frequency and conversation topics. Where appropriate, other Believe & Achieve activity strands are offered up (for instance, invitations to events, peer mentoring), but it is entirely up to the young person to decide whether they would like to pursue these opportunities.

So far, 15 young people have received one-to-one support from the Programme Coordinator; the number of girls versus boys choosing this option are proportionately roughly equal, and slightly skewed towards the older participants (11% vs 4%). Although this strand accounts for few participants currently, the limited staff available to help run Believe & Achieve events means that fewer are likely to be planned in the coming years, with the emphasis shifting to more one-to-one support instead. If this is the case, we recommend that feedback about one-to-one support is gathered alongside other activity strands, even if this type of support is more open-ended by nature.

## Other support

Support from the Believe & Achieve programme is not limited to the activity strands listed above. It also plays an important role in referring young people to other services. These services are both within Meningitis Now (e.g. the Helpline) and organisations outside of the charity, such as the Child Brain Injury Trust. The Believe & Achieve team also offers young people bespoke, one-off phone and email support. For instance sending out factsheets about meningitis and its after-effects and providing advice on interviews and CVs, and references. In addition to this, the team has reached out to schools and employers to educate staff about the after-effects of meningitis. Advice has included how reasonable adjustments can be made to support young people affected by meningitis to achieve their best in the workplace.

The Believe & Achieve programme is unique in that it offers a comprehensive package of support activities specifically aimed at young people. The ability to refer young people to services such as counselling and coaching through Meningitis Now's Rebuilding Futures Fund ensures that participants can still receive the support they need without needing to be signposted to other organisations for help.



## TIERED ENGAGEMENT WITH THE PROGRAMME

The level of engagement with the programme varied between participants. It also varied for different individuals over time. Whilst there were some young people who wanted and were ready to commit to an in-depth and comprehensive programme of activities and support from the outset, this was relatively rare. In most cases, young people engaged in one or two activities/ support opportunities. Some then chose to deepen their engagement by taking part in further activities and opportunities that the programme offered, often over an extended period. For the purpose of this report and particularly when considering impact (next section), we refer to young people who only had the **initial engagement as Tier 1 participants, and those who had a sustained engagement as Tier 2.**

Of the 179 young people involved in the programme, 100 were Tier 1 participants and 79 were Tier 2.

In this section, we offer an overview of both these groups and also consider differences between them where that is relevant.

### Tier 1 vs Tier 2 participants: background characteristics and nature of their meningitis experience

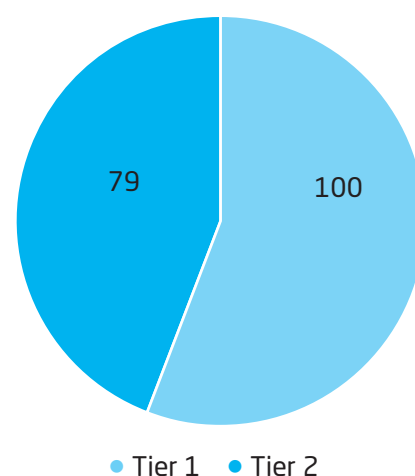
There were no significant differences between Tier 1 and 2 groups of the programme participants in terms of their:

- Age
- Ethnicity (whether they belong to any minority ethnic group)
- When they had meningitis, i.e. whether they contracted it as a baby, child, teen or in early adulthood (for those who experienced it directly)
- Location (whether they live in England or other home nations)

None of the above being amongst the factors influencing the depth and intensity of participants' engagement is very positive. This indicates the programme is inclusive in nature.

In terms of gender, there were indications that female participants were more likely to engage with the programme in depth. Similar proportions of girls and young women were part of the Tier 1 and Tier 2 groups. For male programme participants the picture was contrasting: approximately two thirds engaged with one or two activities (Tier 1), and a third engaged in greater depth.

Another parameter where differences between participants emerged was whether their meningitis experience was direct or indirect. Those who encountered meningitis through their loved one contracting the disease (indirect experience of meningitis) were considerably less likely to engage with the programme in-depth. More than two thirds of young people with indirect experience of meningitis were Tier 1 participants and less than a third were Tier 2 participants. Those who had a direct meningitis experience were equally likely to engage in greater depth or opt for a more light-touch involvement. The proportions of Tier 1 and 2 participants were similar amongst this group. There were indications that those who recovered from viral meningitis were less likely to engage in depth but it was not possible to be fully certain about this pattern in the data due to very low numbers of people in this group (in total, 15 programme participants recovered from viral meningitis).



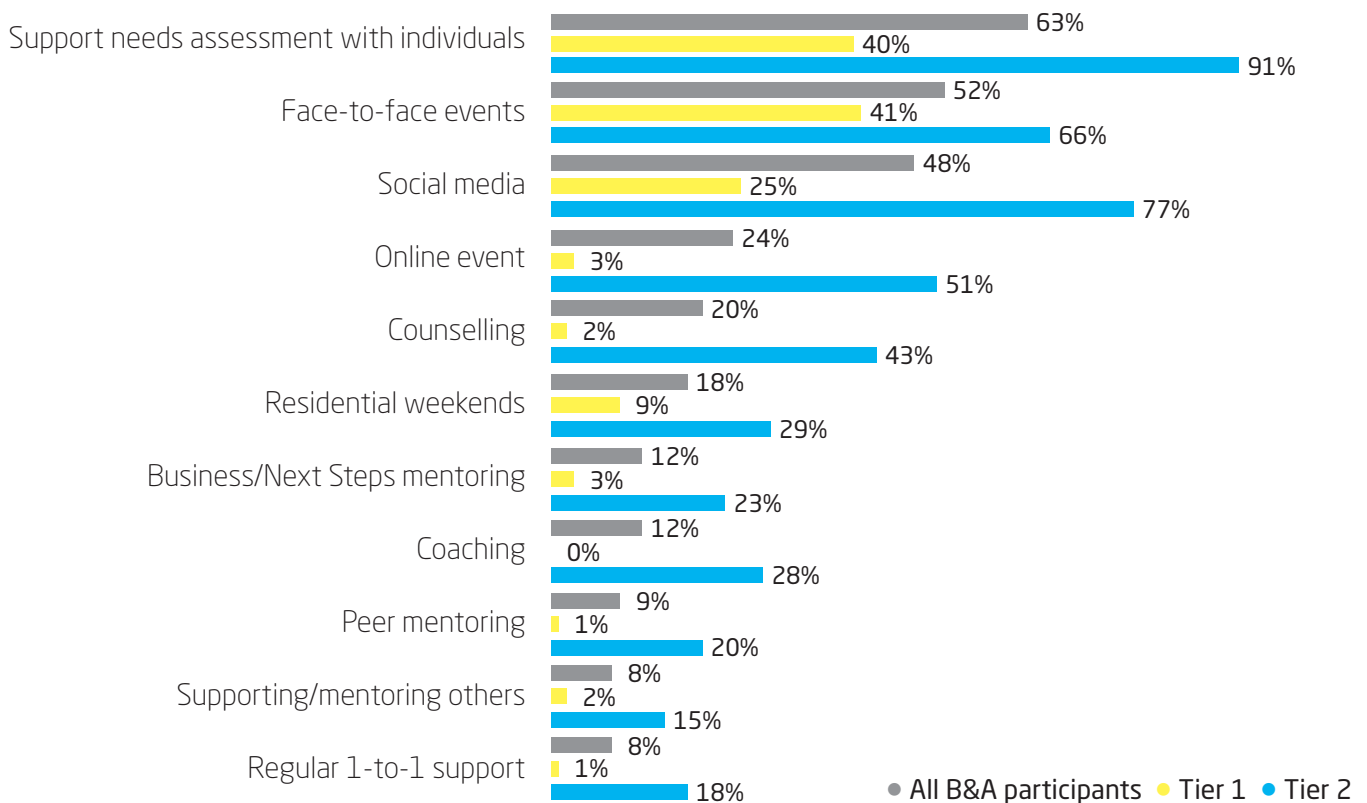
## Tier 1 vs Tier 2 participants: engagement with the programme and its specific activities

There were no differences in the specific types of activities that young people got involved in most often. Irrespective of the depth of young people’s engagement, the three most ‘popular’ types of activity were:

- Support needs assessment with individuals
- Day events (in person)
- Social media

### Figure 4 Young people’s engagement with specific types of Believe & Achieve activities

Source: programme monitoring information. Base : 179 participants in total, of which 100 were categorised as Tier 1 and 79 as Tier 2



It was the intensity and length of their engagement with the programme where differences between Tier 1 and 2 participants were most noticeable.

