

Thank you for taking the time to read this newsletter

Don't hesitate to get in touch with us using the details below if you need any more information



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YORKSHIRE & HUMBERSIDE HAEMATOLOGY NETWORK



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Welcome to the first YHHN newsletter in which we will give you information about some of the research and audit that is being carried out locally. We would like to give you the opportunity to receive further newsletters to keep you up to date about the work that is going on in the area. In this newsletter we'd also like to remind you about who we are and give you the opportunity to have your say by becoming more involved in our research and joining our User Partnership.

Read on to find out more.



WHO ARE WE?

In 2004, the doctors and nurses responsible for the care of people diagnosed with blood disorders throughout Yorkshire and Humberside started working with researchers at the University of York. Together, they set up the Haematological Malignancy Research Network (HMRN), which is a specialist registry for blood disorders that was established to try and find out more about these diseases. The HMRN has now been running for 5 years and we have recently started to examine the findings from this work, some of which are shown over the page.



WHAT WE DO

All patients with haematological disorders should be treated according to local and national guidelines and regular audits are carried out to check this. Since 2004 this information has been collected by HMRN in Yorkshire and Humberside. This information is also being used to find out more about blood disorders including why some people develop these disorders and why people respond differently to treatment. With help from patients who completed our HMRN questionnaire we have also been able to learn more about the symptoms of these disorders and pathways leading up to hospital appointments. All this information is fed back to the doctors and nurses delivering care so it can be used to guide clinical practice. YHHN is the only network in the UK, and in fact the world, that collects data in this way.

RECENT FINDINGS

In 2009 we examined the HMRN data we had collected on 8131 patients diagnosed with a blood disorder between 2004 and 2008. All blood disorders in YHHN area are diagnosed by the Haematological Malignancy Diagnostic Service (HMDS), which is based at St James's Hospital in Leeds, and registered on HMRN. Currently our youngest patient is 4 weeks old and our eldest 99 years – the average age of patients is 70 years. HMDS uses a very detailed system that can classify a much larger number of blood disorders than has been previously possible. This has meant that we could look at these diseases in a lot more detail than ever before. Our research has produced some interesting findings, for example the fact that men appear slightly more likely than women to be diagnosed with most blood disorders. Our research paper was published in the British Journal of Haematology and the full version with all our findings can be seen via the HMRN website: www.hmrn.org

USER INVOLVEMENT

A User Partnership is a group of people who come together to help develop and improve hospital care and services. The partnership may include patients, their relatives and friends, health professionals and researchers. As a patient, your experiences are unique and, whether good or bad, sharing these experiences could lead to real changes that would benefit future patients and those close to them. We would like to invite you to be involved in the YHHN partnership. If you are interested we would be grateful if you would complete the attached questionnaire and return it to us in the pre-paid envelope.