HEALTH AND WELLBEING BOARD: 22 JUNE 2017

REPORT OF HEALTHWATCH LEICESTERSHIRE

'IT'S NOT IN MY HEAD' REPORT

Purpose of report

1. The purpose of this report is to present the findings of Healthwatch Leicestershire's (HWL) **'It's not in my head' report (Appendix 1**). HWL gathered the views, opinions and experiences of individuals with Fibromyalgia from all across the UK.

Policy Framework and Previous Decisions

2. The County Council, following the Health and Social Care Act 2012, is required to directly commission a local Healthwatch. The local Healthwatch in turn has a set of statutory activities to undertake, such as gathering local views and making these known to providers and commissioners, monitoring and scrutinising the quality of provision of local services and a seat on the Health and Wellbeing Board.

3. The 'It's not in my head' report highlights the experiences and insights into the impact of Fibromyalgia on individuals' lives. Fibromyalgia Action UK has referenced research that cites there may be 1.5m / 2.9% of the population in the UK who may suffer from this condition.

Context and Background to the project

4. In January 2016 HWL launched a consultation exercise to understand what areas of health and social care people considered a priority for informing HWL's work plan. The responses were analysed and categorised into themes. Overall, we received 442 completed surveys, via post and online. Twenty-five respondents (6 %) talked about the lack of a Fibromyalgia clinic and the need for a specialist nurse in Leicestershire.

5. HWL decided to focus on a targeted approach around specific vulnerable, marginalised and seldom heard groups and people living with Fibromyalgia was chosen for an intervention as part of our approach to ensure healthcare is accessible for all.

6. In February 2016, HWL met with the Shuttlewood Clarke Foundation, Fibromyalgia Friends Together Group (FFTG), following a response to a question put to University Hosptials of Leicester (UHL). As part of the discussion, members of the group spoke about their wish to have a service where they can receive help and advice over the telephone by a Fibromyalgia specialist.

7. HWL met with the FFTG again in April 2016 and through discussions it was decided that HWL would co-produce a survey with feedback from the FFTG and promote it widely to gather the experience of local patients with Fibromyalgia. The aim was to capture experience and insights to feed into UHL and CCGs on service provision.

Key Findings

8. HWL was overwhelmed with the volume of responses as in total 950 individuals with Fibromyalgia completed the survey. 291 responses were received from LLR respondents, 605 from individuals living elsewhere in the UK and 54 individuals did not provide us with information of where they live.

9. These key findings can be found in the main report and alongside this, HWL want to highlight observations and reflections on a number of experiences and insights into the experience of people with Fibromyalgia.

10. It found that Fibromyalgia impacts on individual's quality of life and limits their chances for education, employment and social life. Individuals are sometimes left unable to perform routine chores and look after personal care needs such as eating, bathing and dressing.

11. The length of time taken for a diagnosis contributes to their isolation and frustrations. Despite waiting a long time for diagnosis, there were contradictory views on individual experiences with their GP. HWL broke the responses down by Clinical Commissioning Group (CCG) areas across Leicester, Leicester, Rutland (LLR) and the UK, and the findings were very similar. Over a quarter of individuals across all areas including the UK reported that their GP was neither knowledgeable nor supportive. However, a higher percentage of individuals reported that their GP was both knowledgeable and supportive.

12. The majority of respondents had not experienced misdiagnosis, however it was concerning that over half of respondents from LLR and the UK were not offered information by the NHS on living with Fibromyalgia.

13. Generally, respondents visited their GP monthly, bi-monthly, or quarterly regarding their Fibromyalgia. It is worth noting however, that nearly a quarter of LLR respondents and almost a fifth of UK respondents stated that they did not see their GP regarding Fibromyalgia because they feel their GP is not supportive or knowledgeable about their condition.

14. The majority of individuals from LLR and the UK reported that non-specialist hospital staff do not have much knowledge of or understand Fibromyalgia.

National Fibromyalgia Day

15. To help raise awareness for the long-term condition HWL released key findings from the survey of local people who suffer from this debilitating disease to mark National Fibromyaglia Day on 12 May 2017. (**See Appendix 2**)

Healthwatch England - 'It starts with you' campaign

16. HWL gave a preview of the findings to the Healthwatch England Committee (24 May 2017) as an example of work with a seldom heard group. The feedback was very positive on the deliberative approach taken, engaging and involving with groups and individuals to improve services.

17. Healthwatch England plans to use the report and approach as a case study as part of their 'It starts with you' national campaign that shows how Healthwatch activities can make a significant contribution to helping improve health and care services.

18. HWL is pleased to able to include in the report the positive outcome from the meeting between the Fibromyalgia Friends Together Group and UHL that has resulted in a jointly badged Top 10 Tips leaflet (refer to Report page 27) for those living with the condition. It will be circulated by UHL to 28,000 people including 12,000 professionals which will help to raise awareness of the condition.

'It's not in my head!' Recommendations

19. The findings from the report will be presented to a range of stakeholders who are responsible for commissioning, providing services and the education of health care professionals. The following simple and practical steps that can be taken to make life easier for Fibromyaglia sufferers and their families have been devised:

    a) Develop a **tool kit** that includes a list of local GPs, both private and NHS, who specialise in Fibromyalgia within LLR, including information about Fibromyalgia, the types of treatment that may be beneficial and alternative therapies that are available.

    b) Provide **support for families and carers** of individuals with Fibromyalgia for example, developing a local support group or a local online forum which would allow patients to participate from the comfort of their home.

    c) More **education and training** to existing GPs and those in training regarding Fibromyalgia symptoms and impact on quality of life for the patient, their families and carers. Part of the training should include increasing awareness of local specialist services that GP's can refer patients to.

    d) To address both health and social care needs, commissioners should explore a **multi-disciplinary approach to diagnosis** and service provision for patients, their families and carers.

    e) More **information** to be made available about Fibromyalgia that includes using online platforms and social media to raise public awareness led by public health, commissioners and providers.

Recommendations to the Health and Wellbeing Board

1. To receive the report, key findings and themes.

2. To comment on the recommendations (a) – (e) outlined above.

3. To note the Top 10 Tips on page 27 the report.

4. To note the national profile of the work.

5. Members of the Board are asked to suggest where else this report can be presented to share the findings to inform commissioning and providers for service improvements and performance monitoring.

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List of Appendices

20. Appendix A – ‘It’s not in my head!’ Patient Experience of Fibromyalgia Report
21. Appendix B – Preview of the findings for National Fibromyalgia Day 2017 – Press Release

Relevant Impact Assessments

Equality and Human Rights Implications

22. Healthwatch Leicestershire is aware that the Public Sector Equality Duty (PSED) applies to all functions of public authorities that are listed in Schedule 19 Equality Act 2010. Schedule 19 list does not include Healthwatch England or Local Healthwatch organisations, however as bodies carrying out a public function using public funding we are subject to the PSED general duty.

23. Healthwatch Leicestershire is committed to reducing the inequalities of health and social care outcomes experienced in some communities. HWL believes also that health and social care should be based on a human rights platform. It will utilise the Equality Act 2010 when carrying out our work and in influencing change in service commissioning and delivery.