

# MSTV: Reaching young people affected by MS

Gemma Leigh, Ali Whittam, Lydia Fallon, Helena Jidborg Alexander and Linden Muirhead  
Information and Engagement Team, MS Trust

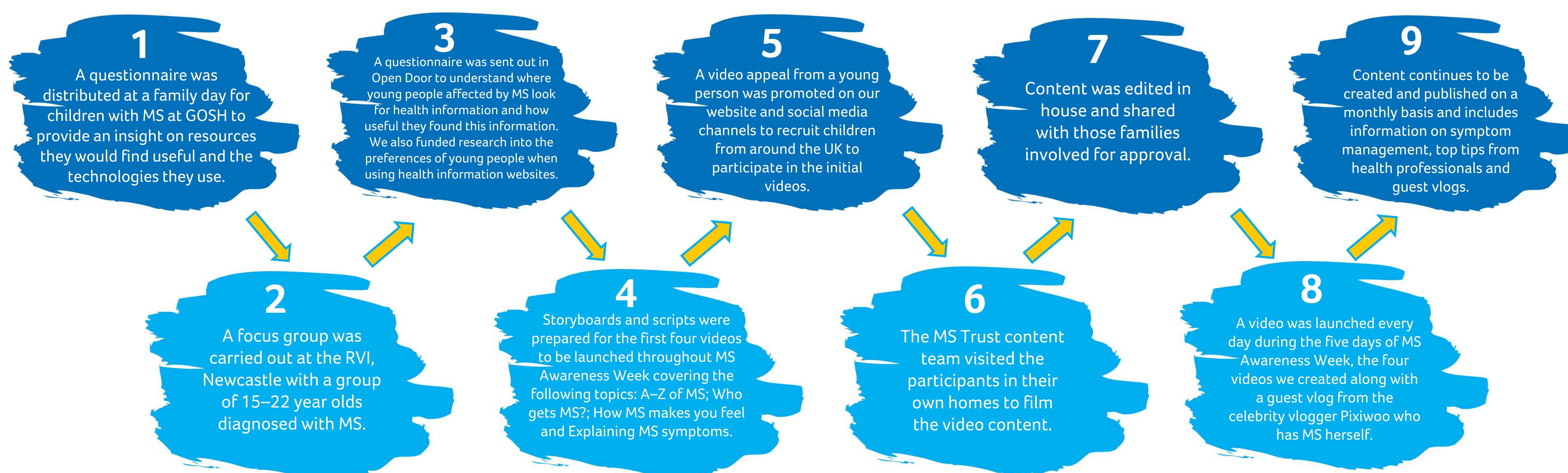


## Introduction and aims of the project

Our YouTube channel MSTV was launched during MS Awareness Week 2018. In the past the MS Trust has developed printed materials aimed at supporting children with a parent with MS. However, children no longer look to printed information when they need information, they prefer channels such as YouTube, social media and vlogs. The aim of this project was to provide our information in a more accessible format for the intended audience. We also recognised the lack of information for children who are diagnosed with MS themselves, so expanded the scope of this project to include information for this group. The aims of the project were to use a digital first approach to support children aged 11–17 affected by MS in an engaging manner, developed with the help of children themselves, to provide:

- a better understanding of MS through evidence-based information
- support in dealing with the emotional and psychological impacts of MS
- support in dealing with the social challenges arising from MS, thereby increasing their social confidence
- reassurance that they are not alone in their experiences.

## Methods



## Results

From our initial questionnaire and focus group it became apparent that the majority of young people no longer look to printed materials when searching for health information. Instead they prefer digital information that's available online and easily accessible through their smartphones and tablets. Our research showed that YouTube is a particularly popular channel amongst young people and is often used when searching for information. A report from Ofcom supported this further when it found that 90% of 12–15 year olds use YouTube. This led us to consider a digital project which delivered health information through engaging videos featuring young people affected by MS.

Results from our second questionnaire showed that the information currently available for young people affected by MS does not fully meet the audience's needs. 75% of the young people who completed the questionnaire said they were scared and confused by the information they found about MS, and many felt that the information was geared more towards older people. It's therefore not surprising that many young people often describe feeling alone when they, or one of their family members, are diagnosed with MS. When asked what their biggest challenges were, three key topics came up: understanding MS itself, worrying about the future and dealing with symptoms. These themes gave us an idea of the topics we should cover in our first videos.