For young people whose engagement in Believe & Achieve was categorised as Tier 1, the average number of activities that they took part in was 1.3. For those in Tier 2 this was 5.1.

There were similar differences when looking at the length of their engagement with Believe & Achieve. The average for Tier 1 participants across the entire cohort was 0.4 years whilst for Tier 2 participants it was 2.2 years.

It is important to note here that the length of engagement (or indeed its depth) is challenging to measure. This is because the Believe & Achieve programme is informal and therefore participation can be fluid. For example, participants sometimes disconnected at times, only to become active at a later stage. Where young people leave the programme, reasons for this are likely to be varied. Some will have left because they progressed to the point of no longer needing support, while others may have disengaged because the programme did not fit with their personal situation at that time. Others will have reached the cut-off age of 25, and unless they trained as Peer or Next Step mentors, this would bring their involvement to a natural conclusion.

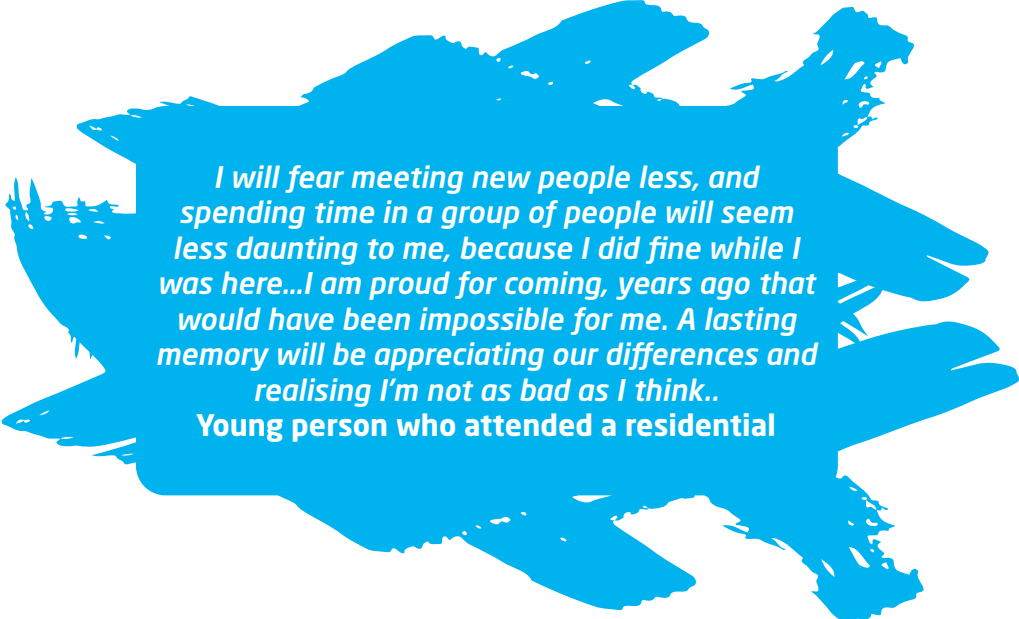
# PROGRAMME OUTCOMES AND IMPACT

## Tier 1 outcomes

As was mentioned in the previous section, Tier 1 programme participants usually engaged with one or two types of activity. For most people, this began with their initial conversation with the Believe & Achieve team. At the start of the programme delivery one of the key aims of the initial conversation was identification (assessment) of support needs. To begin with these were structured around the Outcome Star tools, but became more bespoke and tailored to individual circumstances later on. Other common types of activity included in-person events and social media.

There was evidence of positive outcomes for virtually all young people in this group who attended Believe & Achieve events or residential (which was approximately half of Tier 1 participants). Examples included improved confidence, new skills and feeling more positive, supported and inspired. In some cases there was evidence of young people using this inspiration to carry out further fundraising or volunteering work, typically to support Meningitis Now.

Evidence was more mixed when it came to the initial assessment conversations. Often, these were clearly beneficial for the young people. The conversations helped them reflect on their meningitis experience, surfacing support needs which had not been previously identified, providing them with information or advice that they needed or sign-posting them to other relevant organisations. At this stage it also became apparent to the programme team that some young people did not need their support, at this stage of their life at least. In these cases, the team left information and guidance with those young people, making sure they know that support is there, if and when they need it.



*I will fear meeting new people less, and spending time in a group of people will seem less daunting to me, because I did fine while I was here...I am proud for coming, years ago that would have been impossible for me. A lasting memory will be appreciating our differences and realising I'm not as bad as I think..*

**Young person who attended a residential**

At the same time, for approximately one in five young people in Tier 1 (or around 10% of the entire cohort of the programme participants), there was no evidence of positive outcomes as a result of their - brief - engagement. Usually, these young people had their initial meeting with the Believe & Achieve team and then disengaged, i.e. chose not to take up any support on offer, even though they had a detailed conversation about what can be available to them. Importantly, there was evidence that these young people did not need support. There were also instances when some young people in Tier 1 lacked motivation to engage with the programme. This was often visible from the very beginning of their initial meeting. In others, there was no clear evidence about the reasons behind them not taking up support activities that they had expressed interest in. It is possible, that some of these young people were too anxious and nervous to take part in other programme activities, especially those involving a lot of people or required travelling. Indeed, evidence that young people can get very nervous or apprehensive before they engage with support activities was visible throughout the programme evidence. This was particularly true for the events and residential. Whilst they were described as extremely powerful by those programme participants who attended them, they were also described as 'nerve-wracking' and 'quite a big thing to do' by young people before they got involved. It is therefore not surprising that, initially at least, quite a few young people pulled out of the events or residential that they had earlier wanted to attend. Many of them subsequently managed to join one or more events, which is when they experienced numerous positive outcomes, particularly if they continued and deepened their engagement. Others were persuaded to try virtual support opportunities (such as online events or simply joining the Believe & Achieve Facebook group), but there was a small minority who simply did not get in touch again or respond to communications.

These engagement difficulties are hardly surprising, given that virtually all young people targeted through the programme have had deeply traumatic experiences and many also struggle with considerable physical after-effects. Importantly, the programme team was able to successfully engage the vast majority of these young people and **for around nine in ten of them there was evidence of positive outcomes**. For just over a third (37%) of all young people who engaged with the programme during its first five years, there was evidence that the programme has had **considerable positive impact and across a wide range of areas**. We explore this in the next section.

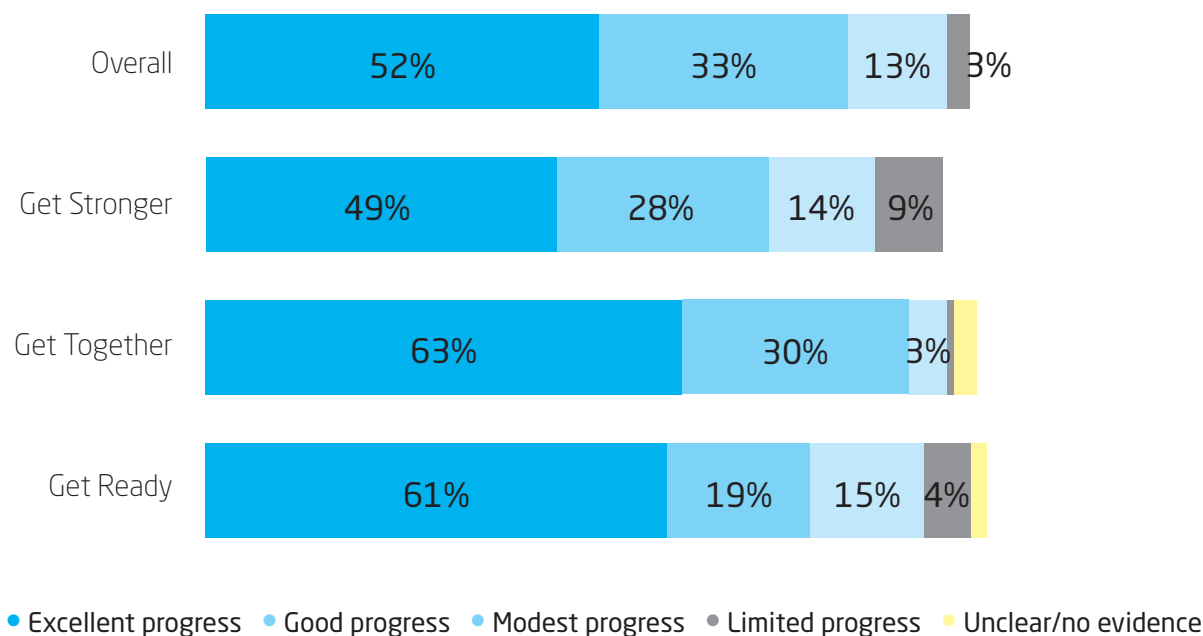
## Tier 2: Overview of impact on participants

