**Feedback on The National Cancer Intelligence Network, Cancer Outcomes Conference 2015: United against cancer. Belfast 8th-10th June**

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To attend a conference that is not just about Lung Cancer is strange yet inspiring too. It makes you think outside the proverbial lung cancer box.

The first plenary session explored how data has had an impact on both patient outcomes but also services and voluntary sectors such as CRUK. Ms Margaret Grayson, a cancer survivor herself and chair of the Northern Ireland Cancer Research Forum, explained how patients wanted cancer data to improve survivorship, rinse treatments but above all prevent cancer. This was echoed by Sara Hiom - Director of Early Diagnosis and Cancer Intelligence and Cancer Research UK. She also advised that 1 in 2 of us will experience cancer in our lifetime. CRUK has shown us that cancer survival has doubled since 1970 and more patients beat cancer than ever before.

Data also supports monitoring and evaluation of screening as discussed by Prof. Robert Steele, Head of Cancer Research University of Dundee. He showed how the collection of data in colorectal screening has proven that Faecal Occult Blood Testing (FBOT) has proven a 10% reduction in mortality however this type of screening does have drawbacks. It is more sensitive in men and women as faecal haemoglobin is lower in women than men. This understanding wouldn't have come about without the evaluation of data.

Mick Peake led the audience down memory lane and gave us a history lesson on the inception of the National Lung Cancer Audit (previously known as LUCADA). Originally done as a 'snap shot' audit by the Royal College of Physicians in 1996 this has progressed over the years (as we know as we have all submitted our own data) and is now included in many reports by Cancer Networks and Trusts to being included in Peer review. The audit has become part of our culture, the 'lingua franca' of the lung cancer world.

The data has shown how lung cancer treatments have improved significantly over the years. For example survey for NSCLC is now upto 23% in some Trusts (although 14 English Trusts still have a resection rate of >10%). The data has also shown how UK 1year lung cancer survival has increased although long term survival is still low compared to our European counterparts.

The second plenary session focused on the role of Primary Care in cancer. Professor Greg Rubin introduced this session by explaining the 4 key areas included prevention, awareness, screening and early diagnosis. Prevention considered not only smoking as a prime example but also diet, managing obesity and alcohol consumption. Awareness campaigns across the UK included the cough and blood in pee campaigns. Screening has been routine in Breast and colorectal cancer for many years although nothing was said about screening for lung cancer. Early diagnosis included the development of Risk Assessment Tools used by Primary Care clinicians and also how GPs are looking at having an improved access to diagnostic imaging.

Dr Peter Murchie discussed to what extent did provider delays affect the outcome on cancer care. This included both primary and secondary care delays. It was acknowledged that an initial delay can come from the patients themselves. Lack of awareness of the signs and symptoms of cancer, not wanting to 'bother' their GP, embarrassment, previous negative experiences are just some of the cognitive, emotional and behavioural 'help-seeking' delays. Primary caregiver delays include lack of awareness of the less common signs and symptoms of cancer, not referring to appropriate specialist teams or more commonly not referring promptly. Statistics show at secondary care delays usually occur at the 62 day point. Diagnosing cancers appears to be quick although prior to the election Ed Milliband stated he wanted 'all cancer tests to be done in 1 week' - an unrealistic goal. The delay in getting treatment has come about because of the increase in types of treatments and treatment regimes. 13 years ago when I started as a Lung CNS we had the ICE chemo regime for SCLC and the MIC regime for NSCLC.

To prevent delays, particularly in primary care, this question was posed 'how can primary care data help set refer all thresholds '? Willie Hamilton, founder of the Risk Assessment Tool (RAT) used in GP surgeries discussed lowering the threshold of symptoms and used lung cancer as an example. Currently there are two thresholds that GPs use,

\* patient has CXR findings that suggests lung cancer

\* patient is over age of 40 with unexplained haemoptysis (new for 2015)

Willie went onto explain that not all lung cancer patients have haemoptysis and not all patients who have haemoptysis have lung cancer yet every single guidance contains it. The same goes for a cough. Thresholds are a guidance only and sometimes a clinician's experience, knowledge and sixth sense is far more important.

