

# Blink and You Might Miss It – Championing the Cause for Narcoleptics in the UK



For most, sleep is a luxury. A chance to re-charge for the day ahead, to indulge in on a Sunday morning. But for around 30,000 people in the UK living with narcolepsy, sleep brings an overpowering fear, a disabling loss of control and complete absence of routine.

In 2018, Narcolepsy UK (NUK) had a vision: to use market research to develop a Patient Charter. Their aim was to raise awareness of the condition, outline the rights of people with narcolepsy, and generate robust evidence to drive change in attitudes and access to support. In May last year, NUK approached Adelphi to help gather the evidence required. We were very keen to get involved, to champion such a worthwhile cause and help be the voice of vulnerable patients.

## Going the Extra Mile on a Shoestring Budget

When NUK approached Adelphi, it was clear from the outset that as a small charity with limited resources, proactive project management would be key. One of the biggest challenges was to facilitate communication between a group of volunteers spread across the UK, whilst keeping to the timelines. Tact and diplomacy were key!

## Recruiting the Hard to Reach

The bar had been set high. We needed to recruit a large and representative sample of people with narcolepsy and their supporters, to provide valuable data for the Charter whilst bearing in mind the restrictions of a small charity budget.

A multifaceted approach to recruitment was taken, using social media channels to direct participants to our survey, and a snowball approach to allow participants to refer others on. Along with a copy of the final results, participants were offered a small token of appreciation. Their eagerness to be involved and support the project objectives meant less than half accepted the honorarium, allowing us to flex the limited budget for additional recruitment.

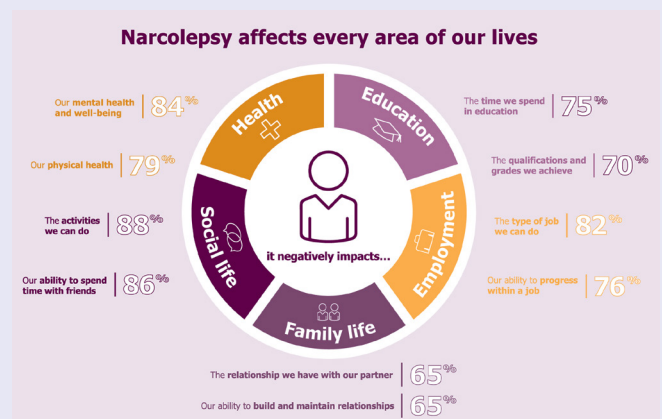
## Adapting the Method

It was important to create a survey that was engaging and easy for people with narcolepsy and their supporters to complete. We applied learnings from behavioural economics and our previous experience with patient research, to frame the questions in a way that combined simplicity with empathy and reassurance. The survey was kept to 15 minutes of multi-select and rating questions, with optional open-end questions to allow participants to add further detail. An overwhelming amount of additional information was shared, more than we expected, adding a rich qualitative element to the findings and highlighting the importance of the research for this community and their enthusiasm to be involved.

After piloting the survey, we soon became aware that many were struggling to complete it in one sitting without falling asleep. By programming the survey in-house, we were able to quickly adapt the settings to ensure participants could complete the questions in several sittings without losing their responses.

## Bringing the Insights to Life

The research explored the impact of narcolepsy on all aspects of daily life. Our findings showed that narcolepsy has a negative impact across multiple aspects. Of the 451 surveyed, a significant number reported impact on their mental health and well-being, the activities they can do, the types of jobs they are able to do, and the time they spend in education. The research also revealed that two-thirds want more support in dealing with the impact of narcolepsy on themselves and their families, whilst just over half want more support in describing the condition to educators and/or employers.



## Presenting at Narcolepsy UK Conference

Alongside the report, the findings were incorporated into an infographic poster which was presented at the 2018 Narcolepsy UK Conference. The team at Adelphi wanted to get involved and volunteered to deliver the findings first-hand at the conference at no extra cost. It was so rewarding to see the research insights brought to life and to really understand the positive impact this evidence is going to have for all those affected by narcolepsy. This is what it's all about!

## Looking to the Future

We are pleased to report the Charter is in its final stages of development, with plans for it to be shared alongside the research infographic at several conferences this year, including the Royal Society of Medicine and the Association for Respiratory Technology and Physiology annual conferences. The Charter will be published in the public domain via the NUK website, and there are further plans to disseminate across schools, workplaces and amongst clinicians.

As budgets are often so limited, it is rare that we have the opportunity to be involved in market research like this, the result of which will change people's lives for the better. We are proud and feel privileged to have been a part of such a worthwhile study and will continue to support NUK in their future endeavours.

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