There was evidence of positive outcomes for all young people who engaged with the programme in depth (i.e. categorised as Tier 2 participants). 85% of them made good or excellent progress across all three outcome areas - Get Stronger, Get Together and Get Ready. Not only did taking part in the programme make a considerable difference to their lives at the time of their engagement but many of the positive outcomes achieved for these young people were long-term, sustainable changes.

Get Together emerged as the strongest area of impact, with more than 9 in 10 participants who engaged with the programme in depth, making considerable progress in this area. Almost two thirds making excellent progress is also worth highlighting as an impressive achievement. Whilst in comparison with Get Together the level of impact was slightly lower in the other two impact areas, it was nonetheless highly positive.

## Figure 5: Overview of impact for Tier 2 programme participants

Source: individual participant records. Base: 79 young people



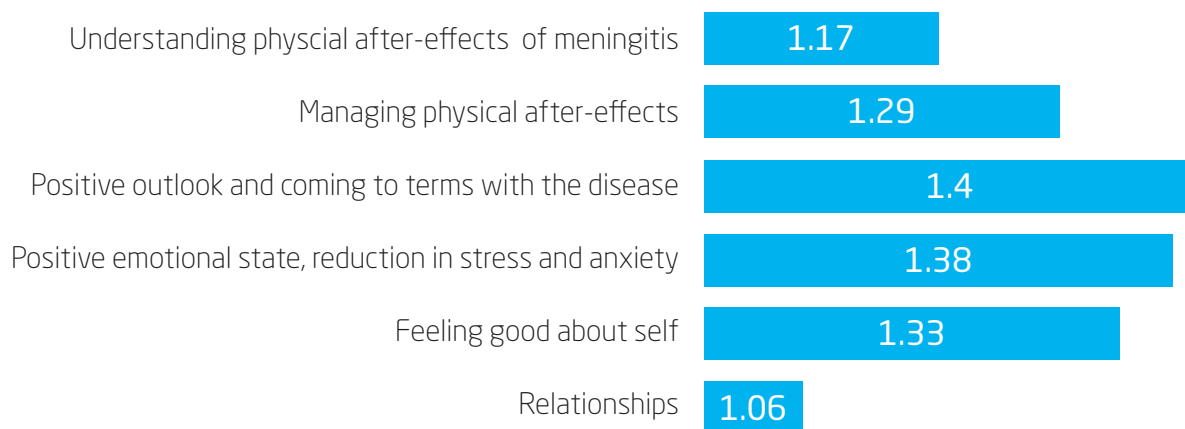
### Get Stronger

Young people’s development in this area was assessed against six outcomes, contributing to their physical, mental and emotional wellbeing. The first two were directly linked to meningitis and learning to manage its after-effects, the next three were to do with young people’s view of themselves, their emotional state and outlook. The last one concerned their relationships with family, close friends and significant others.

As can be seen in Figure 6, improvement and positive changes were evidenced across all of these outcomes. The two outcomes strongly linked with mental and emotional wellbeing (Positive outlook and Positive emotional state) have emerged as the strongest in the Get Stronger area. For these two outcomes, evidence of significant impact (scoring ‘2’ during the analysis and in Figure 6 below) was available for around half of all the programme participants who engaged with the programme in depth (Tier 2).

### Figure 6: Mean scores for each outcome within Get Stronger

Source: individual participant records. Base: 79 respondents.

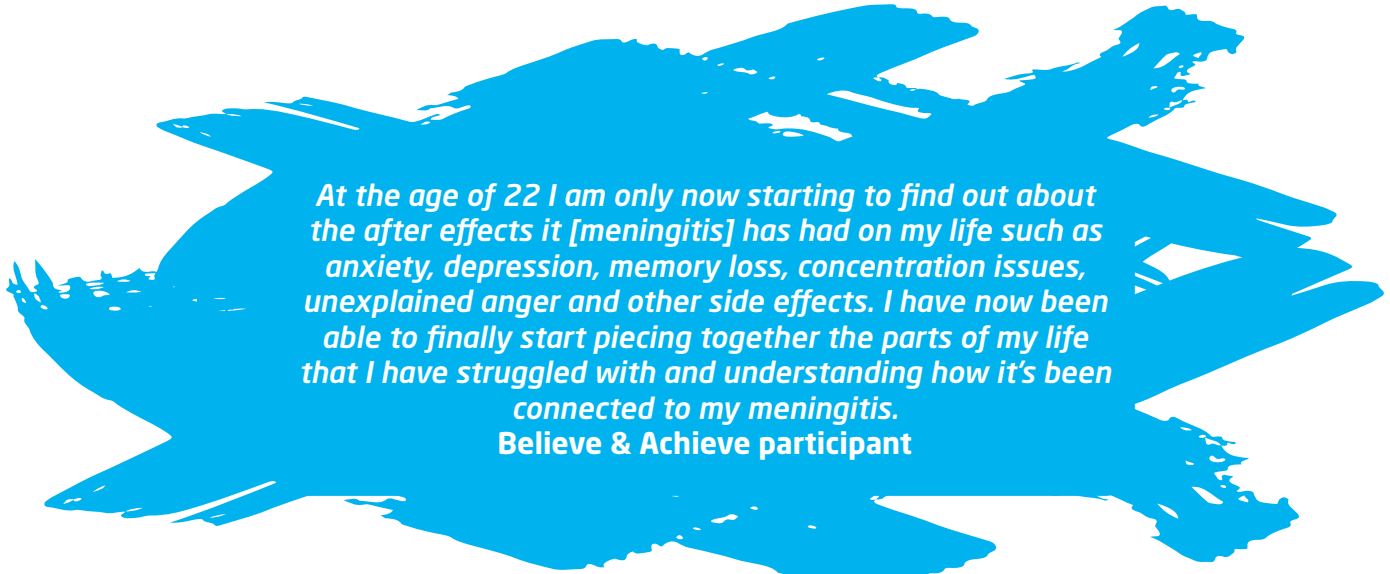


0 = No improvement 1 = Some improvement 2 = Substantial improvement

## Understanding and managing physical after-effects of meningitis

After-effects of meningitis vary greatly, both in their nature and severity. Whilst some are very visible, such as loss of limb or scarring, many young people do not realise that fatigue, mood swings, panic attacks, insomnia or difficulties in concentrating can also be consequences of the disease.

The evidence shows that Believe & Achieve has helped young people to better understand after-effects of meningitis. The programme has helped young people achieve this understanding in various ways. For example, through fact sheets, the helpline nurses, and simply by enabling young people to listen to or read about the experiences of others who have been impacted by meningitis. The Believe & Achieve team also directed young people towards general medical and specialist assessments, e.g. by a GP, or neuropsychologist.



