Scottish Parliament Cross Party Group on Cancer

Tuesday 17thth March 2015 17.30-19.00

Minutes

Attendees and apologies noted in appendices. **Bold underlined text indicates actions/ agreements**

1) Welcome

Nanette Milne MSP ("the Chair") opened the meeting, welcoming all attendees and speakers.

2) **The minutes from the last meeting were approved.**

3) Childhood Cancer

Laura Courtney & Ellen Finlayson, CLIC Sargent

Laura Courtney (LC) began by noting that there are 112 cases of cancer in children aged 0-15 in Scotland each year, and that cancer is the biggest cause of death in children. The cancers that affect children and young people are different from those that affect adults, and they often need different kinds of treatment. She noted that as children and young people are a small proportion of those diagnosed with cancer, their specific needs and experiences can sometimes be overlooked by policy makers.

With this in mind, she continued by laying out CLIC Sargent's policy priorities for children and young people with cancer in Scotland.

- **Improved diagnosis**. In general, a GP will only diagnose around one or two cases of childhood cancer in their entire career. It is thus important that they receive training and support to help them spot the signs and make a correct diagnosis.
- **Optimum routes to diagnosis**. Children and young people are disproportionately diagnosed through emergency routes. She noted that this is not always because of GPs not recognising symptoms, many childhood cancers don't become symptomatic until later stages
- **Understanding patient experience**. She noted the difficulty of measuring children's and young people's experiences, but that it is just as important as for adults.
- **Safe care close to home**. She stressed the importance of maintaining family life as far as possible. Children's cancer treatment is primarily delivered in three principal treatment centres in Edinburgh, Glasgow and Aberdeen, which leaves many children having to travel long distances for treatment, far from their friends and families. The Scottish Government's Managed Services Network for children and young people with cancer has committed to the principle of local treatment where possible and where preferable.
- **Good quality data to show progress over 3 years**.

- **Information and support to build resilience.** It has been shown that access to good information and support increases self-confidence and helps patients to manage their illness and its challenges better.
- **Long term follow up.** Once the new cancer plan for children and young people is unveiled we will need to make sure it is being implemented.

Ellen Finlayson (EF) then went on to outline how these policies are put into practice by CLIC Sargent. They fund specialist nurses, social workers and play-specialists to work with children and young people with cancer. The Prinicipal Treatment Centres in Edinburgh and Glasgow provide a home from home on the hospital grounds, allowing families to live close to where their children are receiving treatment. She noted that this allows children and their families to stay together, and helps relieve financial pressure on families. CLIC Sargent also provides holidays for families at Malcolm Sargent House in Ayrshire, allowing them to spend time with other families with similar experiences.

EF went on to outline the clinical support provided by Paediatric Oncology Outreach Nurses (POONS), who are helping to create better links with GPs and community nurses, for instance creating an online education package to help GPs and nurses learn more about children's cancer. She stressed the importance of collaborative working, and gave an example of one young cancer patient who had benefitted as a result of collaborative working between nurses, social workers and other services.

4) Question and answer session led by CLIC Sargeant.

A number of points were raised, including about the length of treatment, which sometimes lasts many years into adulthood. One member asked whether childhood cancer is more difficult to diagnose than adult cancer, it was noted that this varies depending on the type of cancer.

5) Teenage and Young Adult Cancers
Dawn Crosby & Iona MacMillan, Teenage Cancer Trust (TCT)

Dawn Crosby (DC), began by commenting that the Teenage Cancer Trust support young people aged 13-24. She noted that seven young people are diagnosed with cancer every day, but also the positive news that 80% of young people now survive cancer.

Like CLIC Sargent, DC noted that young people with cancer can be overlooked because they are a relatively small group of patients. They also have an added difficulty as young people are often caught between services designed for children and those designed for adults. There is not always adequate recognition of the unique aspects of teenage cancer, and the specific needs of young people themselves. She noted that when surveyed by TCT young people with cancer wanted to be seen and recognised as young people first, not only as cancer patients. They wanted support to maintain as normal a life as possible, and also support for their families.

DC went on to discuss how TCT is working with the NHS to build age appropriate units, of which there are now four in Scotland. She also noted that work is being done to improve outreach support for those who, for whatever reason, cannot attend principal treatment centres.TCT have fifty specialist nurses and support workers, and also run events where young people with cancer can meet up with others in their situation.

