January 2015 Newsletter

This is our first newsletter of 2015. It has been a busy six months since our previous newsletter and we have now completed recruitment to the DEEP study. We’ve also held a very successful dissemination event for study participants at the Great North Museum in Newcastle at the end of September. We appreciate the effort that people made to get there but understand that it wasn’t possible to find a time that suited everyone so we’d like to use this newsletter as an opportunity to feed back what was discussed.

Dr Justin Durham—Chief Investigator

About the DEEP study

DEEP stands for Developing Effective and Efficient care Pathways in persistent pain. Focussing on pain affecting the face or mouth, we are aiming to gain an understanding of people’s journey through the health service, learning more about their experiences and how these can be improved. People taking part have been recruited from dental and GP practices as well as from hospital clinics. People were eligible to take part if they had experienced pain for more than 3 months which didn’t come from their teeth (for example toothache, gum boil, abscess, gum disease etc).

What was the purpose of the dissemination event?

While we continue to analyse questionnaire and interview data it is vital to us that our interpretation of this data is done in a way which represents people’s experiences so that recommendations we make at the end of our study are meaningful from a patient perspective.

This was also an opportunity for study participants to ask questions and find out what happens to the data from the questionnaires they have completed and returned.

Costs of care

An important aim of this study is to help us to understand how much is spent on face and head pain from a patient and an NHS perspective. There are lots of factors to consider which makes the calculations involved quite complicated. For instance, from an NHS perspective there are the appointments themselves to consider as well as costs associated with medication, physiotherapy or surgery. Clearly this is only part of the picture and there are also personal costs such as travelling to and from healthcare appointments, prescription costs and cost implications for taking time off work (or being less productive at work).

So far we have looked closely at the first set of data that participants have returned on healthcare costs and in our provisional and interim analysis it would appear that one of the largest factors in healthcare costs is the number of appointments that people have with healthcare professionals which appears to be greater than the amount of money spent on pain treatments.

It is particularly important that we now get a detailed understanding of what is happening at these appointments—whether these are a positive experience or whether people feel that they are attending appointments unnecessarily.

As we receive more questionnaire data we will continue to look at costs and how these might change over time.
Experiences of care

Some of you have taken part in interviews we have carried out in addition to the questionnaires we’ve sent. The aim of these was to give us a chance to talk to people, in depth, about the experience of using health services for their pain. We have spoken to 22 people who differ in terms of time since their pain started, diagnosis and services used. We understand that everyone’s experience of pain and healthcare is different, and we are trying to describe the range of experiences reported including what was good and bad about the care people received.

From these interviews. It was apparent that pain influenced many aspects of people’s life including everyday tasks, work, family and psychological well-being. People described very different experiences of the referral process, some people were referred to a specialist straight away from their GP or dentist while others waited a long time. Although some people were happy to be managed in the community, others were frustrated and felt that a lack of progress was being made, particularly when they had not received a diagnosis and when treatment they had tried for their pain had not been successful.

People described several communication issues. Many people were given limited information about their condition, treatment and the healthcare system and others felt that it was difficult to convey the impact of their pain to healthcare professionals. Some people felt that their doctor wasn’t very empathetic towards them.

Other people described a positive experience of using health services for their pain. What made care a positive experience appeared to be where people felt that their pain had been taken seriously by doctors and had progressed quickly towards their pain being well-managed. People described pain as being well-managed when it had limited impact on their life.

Group discussions

At our event we split into groups and talked about what improved care pathways for head and facial pain might look like. People agreed that a way of quickly getting to see ‘the right person’; a doctor who had specialist knowledge of face and head pain, would be an important improvement and limit the time that people are waiting for appointments or left feeling that they are not making progress. Several people talked about the issue of referral and felt it was difficult to get to see the appropriate specialist when their GP or dentist didn’t understand where their pain was coming from.

Some people emphasised the importance of ‘continuity of care’. When people are unable to see the same doctor they thought it was important that the person they saw has a good understanding of their circumstances so that they don’t find themselves having to start from the beginning in terms of describing their pain.

Conferences

There are several large annual conferences which are important opportunities for us to disseminate our findings with leaders in dental research. We have had two sets of results accepted at next year’s International Association for Dental Research which will be held in March. We will be presenting data about costs of care and experiences of accessing health services.

Ongoing data collection

Some people have contacted us to say that their situation has changed and they no longer feel that their questionnaire data is relevant to the study.

We understand that some questions don’t feel as relevant at particular times, for example some people may not be experiencing pain at the time of completing questionnaires. However from our perspective it is important to know about these people so that our data paints an accurate picture of how people’s pain and use of health services may change over time.

If you have any questions or concerns about the questionnaires please get in touch with the DEEP study team (contact details on next page).

We would like to thank everyone in the study for their continued help. Without the data you return to us by post the study would not be a success and we would not be able to help guide decisions on improving care for persistent head, face or mouth pain.

For more information you can visit the study website: http://research.ncl.ac.uk/deepstudy/
Contact: Sally Gerrard, Project Secretary to DEEP, Institute of Health & Society Newcastle University, Baddiley-Clark Building, Richardson Road, Newcastle upon Tyne, NE2 4AX.
Telephone: 0191 208 7976 e-mail: sally.gerrard@ncl.ac.uk
Follow us on twitter: @DEEPStudy