*At the age of 22 I am only now starting to find out about the after effects it [meningitis] has had on my life such as anxiety, depression, memory loss, concentration issues, unexplained anger and other side effects. I have now been able to finally start piecing together the parts of my life that I have struggled with and understanding how it's been connected to my meningitis.*

**Believe & Achieve participant**

Believe & Achieve has also been successful in helping young people better manage the physical after-effects of meningitis. Success has been achieved by encouraging them to share their stories and coping strategies with each other, and by directing them towards specialist medical help and expertise.

In the vast majority of cases, the after-effects of meningitis did not go away but young people learnt to manage them better. Most commonly, young people became much better at understanding their triggers and recognising when they could push themselves and when they needed to stop and look after themselves. This meant that they became more adept at pre-empting anxiety, stress and fatigue. For instance, there were examples of young people leaving social activities in order to rest, and learning to exercise and stay fit whilst taking after-effects into account. Others learnt ways to remember things (where they struggled with memory and concentration). Being able to manage their after-effects more successfully also meant seeking ways (treatment or equipment) that would help them better and improve their quality of life.

Some of the events that were organised by the Believe & Achieve team have emerged as particularly powerful in helping young people learn strategies that help them manage common after-effects such as fatigue or difficulties with concentration and memory. There were numerous examples in both our primary evidence and the programme data collected by the Believe & Achieve team, suggesting that young people not only found those sessions useful but also were able to apply their learning from those events, with noticeable changes to their wellbeing.

## Case study: Support provided at the right time and help with managing some after-effects

Emily\* had meningitis when she was a baby. She had numerous after-effects, including hearing loss. She had cochlear implants fitted when she was still very young. Nonetheless, hearing difficulties had negative effects on her speech development.

Being at school was challenging for Emily: it was hard for her to keep up with her peers and she also felt isolated and was bullied. Despite all that and having to move to a special school to get the level of support she needed, Emily was able to pursue one of the subjects she studied at A level and enjoyed - health and social care - as her career path.

In her late teens, she moved to London and was working on her degree but found herself struggling to cope and fit in. That is when she came across Believe & Achieve.

*Believe & Achieve have been one of the most incredible things for me. It came at the time when I most needed it. I was like, 'I'm struggling with this, then struggling with that.' I couldn't make sense or understand it and that felt quite isolating at the time.*

Her first meeting with the Believe & Achieve coordinator was invaluable for Emily. For the first time in her life she felt heard. By sharing her experiences, she was able to realise 'how big an event' meningitis was in her life. Emily later reflected that only once she understood her experiences and their magnitude was she able to identify what support she needed.

She was able to access counselling and got involved in many Believe & Achieve events. She learnt some of the strategies that helped her manage her after effects.

Meeting others who experienced meningitis was a 'massive, massive experience' for Emily. Overtime, she became very much part of the Believe & Achieve network and developed strong bonds with people in it, which all stayed with her even after she left the programme because of reaching the upper age limit.

*There's just something really lovely about [this shared understanding that we have]. I still now have those people on my phone. We've said, any time that we need to something or we want to have a chat, we're there for each other. There'd be no questions about that.*

*[The programme] has given me the skills and tools to manage my affect effects. There were sessions on anxiety, staying organised, memory, fatigue - all of the things that meningitis [can affect or trigger]. Fatigue is a massive one for me. I really struggle with my memory and I keeping my diary organised, I'm chaos.*

*{Believe & Achieve} gave us this understanding and then also the tools to know how to manage it better. There was also that reassurance that you can do it. And then, others share their personal experience. It all really helped me.*



## Feeling better about themselves, developing a more positive outlook and frame of mind


When young people joined the programme, their state of mental health and wellbeing was often low. This was particularly true for those for whom their meningitis experience was relatively recent.

Young people struggled to come to terms with what has happened to them; the unpredictability of meningitis and the losses it can inflict can be difficult to accept. Many have expressed feeling frustrated and angry, particularly if the after-effects of meningitis have meant a greater dependence on their parents or partner. Those who have had direct experience of the disease sometimes mention changes to their personality. There were also multiple examples of young people suffering from depression and anxiety when they joined the programme.

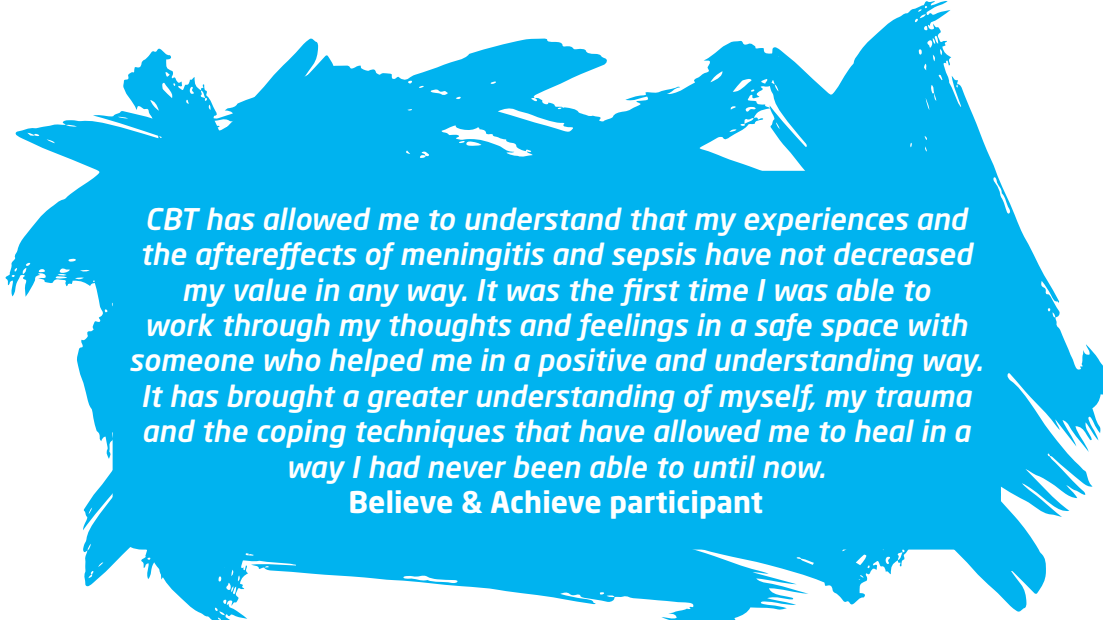
For some, anxiety was triggered by specific experiences, such as a stressful period in their studies. For others it was more ongoing. Some young people spoke about experiencing panic attacks, without understanding what might have caused them. Similarly, many programme participants felt very negative about their future: 'devastated and destroyed by meningitis and its impact', 'struggling to see how things can improve' (Believe & Achieve team's observation notes within individual participant records).

Yet, this is where the programme has made some of the biggest difference to the participating young people.

Through their involvement in the programme young people have learnt what they can and cannot control in their lives. They have learnt not to blame themselves, and most importantly learnt to move on and find new positives - things to achieve, feel proud of and happy about. They recognised that although they would still have bad days, overall, they can look to the future with hope and positivity.



*My wheelchair is not me getting worse; it's me getting better. My wheelchair isn't me "giving in to being ill"; it's me choosing life. It's me embracing disability for what it is - a wonderful fact of human diversity. Your life served you noodles, so you use a fork. My life served me soup, so I use a spoon. Using a fork to eat soup would be unsustainable, so I just use the right implement. It's not "inspiring", it's not "brave", it's logical. It's practical. Yikes, for the first time in five years, it's exciting.*  
**Believe & Achieve participant**



*CBT has allowed me to understand that my experiences and the aftereffects of meningitis and sepsis have not decreased my value in any way. It was the first time I was able to work through my thoughts and feelings in a safe space with someone who helped me in a positive and understanding way. It has brought a greater understanding of myself, my trauma and the coping techniques that have allowed me to heal in a way I had never been able to until now.*  
**Believe & Achieve participant**


A number of the programme activities were linked with strong impact in this area, with counselling (which sometimes meant cognitive behavioural therapy, CBT) and residential events being particularly influential. For around two thirds of young people who took part in either of these two activities, there was evidence of significant improvements to their outlook and it becoming more positive. In comparison, a similar level of impact in this outcome area was visible for only a third of participants who did not take part in either of these two forms of support.