DC finished by noting that the third sector cannot do everything, and that the NHS needs to do more to ensure equality and consistency of services for young people. She would like to see more done to include young people in the Scottish cancer patient experience survey. Finally, she would like greater GP awareness of age appropriate care.

DC then passed to Iona Macmillan (IM) to talk about TCT education programme. Working with the University of Stirling, TCT surveyed knowledge of cancer among young people, finding that their knowledge was generally poor. Since 2013 TCT have had the support of the Scottish Government's Detect Cancer Early Programme which has enabled them to conduct a larger survey of cancer awareness, attitudes and behaviours. This found that there are barriers of worry and fear preventing young people from seeing a doctor.

TCT's education programme is designed to equip young people with knowledge about cancer and to encourage early diagnosis of symptoms. It is visiting secondary schools across Scotland, speaking to second year pupils.

She noted that the most common young adult cancer is melanoma. However, TCT has found that 61% didn't know that getting sunburnt as a child was a risk factor for cancer. 51% reported that they had been sunburnt the previous summer, with 38% having been burnt more than once. Having a tan was seen as very desirable. Worryingly, more than half of young people did not know that a change in the appearance of a mole was a cancer symptom. Following on from these findings, IM discussed that TCT has now set up a sun safety working group with the University of Stirling and is working on creating sun safety resources to encourage behaviour change.

She finished by outlining what TCT would like to see from schools:

- Education of young people through statutory health education
- Promotion of awareness of key signs and symptoms

6) Question and answer session led by TCT

One member questioned why young people were not going to the principal treatment centres. TCT replied that although they would prefer young people to attend, patients over the age of 18 are able to make an informed choice about how they wish to be treated. As TCT supports people up to the age of 24, some of whom may have families of their own that they don't want to leave, there are significant numbers of older young people who don't want to travel to the centres in Edinburgh, Glasgow or Aberdeen.

The group also discussed the potential of expanding the education programme beyond schools. IM remarked that she would like to do so, but that there is always the difficulty of resources, and that it is never possible to do as much as they would like. However, she said that they were hoping to work with new partners to expand the programme.

Another issue touched upon by the group was the need for better training for GPs to better recognise symptoms. It was noted that in updated referral guidelines, childhood and young adult cancers formed a much larger part and that primary care was trying to do more. It was also noted that presentation patterns are important for GPs to take into account. For instance, if a young person is going to their GP several times with the same symptom that could be grounds for referral. It was also noted that the Royal College of GPs has called for the extension of initial training, as most GPs currently do not get much paediatric training.

7) Macmillan Cancer Support's Move More Programme

Janice Preston & Margaret Greer, Macmillan Cancer Support

Janice Preston (JP) began by laying out Macmillan's long term vision: to reach and improve the lives of everyone living with cancer, and to inspire others to do the same through community engagement and volunteering. She noted that Macmillan's workload is increasing as the number of people living with cancer is set to double by 2030. It was noted that more than half of people living with cancer experience difficulty with everyday tasks such as cooking and shopping.

She went on to describe the benefits of physical exercise. This, she noted, goes against the normal advice for people with cancer, who have traditionally been encouraged to rest. However, being active can also reduce some of the long-term after effects of cancer such as osteoporosis and depression and has been shown to decrease the chance of cancer recurring. She referred to exercise as a 'wonder-drug'.

Macmillan are aiming to lead behaviour changes, with the hope that people living with and recovering from cancer will eventually feel confident enough to exercise in a normal setting. The best time to begin is at diagnosis, before treatment and fatigue kick in. She noted that organised physical activity provides social interaction and helps to build confidence, which combats the isolation which many people with cancer feel, and leads to better physical and mental health.

She went on to discuss the barriers to physical activity. She noted that these can be enormous, and primarily consist of fear and confidence issues. There is rarely anyone to encourage physical activity as doctors tend not to, while family members may discourage exercise, advising loved ones to slow down and relax. Fitness providers also have limited knowledge of the benefits of activity for cancer patients. One of the greatest difficulties is that many people were inactive before their diagnosis, and after diagnosis it becomes even harder to encourage behaviour change. She noted the need to build pathways between leisure providers and GPs.