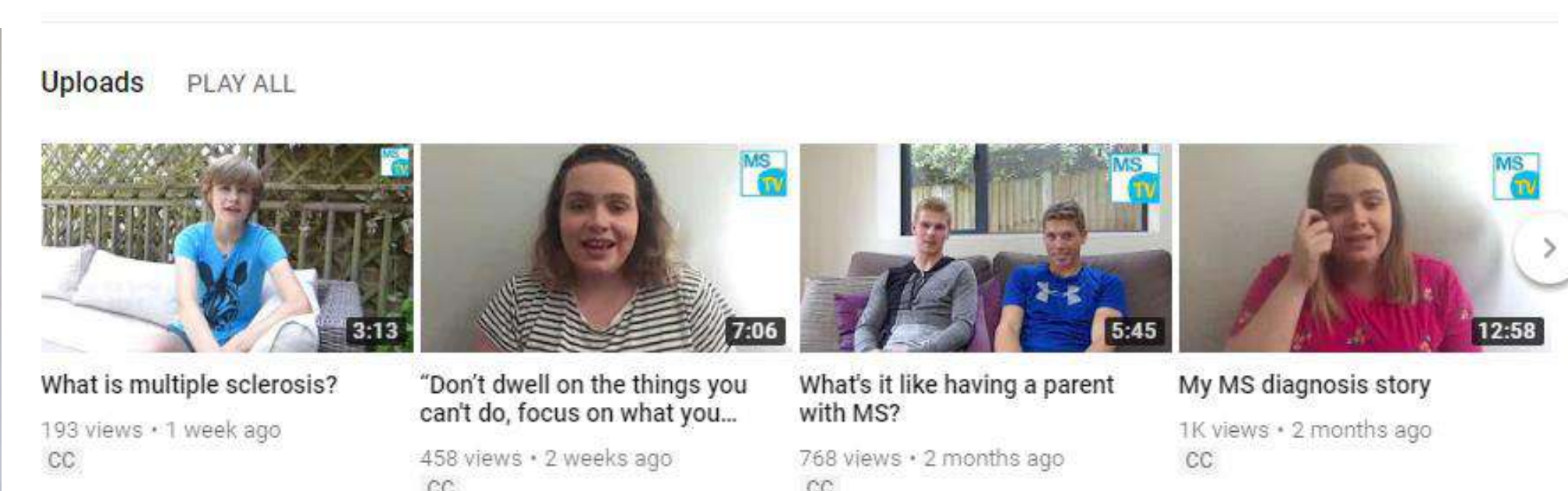
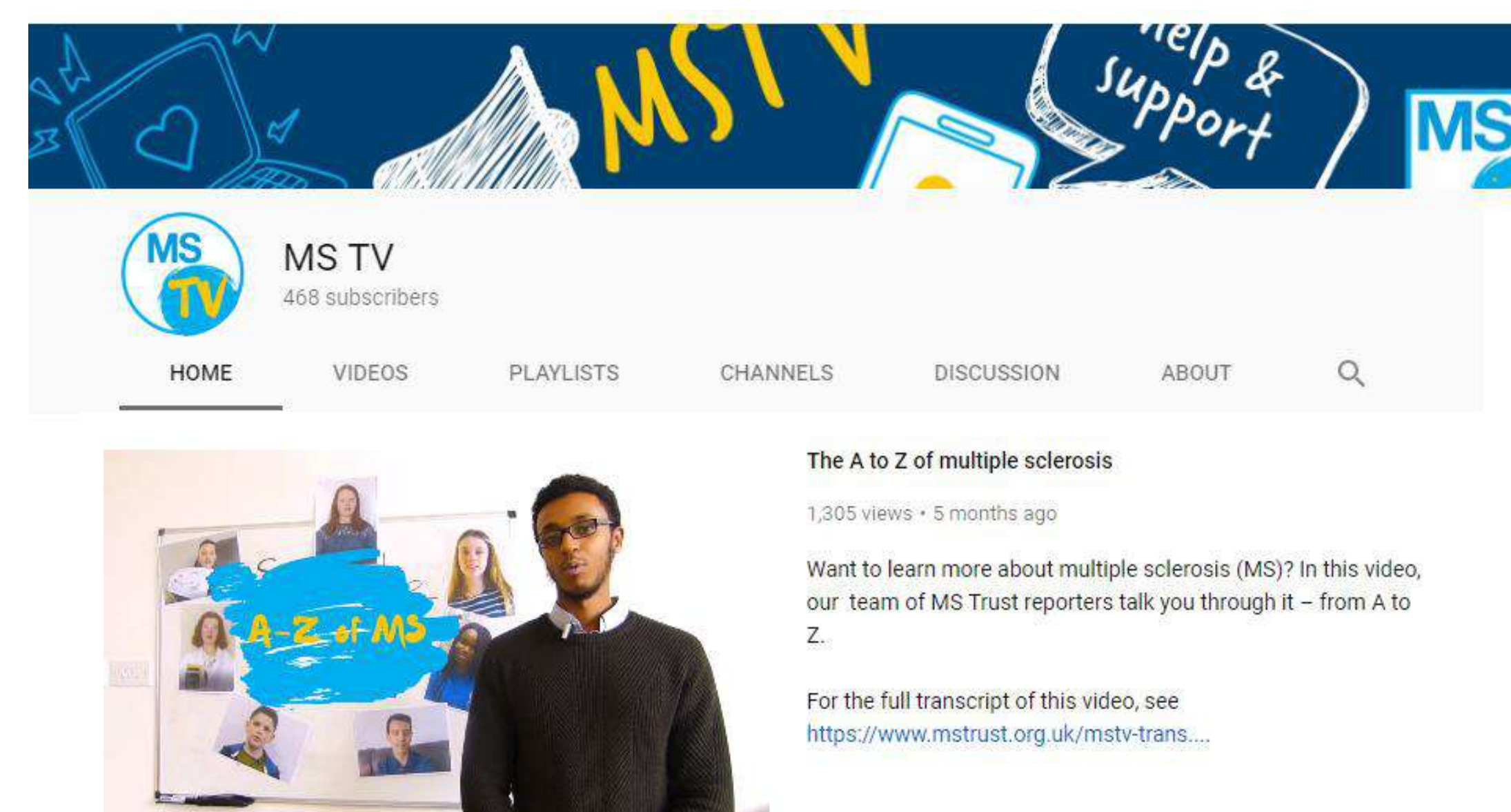
Research we commissioned into the usability of health information websites designed for adolescents revealed that interactive content, videos, images and animations were the website features preferred by young people, along with real stories and testimonials. These findings further supported our decision for the project to be video-led and for young people affected by MS to feature in these videos.