The evidence shows that Believe & Achieve has helped young people to understand how their emotional wellbeing is affected by the physical aspects of meningitis. It has enabled them to improve their emotional resilience and develop coping strategies. They know they will face moments of stress and anxiety in their lives and in some cases rely on medication, counselling, peer mentoring and talking to others to manage these times.

## Relationships

Compared to other outcome areas, impact on participants' relationships with those close to them was smaller. This is because this outcome area is largely outside of Believe & Achieve's sphere of direct influence, so any impact is secondary in nature. In most instances, positive changes to participants' relationships with those around them happened after young people learnt to understand themselves better, developed a more positive frame of mind, outlook and sense of self-worth and got better at managing their physical and mental after-effects. Another factor that appeared helpful was young people developing friendships and bonds with other programme participants and the Believe & Achieve team. Not only was this valuable in its own right but it also meant that young people had a new avenue for exploring and sharing their feelings and emotions. In other words, because of this additional network of support, there was less pressure on the people surrounding the programme participants in their daily lives to provide all aspects of emotional support that young people who had experienced meningitis might need. For some participants, this made their relationships with people around them easier and smoother.

There were also some fantastic examples of the programme affecting young people's relationships with those close to them more directly. Where young people brought their friends, family members or similar to Believe & Achieve events, they were able to share fun and enjoyable experiences and sometimes also to see each other in a different light, which helped strengthen relationships.



*Counselling helped me to process my meningitis experience, mainly what effect the trauma had on my friendships, studies, and mental health at the time. I feel it helped me to move forward and accept what had happened and now I am able to work on my future plans and try to put some of what happened with meningitis in the past. I've taken away some skills to help me with my emotions.*  
**Believe & Achieve participant**

## Get Together

Three outcomes were assessed within the Get Together area. They included young people feeling supported, being part of a community and supporting others.

### Figure 7: Mean scores for each outcome within Get Together

Source: individual participant records. Base: 79 respondents.



0 = No improvement 1 = Some improvement 2 = Substantial improvement

Evidence gathered and analysed for this evaluation shows that there was substantial improvement across all outcomes in this area. This is an exceptional achievement, particularly given that starting points for the vast majority of the programme participants were extremely low. Prior to joining Believe & Achieve many of them felt extremely isolated and some had poor treatment experience and virtually no aftercare available once they left hospital, which left them feeling like there was no support out there.

### Feeling supported

An important indicator of mental and emotional wellbeing, feeling supported was the strongest outcome area for Believe & Achieve. Positive changes in this area were visible for all young people who engaged with the programme in depth. For more than two thirds of participants there was evidence of substantial impact. Throughout the entire programme evidence-set there were numerous comments from young people saying that whenever they need help, however small the issue might be, the Believe & Achieve team and programme participants would be there for them. This created a strong sense of emotional security for young people.

*I know if I am struggling in anyway whether that is academically or emotionally there is always someone out there willing to help.*

**Believe & Achieve participant**

It is important to note that this specific impact could not have been achieved if it was not for the exceptional level of effort and commitment from the Believe & Achieve team. They do not simply deliver the programme activities. They are highly responsive, flexible and go the extra mile every single time. Participants commented that they know that if something can be done, the Believe & Achieve team will find a way. Importantly, they were always there for the participants, gradually and surely earning their trust and then being always on standby, ready to offer support as needs change.

Feeling supported also comes from young people knowing that other programme participants are there for them. In other words they are an integral part of the community that Believe & Achieve has become.

## Becoming part of a community and a sense of belonging


There was a very strong community feeling among participants engaging in Believe & Achieve, which was almost palpable during the event attended by the research team and consistently present in all other evidence. This sense of community was visible in young people's anticipation of seeing each other and enjoyment of each other's company. They felt safe and understood when together. This sense of community was strengthened by the young people's willingness to contribute to support others in the group and their own efforts to keep their relationships active and alive.

Many participants explained why this mattered so much to them. Prior to their engagement with Believe & Achieve they have not come across many other people who had experienced or been affected by meningitis. This experience was often obscure to people around them who had not been affected. It is only when being around people who had been through similar things, that they felt they could be themselves. For example, they did not have to hold back. Importantly, not only did they have a chance to explore their feelings and talk about the challenges they faced, they also shared many positive and happy experiences when taking part in the events and activities prepared for them by the Believe & Achieve team.

According to several young people, creating a self-sustaining and highly positive community of young people affected by meningitis is what sets the programme apart from others.

### Supporting others

For some programme participants, their desire to support others was what motivated them to take part in Believe & Achieve. Others gradually discovered the joys of helping others around them and the healing power of such experiences. Their journey started by finding the strength to share their story and their struggles with others. It was at that stage, that they discovered how helpful and inspiring this was to other people, particularly those in similar circumstances. From there, some people started to welcome newcomers and offer them informal support and reassurance. Others opted to do volunteering or chose more formal peer mentoring.



*...there's support there [within our Believe & Achieve network], even when you haven't met some people. We've got a little Facebook group and if someone puts up something that they've done, everyone's congratulating them in the comments or saying this is great, how do you feel about it and everything. There's a great support network there and it does make you feel a lot less alone. There is a real loneliness attached to having had a diagnosis and then not knowing anyone who's had it. Being able to meet someone and share experiences [helps you] realise you're not alone in it.*

**Believe & Achieve participant**

## Case study of a peer mentor: the value of helping others

Jack\* is in his early twenties and works as a teaching assistant in a secondary school. He had meningitis as a toddler.

With his family fundraising for Meningitis Now for years, he was aware of the charity, but only got involved with Believe & Achieve in his late teens.

Becoming a peer mentor with Believe & Achieve was invaluable for Jack. It helped him develop his self-esteem and sense of identity, making him realise that helping others is something he enjoys and that gives him a sense of purpose.

From a teenager who was self-centred and at times struggling to deal with his emotions, not least because of the fatigue which he could not explain and found frustrating, he turned into a kind and caring young man, who changes lives of others for the better and is able to feel good about himself as a result.

*At school, I [would] keep myself to myself... I wouldn't really speak to many people, but if I did, it would be [the few] people that I trusted. I had very low self-confidence, self-esteem, because I was struggling academically and people didn't think I was good enough. When I was in Year 11, coming up to GCSEs, threw everything out, I was like I'm listening to music, I'm coming home, I'm sitting in my room. Just basically shut myself out from the world. I got to the point where I realised I was getting quite angry, quite quickly at certain things.*

*Joining the Believe & Achieve and growing up at the same time I was able to grow my confidence and my self-esteem, [ I discovered that I] wanted to help other people, wanted to be 'the life of the party', that sort of thing. [When I joined Believe & Achieve] I could be myself and could relax. From that first event, coming away I was a different person in the sense of letting go and being like, okay I have it, but it's not just me.*

His peer mentoring experience is helping him with his career too. He was able to apply the skills of supporting young people, which he developed through peer mentoring, to his classroom and interventions work that he does as part of his teaching assistant role at school. One day, Jack is hoping to become a teacher.

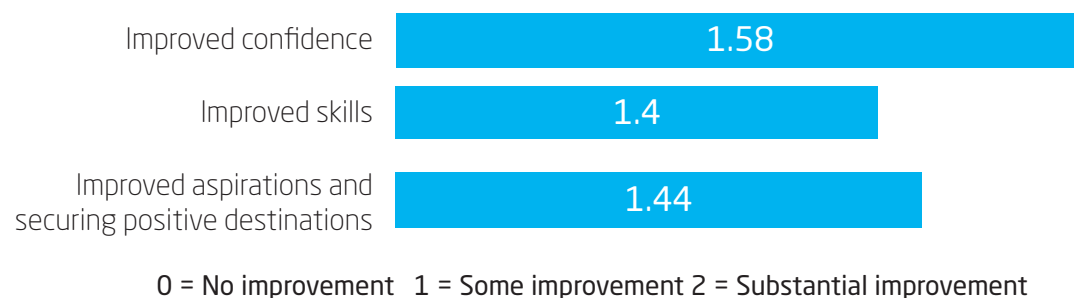
*I'm the type of person that [during Believe & Achieve events and challenges] would encourage people and get everyone through it. And then, at the end of that, 90% of the time, at least one or two people come up to me, and say, 'If you weren't there, or around me, I wouldn't probably have done it, because I'm quite nervous or quite anxious. I've always been that sort of a person, but now, [in this] environment, I can be even more like myself than I was before. Now, I can be myself outside and inside the programme, but at the start it was more only inside the programme.*

## Get Ready

Within the Get Ready area, three outcomes were assessed: improvements, if any, to young people's confidence, skills and aspirations as well as their ability to move towards positive futures.

