



COPE^eSUPPORT

LAY SUMMARY

Thank you to those of you involved in the EFFIP project, and to those of you who used the **COPE-support** website. **We greatly appreciate the time you spent** helping us understand how well this website could support families, friends and carers of people who experience psychosis. We have some outcomes to share with you and some ideas for our next steps, but initially we would like to give you a reminder of why, how and what we did.

The Why

As we're sure you're aware, psychoses including schizophrenia are very common mental illnesses that affect at least 1% of the population (in England this would be over half a million people in 2021), and the care given by family and friends is often invaluable. **Looking after this informal and often un-sung 'workforce'** is therefore really important and we wanted to find a way to do that in an informative, supportive and accessible way.

The How

In 2014, there was a different study which looked at helping brothers and/or sisters of those who have psychosis and this showed that a website could be helpful. With this knowledge we wanted to expand and include not just siblings, but other people too who are involved in the care of those who experience psychosis. With this in mind the EFFIP (E-support for Families and Friends fOr Individual with Psychosis) project was designed to create some interactive webpages which we called "COPE-support" as a resource and to measure any difference it made to its users.

The What

In 2016 the development of COPE-support started, with input from a variety of people with expertise in different areas, for example, carers and patients themselves, web development experts, and experts in conducting studies. Plus, we included various sources of information such as previous studies and lived experience testimonies. After much conversation, discussion and work, an interactive website was designed that carers were able to: find out information, ask questions to relevant medical experts and other carers, and be signposted to other information that was beyond the scope of the project.

By 2018, the COPE-support webpage and mobile app had been built and checked, and was being used by the carer participants. To be able to decipher the difference between having access to the COPE-support interactive website and not, we randomly picked half of the 407 users to have just a static website with information only. This gave us two groups to compare and see if there were any differences. Those who received the static website were then able to access interactive COPE-support at a later date.

The Outcomes

Even though we started with 204 carers in one group and 203 in the other, some people were not able to complete the questions that were asked at intervals during usage. We still had an incredible number of people who did complete the study (346, 85% participants, at 20 weeks).

Thanks to the team involved we were able to do some complicated calculations that showed there wasn't any big difference between using either sort of website. The good news is that some of those who did use the website were **interviewed and had a number of positive experiences.**

Carers found **COPE-support to be a convenient, flexible source of knowledge and support** from other carers and relevant experts. Carers gained self-confidence, hope, and a sense of community from connecting with others in the same situation, which helped reduced stigma and feelings of isolation. Best of all, self-care of carers was increased through their use of COPE-support. Carers' usage and experience of COPE-support differed widely depending on carer age and how comfortable they felt using the internet.

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The Next Steps

We are still trying to understand how best to optimise COPE-support, and find out if particular groups of carers found it more helpful than others. We would like to do further COPE-support studies, making it better and reaching more carers. We'll keep you posted!



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