

Cancer Outcomes Conference – NCIN 2015 – 8th June – 11.10 to 11.20

“What do patients want from their data”

Good morning! May I start by saying congratulations to NI Cancer Registry on celebrating 21 years of data collection and analysis – to all the team under the leadership of Dr Anna Gavin – thank you from the people of NI.

Why are you here at this NCIN Conference in Belfast in June 2015. Here in this audience we have researchers, clinicians, commissioners, allied health professionals, patients, carers, academics, statisticians, 3rd sector organisations, press, PRin a minute I am going to ask you to stand or if that is difficult for you then raise your hand because I want to ask you a question.

Please stand or raise your hand – have you or a family member or a close friend accessed health services in any way over the past 2 years? (any still standing – do you have HSC/NHS number?). If you have please sit down.

I am not sure what hat you were wearing when you came through the door this morning but how you have answered this question shows that data is important to you not only on a professional level but on a personal level.

Data/deita – small word – massive importance. Oxford Dictionary definition: mass noun – facts and figures gathered together for reference or analysis. In latin the plural of datum. This morning I am sharing on a personal level – I am a statistic but behind that HSC number I am Margaret Grayson, a person.

I want to acknowledge your part in audit, in expert analysis – monitoring patterns of patient care – that drives improvement in that care, asks the right research questions, impacts outcomes. What has asking the right questions meant to me – surgery technique in relation to my mastectomy – combination of drugs in chemotherapy – dose and technique in radiotherapy – aromatase inhibitors I am still taking 11 years on (love to have more hair) – the long term impact of living with cancer such as lymphoedema.

I believe as a patient that I have a responsibility to the rest of society in permitting the use of my data but I also have the right to ask you, rather demand, that my data is used – remove the barriers - use for purposes of audit, comparison, research. I said before that HSC/NHS number is Margaret

Grayson. I want that data to be used in ethical research, oh I want you to be careful of Margaret but I don't want Margaret to be locked in a box, padlocked, probably tripled padlocked, access to Margaret is becoming more and more difficult. I know legislators will say they are "protecting Margaret" but can I ask are you protecting Margaret or yourself. Oh I don't want you to sell Margaret to an insurance company.

I have asked the views of my fellow members of NI Cancer Research Consumer Forum – here are snippets – use it, benefit others, look for initial permission for secondary use with safeguards in place, anonymise, pseudoanonymise, others anonymity not an issue, I have benefitted from the generosity of others, churlish in the extreme to deny others, use my late husband's data to help others. All passionate about wanting their data to be used but all said safeguards around the "selling" issue.

NICR able to publish clinical outcomes but let me share my personal statistics, 7 diagnosed with breast cancer in 2004, became friends with a common bond – cancer – by the 5 year stage I had been to the funerals of the other six. I want to see those outcomes changing for a group of 7 people diagnosed in 2015.

The Conference theme is "United against Cancer, locally, nationally and internationally " building on the 2014 conference on "the power of information". Central to all that is presented over the next three days is data and how it is used – to benefit and impact on prevention, diagnosis, treatment, services, care and those living with cancer. Patients are an essential part in working in partnership with you! Perhaps in your area in your professional life you don't often have the opportunity to speak to people behind those numbers but over the next 3 days you have that opportunity, there are over 70 patients and carers here, people whose lives have been impacted by cancer. People who are as passionate as you are, we are here to work with and support the work of National Cancer Intelligence Network, to further research not to hinder. I am passionate, I talked about my six friends but also I don't want others to sit in a hospital room with my 32 year old niece, Elaine and her husband as she cuddled and said goodbye to her baby son, on the day she died with non hodgkins lymphoma.

So take this opportunity, even as you are standing in the queue for lunch or coffee, or come to meet us at Dragons Den listen to the patient voice! Have a great conference! Thank you!