### Figure 8: Mean scores for each outcome within Get Ready

Source: individual participant records. Base: 79 respondents.



### Improved confidence

Improved confidence was consistently cited by young people themselves as a key outcome that they gained through Believe & Achieve.

Positive changes were noticeable for the vast majority of the programme participants and for almost two thirds they were substantial. For example, young people who had previously struggled to speak out and make eye contact had learnt to feel comfortable when meeting new people or sharing their experiences in public. The programme participants overcame many challenges during the events that they attended, with each filling them with pride about what they can do and a sense of achievement. Young people's engagement in activities, where they had previously opted out or simply observed, was perhaps the best sign of them growing in confidence during the events.

#### Case study: Improved confidence

David\* is 18 years old, currently in college. He had meningitis as a child, towards the end of primary school, and was struggling to 'take it all in'. He had panic attacks at the time.

Reflecting on his Believe & Achieve experience, he spoke about the different events he attended and how welcoming and supportive the charity staff and other participants have been. He feels that the programme helped improve his confidence and sense of self-worth, as well as his mental health.

*My confidence to speak to people [is where Believe & Achieve made the biggest difference]. I was very shy and timid before and just being able to talk to different people, people from all over the UK, [made] me feel confident in myself. After I was ill I struggled with panic attacks. [I had] counselling but it just wasn't helping me, [but with Believe and Achieve], because I talked to the staff and to the other people it, just made me feel more comfortable and the panic attacks eased.*

## Improved skills

The programme participants developed a range of important and valuable skills as a result of their engagement, including (displayed in the order of achieved impact, from strongest to less pronounced):

- **Employability and life/essential skills and qualities**, such as communication and teamwork, persistence and determination. For some young people learning how to set goals, in specific activities and more generally in life, and how to plan and be organised in order to achieve them was particularly important.
- **Career management and study skills**, for example revision and study techniques that participants learnt through the programme, or developing their skills to prepare an effective CV or to do well in a job interview. Strongest impact was often associated with bespoke and intensive (one-to-one) support that young people had when for example preparing their UCAS applications.
- **Skills linked to interests and passions**, such as photography or fitness. Importantly, there were numerous instances where the programme participants discovered new interests and activities that they enjoyed. There were also numerous examples, where the programme team tapped into support available elsewhere, including the charity's own Rebuilding Futures Fund, to enable young people to develop their skills and pursue their interests. For example, one participant who has difficulties using his legs because of meningitis had a grant to purchase a kayak. Familiar with it from scouts, he really enjoys kayaking, something which he shares with his dad. As well as enabling this participant to improve his skills, kayaking together gave the family a chance to bond and do exercise outside, much needed after COVID-19 lockdowns, boosting their physical and mental health.
- **Independent living skills**, such as cooking or planning own travel.

The latter was interesting as it emerged in relation to young people attending events (and needing to travel to them) as opposed to being part of formal activities. Such informal learning activities were supported through the programme by the Believe & Achieve team. Sometimes other Meningitis Now staff were there to give advice and guide young people. For example help them develop ideas whilst also providing the necessary information. From the outset, a lot of emphasis has been on encouraging programme participants to be independent. This might include taking advantage of small but important informal learning opportunities that presented themselves as a matter of course as they engaged with the programme. Importantly, progress resulting from such informal learning activities was very much noticed and celebrated. In many cases being more self-reliant was something that participants themselves desperately wanted or needed when they joined the programme. This was particularly true where their meningitis experience had led to them being dependent on others or people around them being too protective. This was sometimes to the point of disrupting the natural process of young people becoming independent as they become young adults.




## Improved aspirations and reaching positive destinations

This is a highly important outcome area for Believe & Achieve. It contains real life manifestations of the 'achieve' element of the programme and its vision. It is also important to note that unlike some other outcome areas explored in this report where short term changes are sufficient to categorise them as a success, this outcome area is all about long term changes.


For these reasons alone, most young people who engaged with the programme in depth making progress in this area is impressive. In combination, two thirds of them showing significant improvements is a remarkable achievement and a clear indication of the programme's effectiveness and impact.

In concrete terms, this means that more than sixty young people affected by Meningitis were able to continue and successfully complete their studies, start the next phase of their education or start working. This is heart-warming considering prior to taking part in Believe & Achieve they doubted they would be able to pursue a career of their dreams or find a path that they would enjoy. Programme participants were able to fulfil their other (non-career related) dreams and ambitions too. These might be starting a family, travelling or learning to drive. In



*[Believe & Achieve has] changed my life, I don't think I'd be where I am right now if it wasn't for them!*  
**Believe & Achieve participant**

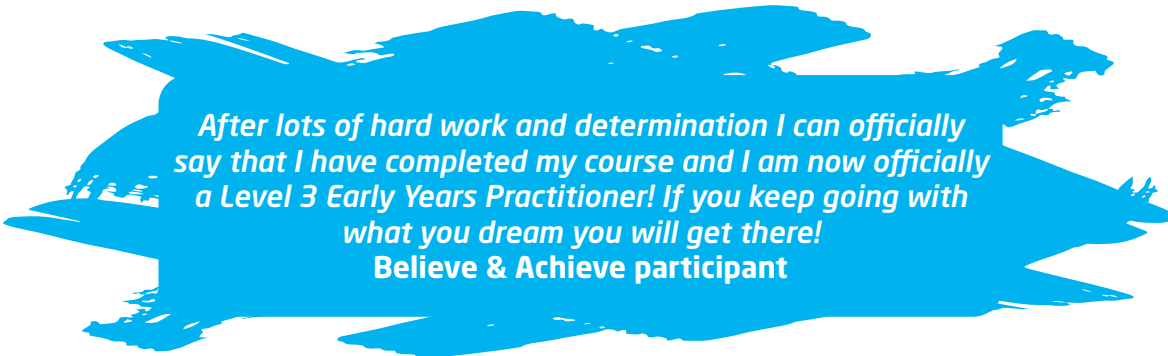
addition to those sixty young people, there were also many more, whose personal achievements were perhaps smaller at the time of reporting but no less important.



*[Name of Believe & Achieve participant] passed his [exams]. He's delighted, I'm delighted!... Thanks for all your support in helping him with his schooling!*  
**Believe & Achieve participant**

Very rarely were these journeys to success easy and straightforward. There were numerous times when the programme team had to support young people when they left their jobs or tried a study course and had to leave it. Sometimes they discovered it was not for them or that due

to their after-effects some of the things that they wanted to achieve were too demanding and therefore badly affecting their physical or mental health and were thus not sustainable long term. Believe & Achieve helped some of them to persevere, by offering further and different support, and helped others to take stock and set alternative goals. These goals might be realistic yet aspirational, including starting their own business. Sometimes, rather than 'changing course' completely, simpler solutions were possible. For example, looking for employment where working from home is easy or speaking to employers about reasonable adjustments, so that their after-effects were easier to manage.



*After lots of hard work and determination I can officially say that I have completed my course and I am now officially a Level 3 Early Years Practitioner! If you keep going with what you dream you will get there!*  
**Believe & Achieve participant**



## Case study: From long recovery to achieving career goals

When she just turned 20, Rachel\* felt unwell. For weeks she struggled from headaches which were progressively getting worse. Her eyesight deteriorated and she was having hallucinations. At hospital, she was initially misdiagnosed, only to find out later that she had bacterial meningitis. When she was leaving hospital following her four weeks' treatment with antibiotics, Rachel was told that it might take her a year to fully recover. In reality, it took a lot longer.