Margaret Greer (MG) went on to discuss where 'Move More' came from. Macmillan had identified the need for more support to help people living with cancer to exercise. The programme works with leisure providers, councils and health services. Macmillan recognise that different levels of classes are necessary, with some people able to attend normal exercise classes while others will need the support of a specialist class for people with cancer. She concluded by noting economic challenges which mean the programme is dependent on the goodwill of volunteers.

8) Question and answer session led by Macmillan

It was noted that the ideal scenario is for individuals to be already active before a cancer diagnosis, and to maintain activity after diagnosis. Other members questioned whether Macmillan has any power to encourage the NHS to build in a programme of rehab after treatment. It was noted as surprising that there is currently no such programme, while for other conditions these services are provided. It was noted that although this is important it tends to fall by the wayside as doctors, nurses and the NHS in general is becoming busier and busier. Macmillan noted that they are trying to build up the evidence of the benefits of physical activity to encourage this.

It was also noted that patients themselves need to feel confident to get involved in exercise, as cancer can be isolating, and patients may be afraid that physical activity will make their condition worse. Programmes like 'Move More' are valuable in helping to build confidence.

9) **Any other business**.

A notice of a Fun Day by Brain Tumour Action and the Brain Tumour Charity at Blair Drummond Safari Park, 6th June 2015. Please contact 0131 466 3116 or administrator@braintumouraction.org.uk for more information.

10) **The Chair closed the meeting with the next meeting confirmed as Wednesday 17th June 17.30-19.00.**

Attendees

Philip	Atkinson	Health Policy Scotland
Lynne	Barty	Brain Tumour Action
Karen	Bell	SCRN
Roger	Black	NHS
Ian	Campbell	NHS
Malcolm	Chisholm	MSP
Ellen	Clark	Boehringer Ingelheim
Laura	Courtney	CLIC Sargeant
Dawn	Crosby	Teenage Cancer Trust
Jeannie	Erskine	Patient
Ellen	Finlayson	CLIC Sargeant
Heather	Goodare	
Margaret	Greer	Macmillan
Roseann	Haig	Circle of Comfort
Peter	Hastie	Macmillan
Trisha	Hatt	Macmillan
Peter	Hutchison	Scottish Primary Care Cancer Group
Lesley	Kidd	SCAN
Kate	MacDonald	NHS Lothian (SCAN)
Gregor	McNie	Cancer Research UK
Nanette	Milne	MSP
Angus	Ogilvy	SCAN
Rachel	Pont	Cancer Research UK
Janice	Preston	Macmillan
Neil	Pryde	NHS Fife
Heather	Rankine	Boehringer Ingelheim
Katie	Robertson	NHS Forth Valley
Colin	Selby	SCAN
Kate	Seymour	Macmillan
Ewan	Shannon	Patient Family
Lesley	Shannon	Patient Family
Leigh	Smith	MASSCOT
Suzanne	Spencer	Cancer Research UK
Ian	Somerville	
Helen	Stevens	Scottish Government
Niall	Taylor	Scottish Government
Jeff	White	NHS Greater Glasgow & Clyde
Judith	Zich	Edinburgh Cancer Research Centre

Apologies

Emma	Anderson	Bowel Cancer UK
Elspeth	Atkinson	Macmillan
Prof David	Cameron	Edinburgh Cancer Research Centre
Susanne	Cameron-Nielsen	Royal Pharmaceutical Society
Alison	Campbell	NHS
Chrisitne	Campbell	Centre for Population Health Sciences
Lindsay	Campbell	NHS Glasgow
Emilia	Crighton	NHS
Jackie	Baillie	MSP
Valerie	Doherty	SCAN
Sheena	Dryden	NHS Lothian
Mary	Dunlop	Cancer Research UK
Adam	Gaines	Prostate Scotland
Alex	Holme	NHS Lothian
James	Jopling	Breakthrough Breast Cancer
Alison	McInnes	MSP
Kaz	Molloy	Womb Cancer Support UK
David	Park	Pancreatic Cancer UK
Peter	Philips	SCAN
Katie	Robb	University of Glasgow
Alan	Rodger	NHS
Kim	Rowan	Patient
Jacqueline	Shaw	NHS Lothian
Mhairi	Simpson	NHS Lanarkshire
Morag	Stocks	Cancer Research UK
Diane	Thompson	Pfizer
Samantha	Walton	Pancreatic Cancer UK
Nicolas	White	Breast Cancer Care