The eAcademy for Tay-Sachs & Sandhoff Disease App

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Objectives

Technology has been at the forefront of healthcare and with the increase in dependence on smartphones The CATS Foundation wanted to take advantage of the potential of this media by developing an app that could provide support and information to carers of children affected by Tay-Sachs or Sandhoff.

Method

We won the prestigious Patient Advocacy Leadership Award that is run by Genzyme Corporation to create the app. Interviews with families affected by the diseases on subjects ranging from symptom management to advice on care were recorded for the app to provide the ultimate in peer-to-peer support.

Results

We were given the Patient Advocacy Leadership Award grant in November 2014 which enabled us to set a product launch date of the 28th February 2015. This date was chosen to coincide with the International Rare Disease day where the app was featured in the national press and publisised through social media. With an objective of educating carers and parents the app was given the title of the "eAcademy for Tay-Sachs and Sandhoff Disease".

The app was launched across simultaneous mobile phone and tablet operating systems (Android, IOS and Windows) which meant that the majority of people would be able to access and download it to their devices. Between the launch date of the 28th February 2015 to the 1st December 2015 the app has been downloaded a total of 221 times in twenty-five different countries from all over the world.

The majority of downloads have been from people in European countries (47%) and those in the US (39%). As the app was developed by a UK based charity and is in English, it is no surprise that the majority of downloads are from people in English speaking countries (71%). The success of a mobile app can be measured through a variety of Key Performance Indicators (KPI). An engagement metric KPI called "time spent in app" is important as it measures the amount of time a user spends in an app whenever they use it. We found that 29% of users spend over two minutes watching and reading the content available in the app and this shows that it is a valuable resources to people. Another KPI is the "total number of unique visits" of our users. Since the launch there have been 3,051 unique visits to the app to access its content.

Conclusion

The development and launch of The eAcademy for Tay-Sachs and Sandhoff Disease app has shown that parents and carers place a high value on our peer-to-peer support model. Users of the app have been able to gain advice on various care related subjects that can have a dramatic affect on their ability to provide high quality care to their children. As a rare disease, which is notoriously difficult to diagnose, and which has a prevalence rate of only 1 in 320,000 births it was never expected that the app would have a huge download rate. However, the volume of downloads exceeds the total members of The CATS Foundation with children currently affected by Tay-Sachs and Sandhoff, and also the other two main charities offering support, the National Tay-Sachs and Allied Disease Association (US) and Acción y Cura para Tay-Sachs (Spain) combined. Individuals who have downloaded the app from outside these three main regions (UK, US and Spain) shows that there are users who have accessed and used the app but who do not have a national or organized support body. This has actually led to some families in these countries reaching out to the charity for additional support and information. As the app was in English we have identified that there is a significant need to develop it in different languages. We have received feedback that users would like access to the videos if they could be translated into different languages. Due to this, we have begun the process of having all of the content translated so that we are able to offer the app in Spanish, Portuguese and German. We view the app as ever evolving where the content is regularly updated and new languages being made available in the future. We believe that the app should form a framework for other disease specific organisations. Hearing directly from families about how they manage symptoms and other aspects of care can have a positive impact on users and can lead to them providing a higher level of care for their child.