Yet, apart from her very supportive family who looked after her for years and supported her financially, others struggled to understand why after all these years, she was still unwell. Some did not believe she had any after-effects at all.

*For a full year, I had a headache and major fatigue. [What] I found really, incredibly difficult was that after that year, I still wasn't better. After about 1.5 years, I still couldn't really walk any further than half-an-hour. My memory and concentration was impaired so much that I would try to learn [what] I needed to for uni and [it was just impossible]....It really took 4 years for me to recover...*

*I had just started [my teaching] placement, and I was really stressed. I thought that by [that point] I would feel less stressed and less anxious and I would be in a better place, and I just wasn't. So I was just like, 'I think I need counselling. I need something. I am not coping.*

She reached a difficult point a few years after she had meningitis, when she started doubting she would be able to complete her degree and most importantly do the job that she was training for.

She reached out to Meningitis Now. Her first conversation with the Believe & Achieve Programme Coordinator not only reassured her that help was available, but also made her feel understood.

She was able to access counselling through Believe & Achieve, which helped her process the impact that

meningitis had on her life. It helped her deal with 'the stress and anxiety that comes from your body not functioning and being sick'. She also had help with managing some of the physical after-effects. She learnt from Meningitis Now that an osteopathy course might help with her headaches by relieving tension.

She accessed other Believe & Achieve support too. Life coaching helped her build up her confidence and also helped her prepare for her first experiences in the classroom, as a teacher. Despite having achieved her goal of graduating from university and becoming a teacher and generally doing well, Rachel is grateful to have continued support from her Believe & Achieve peer mentor.

*It was a 10 weeks' [treatment course] and it definitely helped with my headaches. [Before I got in touch with Believe & Achieve,] I didn't even know that that was possible, but it made such a difference, it was amazing.*

*It's been so good to have someone who I can talk, who understands... If something goes wrong in the classroom or something just goes wrong throughout the week, having that security of, 'I know that by Thursday I'm going to talk to [peer mentor's name] about it.' So, I can put it to the back of my head, ... and I'll speak to her about it then... Knowing that I've got support coming is what I've needed more than anything.*

## WHAT WORKS IN SECURING ENGAGEMENT AND IMPACT

All available evidence suggests that Believe & Achieve is a highly successful programme, achieving impact of exceptional breadth and depth for its participants. In this section, we consider some of the factors that make it work, as well as offering some suggestions for its further development. In doing so, we draw not only on all the documentary evidence that was shared with us but also interviews with the programme team and its participants.

The programme comprises a large number of activities and forms of support, which has expanded over time and keeps growing. When scrutinised, it became apparent that each of those activities and forms of support has a role to play and is effective in its own right. Our analyses and different sources of evidence highlighted the benefits of all those varied forms of support. For example, our analysis of the programme data alongside evidence of impact showed the value of activities such as Next Steps or Peer Mentoring. For four in five young people involved in these activities there was evidence of substantial impact across all impact areas. This was twice as high as for those who did not take part in those forms of support. Yet, other evidence, including participant interviews, was consistent in highlighting the power of counselling, events or bespoke support from the Programme Coordinator, including the very first meeting that triggered their engagement in the programme.

Young people's feedback was consistent with this pattern in the data. When asked directly about what was not working, or is simply less effective, they answered unanimously - 'nothing'. Similarly, they did not think that anything was missing and should be added. This is hardly surprising, given that from the outset that programme has been constantly evolving in response to evidence of young people's engagement, emerging needs and their direct feedback.

*It's really hard [to suggest any improvements] because [Believe & Achieve] team have done so well. There's nothing I can fault really because every opportunity where I've said to [the programme coordinator], 'I need this,' she's given me absolutely [everything, to help me do what I want to do and move to where I want to be in life].*  
**Believe & Achieve participant**

What has emerged as highly important is having a range of activities and support on offer. This means that every participant can (with support) configure their own bespoke and personalised journey through the programme.



## Case study: Sequence of Believe & Achieve support activities within one recovery journey

Mia\* had meningitis in her late teens. When she left hospital, she discovered that there was no aftercare available from the NHS, yet she was really struggling, with her confidence and mental health in particular.

*You're very much on your own after [you leave hospital], dealing with the physical, but also the mental things that come with having had such a bad experience.*

Her parents suggested getting in touch with Meningitis Now but she felt scared. The Believe & Achieve programme coordinator contacting her and suggesting an initial chat made it easier for Mia to get involved.

She has been with Believe & Achieve programme for a few years, accessing different types of support that it offers and engaging in many activities. For Mia, there was a particular journey through the programme, a sequence to the support that she had accessed.

*Once I'd done [CBT], I started to come to terms with things and realised my experience doesn't decrease my value in any sense. Then, when I went to do the peer mentoring, I was more open about talking about my experience. When I then went to do the in-person meet-up, it just felt a lot more natural to talk about it and even not talk about it at the same time. If I hadn't had all those steps, I don't know if I would've been able to do the meet up.*

She started with doing a course of CBT through counselling and speaks passionately about its importance and value to her recovery, describing it as something that she 'desperately needed'. She could not afford to cover the costs privately and prior to joining the programme she had been on the NHS waiting list for almost a year.

Next, she had support from a peer mentor. For six months, they spoke every one-two weeks. Mia felt that meeting another person who could really understand her, without too many words and without judgement, was very important for her. This was the first time she felt able to share her experiences. With her peer mentor, she 'could talk about anything because [they] both knew how hard it had been, how hard it could be'.

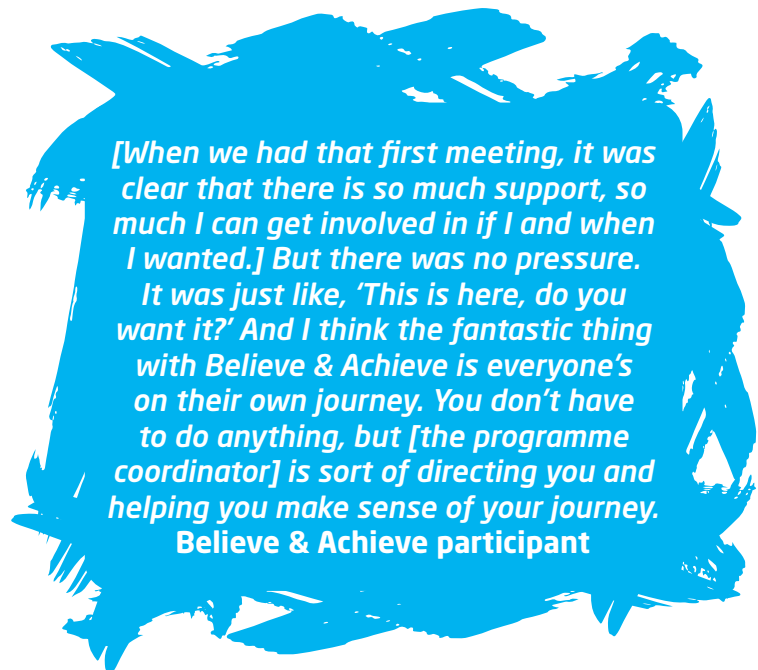
She was then ready to attend some events, in person and then virtually. She said she really needed those initial steps (counselling and peer mentoring) to be able to join events that involved a lot of people.

Once she was able to join various events, she discovered a community of people like her, which has since given her the strength, motivation and support to rebuild her life.

