

DEEP Study Lay Summary – January 2017

Pain affecting the face or mouth which lasts longer than three months (persistent orofacial pain, POFP) affects around 7% of the population. Previous research has shown that healthcare professionals find it difficult to manage POFP which can result in delays to diagnosis and treatment which can worsen POFP. Those seeking help are likely to receive referrals between different healthcare practitioners and therefore end up attending multiple appointments. However the care pathways patients have to travel are not fully understood and the DEEP study was designed to help us to better understand these from a patient and NHS perspective. This information will enable us to make suggestions as to how these could be improved to be more efficient and effective.

In order to capture people's experience of health services over time, the study was designed to follow a group of patients over a two year period. Because POFP can be a long-term condition we wanted to recruit people at different time points i.e. those whose pain began recently as well as those who had experienced POFP for a number of years. In order to do this we recruited people from Primary Care (GPs and dentists) and Secondary Care (hospital specialists).

Over 200 people initially expressed an interest in the study and eventually 198 people participated in the study. Participants were sent 6 sets of questionnaires over the 2 year period. We used 'trialled and tested' questionnaires that asked about several different areas including: Quality of life, severity of pain and associated disability, treatments used and visits to healthcare professionals, mood and out-of-pocket expenses. In addition to the questionnaires we conducted in depth interviews with a group of participants to talk about the impact of their pain and their experience of seeking care.

In the interviews participants often described severe pain that impacted many aspects of their lives including their family, social life, work and everyday tasks. People described moving between several healthcare practitioners in attempts to manage their pain but despite multiple appointments reported a failure to make progress towards an effective diagnosis or treatment for their pain. From a healthcare perspective, the majority of costs of managing POFP came from the amount of appointments attended; these costs were much greater than those relating to the treatment of pain. People who indicated on their questionnaires that they were experiencing higher levels of pain intensity and pain related disability were likely to have the highest healthcare costs. Additionally the information we received about out-of-pocket expenses indicated that, in addition to health service costs, POFP has an impact on people's personal finances with costs such as travel, over the counter medication, dental treatment and time away from usual activities. Although those in work were likely to report low rates of sick leave, they understandably described being less productive in terms of the quality and quantity of their work when at work suffering from POFP, which may have financial implications for employers.

This study is the first study to examine healthcare costs of POFB in combination with patient experiences and, as such, has provided us with a clearer picture of the current care pathways for people with POFB and how these might be improved. POFB has profound effects on people's lives and currently large amounts of healthcare resources are used on appointments, which often do not meet people's needs. Redesigned care pathways should focus on helping patients to access appropriate services quicker i.e. the right person, in the right place, at the right time. 'Stratified care pathways', which have been piloted in other pain conditions, may offer an opportunity for those with the highest levels of pain and disability to be referred directly, and quickly, to a specialist in secondary care while those with lower levels of pain and disability could receive care in primary care from a bespoke orofacial pain service. We are now moving forwards to applying for funding to trial such a stratified care pathway.

Finally, we would like to thank all those involved in the study for their help providing data on the impacts and costs of their pain, as without their generosity this study would not have been possible. The outputs from the study thus far have attracted national and local media attention and relevant stakeholders are aware of our results and are very much engaged in helping us find a way to trial a new system of care and improve care pathways.