Overall, our research made it clear that when looking for health information, young people prefer digital resources which are easily accessible online through their smartphones and tablets. As YouTube was found to be particularly popular among our target audience, we chose this as the platform on which to publish our videos and we set up the MSTV YouTube channel.

## Discussion

Following this research, we began planning, filming and editing our first set of videos which went live during MS Awareness Week. These included:

- A–Z of MS – A group of young people provide an easy-to-understand introduction to MS.
- Who gets MS? – Chloe, a young person with MS, quizzes her neurologist on the most frequently asked questions about multiple sclerosis.
- How MS makes you feel – People affected by MS talk through the range of emotions they went through after diagnosis.
- Explaining MS symptoms – A group of scouts and two MS researchers explain and demonstrate some of the most common MS symptoms.



## Conclusion

Overall we have met our aims for this project by creating evidence-based videos that allow young people to better understand MS and the symptoms it can cause, and support them in dealing with the emotional impacts and social challenges that MS can bring. By heavily involving our target audience in the development and production of these videos we have created a platform that reassures young people that they are not alone in their experiences of MS. Since the launch of MSTV in April 2018, video views and subscribers to the channel have been steadily growing – our most popular video has over 1,000 views and we currently have over 450 subscribers. We hope to continue publishing more videos on the MSTV YouTube channel, grow our number of subscribers and reach even more young people affected by MS.