



Noirín O'Neill (unaffiliated)

“At 30 years of age I was diagnosed with Acute Promyelocytic Leukaemia - an aggressive and rapidly fatal haemorrhaging disease if not correctly diagnosed and treated immediately. It is a rare disease which affects one in a million people in Europe.

“My treatment was successful and as a result of my own positive personal experience I am now a high profile and influential cancer survivor, ePatient, expert patient and patient advocate at local, national and European level. I believe that there should be greater collaboration between patients, academia and industry to ensure patient safety and improved outcomes. There is a necessity for greater communication and transparency particularly with regards to publication of the results of a clinical trial. Patients need to be recognised and valued as experts. Expert patients can influence, educate and inspire others to change the status quo. Patient empowerment is a collaborative journey. Expert patients provide a unique perspective about living with a particular illness.

Expertise / Areas of interest

- EUPATI Fellow
- Postgraduate Diploma in Applied European Law, Law Society of Ireland.
- LL.B. Law Degree, Trinity College Dublin.
- Admitted onto the Roll of Solicitors, Law Society of Ireland (2001) and N.Ireland (2006)
- Member of the Law Society of Ireland.
- My article “The Expert Patient” was published in the BMJ - Evidence Based Nursing. April 2016 | volume 19 | number 2 | 41: <http://ebn.bmj.com/content/19/2/41.full.pdf+html>
- I am also a BMJ Blogger. <http://blogs.bmj.com/ce/2015/09/15/one-of-the-most-fascinating-stories-in-the-history-of-medicine/>
- Northern Ireland Rare Disease Partnership, Annual Conferences, 2015 & 2016.
- NHS Confederation Annual Conference, 2015.
- Northern Ireland’s first Healthcare Social Media Conference, 2014.
- eHealth Conference, Northern Ireland, 2014.
- View from the Top Series (Healthcare Leaders) Northern Ireland, 2014.
- Follow me on Twitter: @NoirinO'Neill
- Website: www.xpertpatient.com

Patient involvement experience

- Participant (passive) in AML Clinical Trial 15. This trial was to see if longer but less intensive was to see if longer but less intensive chemotherapy worked as well as standard chemotherapy for the rare disease - Acute Promyelocytic Leukaemia and to see if adding a drug improved either treatment plan. This has led to an increased desire to be more active in research.
- Member of the ASTERIX FP7 Patient Think Tank – ten patients across Europe were invited to take part in the Think Tank. ASTERIX is a novel EU funded research project focusing on the development of more efficient and effective research designs to study new drugs and treatments for rare diseases.