

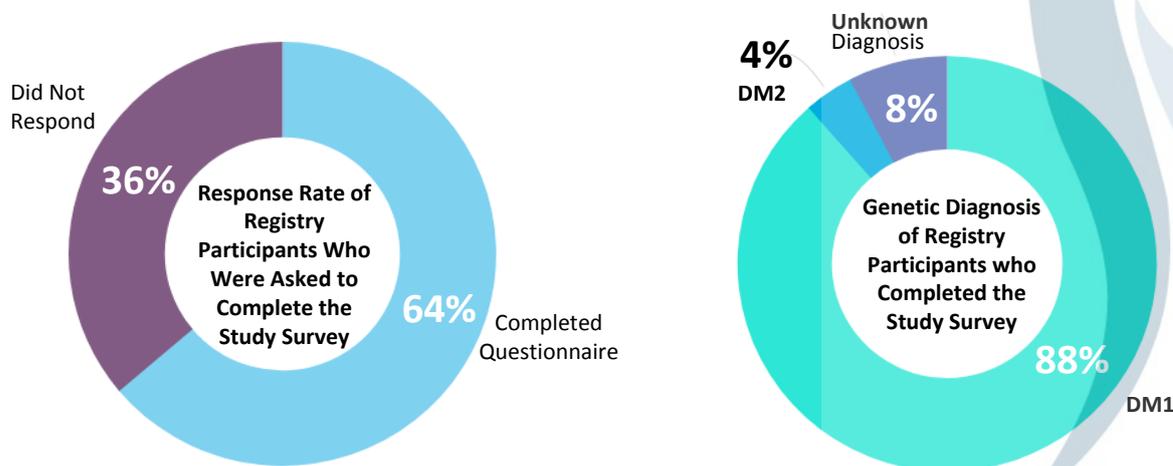
# Benign and Malignant Tumors in the UK Myotonic Dystrophy Patient Registry.

July 2017

A research paper on the prevalence of benign and malignant tumors in people diagnosed with Myotonic Dystrophy was recently published in the *Journal of Muscle & Nerve* (2017). In the paper analysis is carried out on the results of a survey that was distributed via the UK Myotonic Dystrophy Patient Registry. The purpose of the study was to assess the prevalence of benign and malignant tumors and to collect lifestyle information from people diagnosed with Myotonic Dystrophy Type 1 (DM1) and Type 2 (DM2). Publications like this raise awareness of the patient registry among scientists and researchers whilst providing new information about Myotonic Dystrophy to the wider community.

According to research carried out by Cancer Research UK, there are more than 2 million people living with cancer in the UK. More than 331,000 people are diagnosed with cancer each year in the UK, that is around 910 people every day. Most cancers start due to gene changes that happen over a person's lifetime, however some cancers start due to inherited faulty genes passed down in families.<sup>1</sup> Better understanding of tumor burden and factors that impact the production/formation of tumours in Myotonic Dystrophy patients will inform clinical care and provide insight into the causes of tumor development in the population.

The published paper is called "Benign and Malignant Tumors in the UK Myotonic Dystrophy Patient Registry" and was written by Dr Rotana Alsaggaf and Dr Shahinaz M Gadalla from the National Cancer Institute (USA), with help from the following researchers based in the UK and USA. In total 220 UK Myotonic Dystrophy Patient Registry participants were included in the analysis, a summary of which can be viewed below:



## GLOSSARY

Benign = non cancerous, no risk of spreading.

Malignant = cancerous and risk of spreading.

Prevalance = The total number of cases in a given population at a specific time.



39 benign tumors reported in 30 patients

92.3% of benign tumors occurred in DM1 patients, 7.7% in DM 2 patients



16 malignant tumors reported in 15 patients

100% of malignant tumors occurred in DM1 patients

12.4% of the DM1/DM2 patients reported at least one benign tumor and 6.2% reported at least one malignant tumor.

Increasing age and earlier age at DM diagnosis were associated with benign and malignant tumors.

Skin cancers were the most commonly reported malignant tumors, followed by breast cancer.

No associations (unique to DM population) were observed between tumors and smoking, alcohol consumption or BMI.

In light of the current knowledge, it is important to incorporate population-based cancer screening guidelines into Myotonic Dystrophy patients' clinical care, and to carefully evaluate new symptoms that may be indicative of cancer. Further research is needed to elucidate factors associated with tumor development in Myotonic Dystrophy.

1. [www.cancerresearchuk.org/about-cancer/what-is-cancer](http://www.cancerresearchuk.org/about-cancer/what-is-cancer)

To request a pdf copy of "Benign and Malignant Tumors in the UK Myotonic Dystrophy Patient Registry" article, or if you have any questions about the UK Myotonic Dystrophy Patient Registry please get in touch - [phillip.cammish@ncl.ac.uk](mailto:phillip.cammish@ncl.ac.uk)

If you have any concerns related to your health, speak to your GP