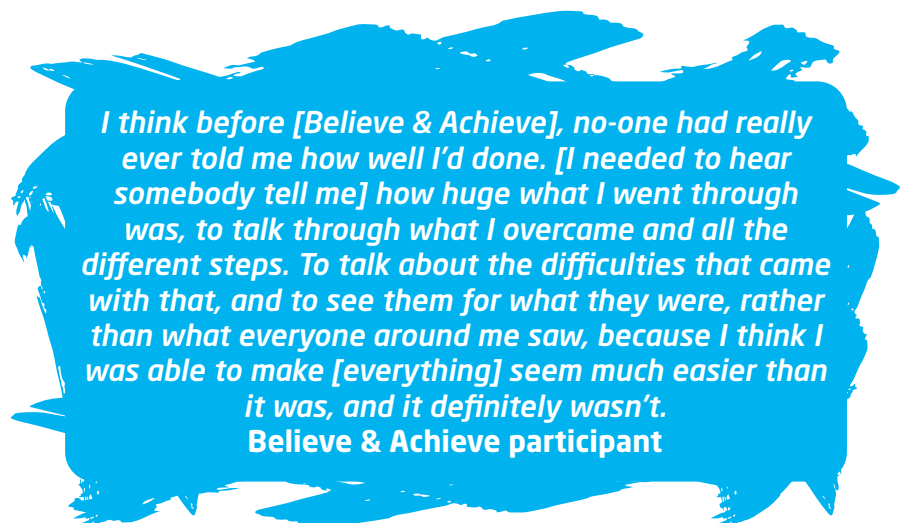
*Because we've all been through something, we are able to connect through that, but also there's an underlying zest for life. We all want to be alive and we're all so glad we're alive. Seeing that the other people within the group are doing well, ... how far they've come - it's just magic to see. It really gives you that sort of, 'I can do this' [feeling]. We inspire each other to just keep going. Sometimes it is just getting out of bed and going to work and coming home and having dinner. Sometimes it's not a massive thing, but to you it's a massive thing... [Believe & Achieve] is a place where you can be less lonely and realise that your feelings are valid and that there is support. Knowing that I've got support coming is what I've needed more than anything...*

Sequencing activities emerged as highly important in the programme evidence, in a number of ways. Firstly, as illustrated in the case study above, there were some activities - events and residential in particular - which have a unique and powerful role to play in achieving the programme outcomes. However they can also be difficult for some young people to engage in, so preliminary steps are needed to prepare them. As well as offering young people a chance to take part in other (usually one-to-one) forms of support first, the programme team has done a lot to make sure that some events at least are perceived as 'light touch', casual and easy to try out. In addition they made sure that every person attending feels welcome and 'part of the family' from the moment they walk through the door. Secondly, and again illustrated in the case study above, sequencing of activities enables layering of outcomes, from addressing urgent needs to achieving long term impact.

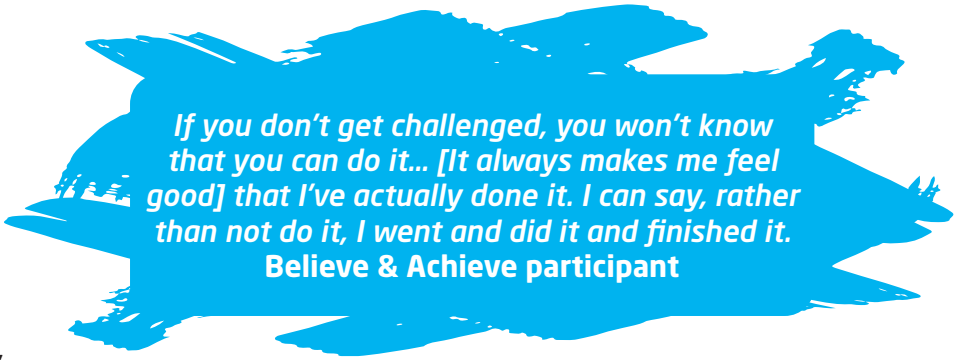
Apart from the broad patterns suggested above (starting easy and light-touch or focusing on urgent need and then gradually deepening engagement and impact) there were no easy answers of how to sequence the programme activity so that it works for everyone. Going forward, if they are to achieve similar levels of impact, the Believe & Achieve team should avoid looking or applying any ready-made, 'one-size fits all' tactics and continue with its highly personalised approach, supporting everyone to find their path and shape their participation. This should include engaging in the first place, on their own terms. Young people involved in the programme highly valued that they were given the time and space to decide and that they were not rushed or pushed into anything.



Young people's ownership is visible not only in the choices they make as they take part in Believe & Achieve, it is key to the programme impact too. Whilst the programme creates the environment and conditions in which young people can succeed, every achievement is due to each participant's own hard work, determination and incredible inner strength. Noticing and celebrating their wins, however small, and the level of effort that is required to achieve them, is something that the programme team are so good at. This created a virtuous circle of success, helping participants to move from small achievements to bigger ones.



Believe & Achieve is not all about being supportive and patting young people on the back though. Challenge is an important part of the programme. This is most visible in young people being encouraged to try new things. For example, activities during events which they had never done before, or something more substantial,



*If you don't get challenged, you won't know that you can do it... [It always makes me feel good] that I've actually done it. I can say, rather than not do it, I went and did it and finished it.*

**Believe & Achieve participant**

perhaps to do with their education or career. The programme participants were very clear about the value of this, recognising that more often than not they succeed when trying new things and that every challenge or new activity they try boosts their confidence and self-efficacy.

The breadth of the programme, both in terms of its activities and its intended outcomes emerged as crucial too. For example, different themes and activities at various events became the reasons why specific young people engaged with the programme. Skiing might appeal to one person as their entry point into the programme, whilst somebody else would be keen on art, cooking or photography. Once engaged, this variety and breadth pushed young people out of their comfort zone and expanded their horizons. This was really important: the programme tries to be comprehensive for its participants. This involves covering many aspects of their lives, having numerous activities that give their lives meaning, having many people that support them and share experiences with them, having different strategies that help them cope with after-effects of meningitis and counteract its negative impact.

Despite it being excellent, expanding this breadth further is perhaps the only area that merged as a potential programme development opportunity. The available evidence suggests that there is scope to do more in terms of targeting engagement of specific groups of young people. Particularly in relation to their gender and ethnicity. In terms of gender, boys and young men remain underrepresented in the programme. This is despite the efforts of the programme team to increase its appeal and relevance to this group. Interestingly though, those males who do take part find the programme particularly worthwhile. The level of impact for boys and young men was greater than for girls and young women. The pattern was reverse for ethnicity. Whilst there was reasonably good representation from minority ethnic groups within the programme, impact data indicates that their outcomes were slightly less visible compared to white British participants. Looking for activities and forms of support that would appeal to these two groups (and any other groups the programme team identifies as priority) will be important in ensuring that Believe & Achieve is reaching all young people affected by meningitis and enabling them to rebuild their lives, irrespective of their background or other characteristics. According to the male participants who were involved in our research, boys and young men, might find gaming, cars and sports and fitness attractive. It might also be that single gender events could be worthwhile, not only to attract boys and young men, but also people from some ethnic groups where gender mixing is less culturally accepted. Exploring with representatives of target groups the specific activities that they would want to take part in and conversely what would put them off, might be a good way of ensuring that the programme caters for a range of interests and needs and is as diverse as possible. This is particularly important at the entry point stage, when young people are deciding whether to get involved or not.

Crucially, there was no evidence to suggest that special needs or disabilities, or young people's after-effects be they physical or mental, negatively affected their engagement in the programme and the impact achieved. It was apparent throughout, how much effort and thought was put into making sure that nothing becomes a barrier to participation.

Finally, we want to note the role of the Believe & Achieve team in making the programme the success that it is. Believe & Achieve is not simply a sum of its activities and forms of support. It is the people in the team that make it so much more. They shape each young person's journey, ensuring they get exactly what they need and when they need it. They are always there for the young people taking part. So much of the support is delivered through informal keeping in touch and gradually building trust and relationships. Even with the Believe & Achieve community, which is largely self-sustaining because young people support each other, it is the Programme Coordinator and her team that have set it up in the first place, and have been keeping it going ever since, making sure that it remains the safe haven of support and inspiration that the programme participants value so much.





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### Get in touch

**Nurse-led Helpline:** 0808 80 10 388 or [helpline@meningitisnow.org](mailto:helpline@meningitisnow.org)

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Believe & Achieve relies on donations, please get in touch if you would like to help fund this work. We are extremely grateful to all our supporters who have helped to make this impactful programme possible so far, including the National Lottery Community Fund, St. James's Place Charitable Foundation, Quilter Foundation, BBC Children in Need, GSK, The Gannochy Trust, Pantheon Charitable Trust, Pixel Fund, the Leeds Convalescent Society, as well as other anonymous supporters. Thank you for helping to rebuild futures.