Plenary session three covered the International issues in cancer. It was encouraging to see smoking was top of this agenda. Sir Richard Peto gave quite remarkable statistics regarding smoking. If 10 cigarettes a day are smoked upto the age of 40 then you are ten times more likely to develop lung cancer, similarly if 30 cigarettes a day are smoked this figure rose to twenty times more likely. However giving up smoking before the age of 40 avoids >90% later risk (BMJ 2004, Lancet 2013). Since 1990 the number of smokers has significantly dropped which naturally has reduced the mortality trends. In particular this is noticed in Breast Cancer in females and significantly in lung cancer in males. Despite decreases in recent decades tobacco still causes 0.3 million of the 1.3 million EU deaths from any cause before the age of 70.

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Plenary session 4 - Childhood, Teenage and Young Adult Cancers (CTYAC) the bulk of these presentation were around the future care of these cancer patients. CTYAC patients are more likely to develop a second primary malignancy in later life than someone who hasn't experienced cancer in their earlier years. Other chronic illnesses relating to treatments have been found following a study done by Professor Mike Hawkins. For example radiotherapy changes to the lungs following treatment for Lymphoma. Prof Hawkins followed up 250,000 individuals treated for cancer when they were young. Data from this group identified other problems that these patients may have in letter life such as young children who undergo brain radiotherapy are less likely to fulfil high academia qualifications.

SIGN guidance on the follow up of these patients advises that the survivors have access to an appropriate designated key worker to coordinate future care. SIGN also recognises that a training programme and a structured career pathway should be developed for nurse practitioners specialising in long term follow up.

The last session was a question and answer session. Delegates had the opportunity to put forward their questions to the panel the day before. The debate was titled 'the future challenges for cancer services'. Naturally the panel had the opportunity to see the questions before hand and choose ones they wanted to discuss further. I decided this was an ideal opportunity and diligently wrote down the following statement and question:

'Throughout the patient pathway the Clinical Nurse Specialist is a vital member of the Multidisciplinary team. They offer support and give care management from pre-diagnosis, treatment phases, trials, survivorship and end of life. The National Lung Cancer Audit has documented evidence that those patients who do not have a Lung CNS are less likely to receive active anti-cancer treatment. However the numbers of CNSs to patient ratio are not consistent throughout the tumour groups. Vacant posts are not filled and many CNSs are being asked to work on wards.

Question: what do you think the NCIN can do to reinforce these important roles and prevent future cancer patient care from being threatened ?'

My question was accepted for discussion so I duly read out my statement and question - out of the corner of my eye could see Mick Peake nodding away!!

Three of the panel were courteous enough to agree that specialist nurses are a fundamental part of any patient care. Margaret Grayson, herself a cancer survivor, really went to town on the support she received however didn't answer the question. David Dunlop stated that the only way to prove with hard data (obviously) was to measure patient experience using both quantitive and qualitative approaches and identifying patients who had experience and those who did not. He stated that services needed to be tailored to individual patient care using a Holistic Approach. Mmmmm thought we were doing that already David. The head of Macmillan Services for Northern Ireland (a last minute stand in so I didn't catch her name) agreed that inconsistencies did occur across tumour sites, something Macmillan had identified and were working on. Her other concern was for succession planning. She stated that the vast majority of CNSs would be retiring within the next 5 years and there wasn't evidence to suggest that training younger staff to take over was happening. Maybe this is something we need to look at - supporting nurses through education who are interested in becoming a Lung CNS.

In summary the NCIN has driven the immense development of knowledge and brought together information intelligence. The conference highlighted that data drives change and improvement in services although there is an ongoing challenge around capacity with ever increasing numbers of patients, more advanced treatments, patients living longer, greater demand on services but with the same or not great increases in resources. The conference also valued the importance of the patient voice, listening to those who have experienced care good and bad to make sure that's services are the best possible for those living with cancer.

A worthwhile experience? To be honest only partly - the programme was very statistically orientated. Would I change my practice based on what I had learnt ? - No. Looking through the delegate list I was the only nurse listed and I only knew two other delegates!!!

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