

## **FOR IMMEDIATE RELEASE**

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### **Fibromyalgia Awareness Day 12 May 2017**

To help raise awareness for the long-term condition called fibromyalgia, Healthwatch Leicestershire is releasing key findings from their recent survey of local people who suffer from this debilitating disease.

In January 2016, Healthwatch Leicestershire were made aware in January that local services for people with fibromyalgia were not meeting their needs. They launched a survey the following September to find out why.

Fibromyalgia is a chronic and currently incurable condition that causes pain all over the body. It can often be difficult to diagnose as symptoms vary and fluctuate and can be mistakenly attributed to another condition.

What emerges clearly from the findings of Healthwatch Leicestershire's survey is that fibromyalgia impacts on both a person's day-to-day living and their long-term quality of life.

The survey received a total of 950 responses from people all over the UK with just under 300 people responding from Leicester, Leicestershire and Rutland (LLR).

Fibromyalgia is largely a diagnosis of exclusion; it can take time to carry out tests and receive the results to rule out other conditions.

- **89% of LLR respondents lived with the symptoms of fibromyalgia for 2 to 20 years before a proper diagnosis was made.**
- **47% of LLR respondents were diagnosed with the disease by a Rheumatologist.**
- **Over half of LLR respondents who were diagnosed by the NHS, were not offered any information on fibromyalgia.**

Whilst the findings regarding GP services appeared positive, the reported experiences of secondary services were less favourable. The majority of individuals from LLR reported that non-specialist hospital staff do not have much knowledge or understanding of fibromyalgia. Healthwatch received a

number of qualitative comments from individuals across LLR stating that, doctors and medical staff in hospitals do not see fibromyalgia as a “real thing” and their symptoms are dismissed.

*“Most hospital A&E doctors simply laugh at the suspected fibromyalgia- to them it’s a made- up condition”*

Female, 16-24, Hinckley & Bosworth

*“A lot of health care staff don’t understand and a lot of the times when I explain I have Fibromyalgia it gets brushed off as if it wasn’t a real health issue.”*

Female, 25-34, North West Leicestershire

Healthwatch Leicestershire are due to publish all the findings in their report titled ‘It’s not in my head!’ at the end of May.

They will present the report to local stakeholders responsible for commissioning and providing local services. In the report, Healthwatch recommends five simple and practical steps that can be taken to make life easier for fibromyalgia sufferers and their families.

Healthwatch Leicestershire worked closely with The Shuttlewood Clarke Foundation and Fibromyalgia Friends Together Group throughout this project. Kathleen Wass, The Support Services Manager at Shuttlewood Clarke Foundation commented;

*“We’re pleased Healthwatch are raising awareness of Fibromyalgia and are working to improve the services for people living with the disease.*

*Following a meeting with a representative from the local NHS, facilitated by Healthwatch, we have produced our top 10 tips for living with fibromyalgia, which is to be circulated to 28,000 people including 12,000 health professionals; this will certainly help to raise awareness of Fibromyalgia.”*

To download a copy of the report ‘It’s not in my head!’ visit [www.healthwatchleicestershire.co.uk](http://www.healthwatchleicestershire.co.uk) on 30 May 2017.

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Notes to Editors

#### **About Healthwatch Leicestershire**

Healthwatch Leicestershire is an independent consumer champion for health and social care in Leicestershire. The organisation helps to shape and improve local health and social care in our community. Healthwatch Leicestershire is part of the Healthwatch England a national network, established by the Government to ensure local patients and users have a greater input to shaping and designing local services.