Scottish Parliament Cross Party Group on Cancer

Wednesday 9th December 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) **Annual General Meeting.**
Nanette Milne MSP and Malcolm Chisholm MSP were re-elected as co-conveners. Cancer Research UK was approved as the Secretariat.

3) **The Draft Annual Return was approved**

4) **The Draft Minutes from the last meeting were approved, with some amendments to Dr Peter Hutchison's presentation.**

5) **The Chair welcomed Richard Meade (RM) of Marie Curie to speak on palliative care.**

RM began by noting that Marie Curie is an organisation which helps and cares for people with all terminal illnesses, not just cancer. He notes that they are working to change the perception of the charity as being solely a cancer charity by formally changing the name this year from Marie Curie Cancer Care to simply Marie Curie.

Last year Marie Curie cared for around 7,500 people in Scotland. The charity provides nursing services in 31 out of 32 local authorities in Scotland (none in Shetland) and runs two hospices in Edinburgh and Glasgow which provide in-patient and out-patient services. They have also recently launched an information and support line.

What is palliative care?
Palliative care aims to treat or manage pain and physical symptoms, but it also aims to support psychological, social and spiritual needs of terminally ill patients. Palliative care is delivered by both generalists and specialists. 90% of a person's palliative care will be delivered in the community by GPs, community nurses, social care staff and others, including the person's own family and friends. More specialist care is provided by experts in palliative care such as consultants in palliative medicine and clinical nurse specialists. This may take place in a hospital or hospice.

Over 54,000 people die from terminal illnesses every year, and of these around 30% are from cancer.

End of life care in the UK has been ranked as the best in the world, and was described as “second to none” by an Economist study comparing 80 countries. RM noted that we should recognise this as a great success, but notes that there is still always room for improvement to ensure that everyone gets this world class care. 11,000 people who need it still miss out on palliative care each year. The Scottish Government has acknowledged that more needs to be done, and RM noted this is a growing challenge as by 2037 death rates will have risen by 12%.

There are many reasons why people are missing out on palliative care. Diagnosis, age, location, level of deprivation, ethnicity and whether the person has a live-in carer can all have an impact on access. The role of the carer is crucial in allowing care to be delivered at home. Those with a spouse or partner are the most likely to be able to die at home. Increased levels of multi-morbidity and frailty in an aging population can also make delivering palliative care more difficult, as it can be challenging to know at which point to begin delivering palliative care. He noted that 3 in 10 hospital in-patients are in their last year of life, rising to 45% of in-patients over 85. He also noted that patients with terminal cancer are much more likely to receive palliative care than patients with other terminal illnesses: 75% of cancer patients compared to 20% of non-cancer patients.

Why do cancer patients have better access to palliative care? Firstly, this is because palliative care was developed alongside oncology, and strong links have been established as well as strong evidence of the benefits. Another reason is that cancer has a much clearer prognosis and terminal phase than other conditions such as organ failure or frailty.

However, even many terminal cancer patients are also missing out on palliative care. One reason for this is that they are not identified by their GP; others may choose end of life treatments and medications to extend life. However, RM argues this does not have to be in opposition to palliative care, but can work alongside it. Furthermore, patients with rarer cancers are generally less likely to receive palliative care. Finally, even GPs and care staff as well as family members can find it difficult to discuss these issues with patients, meaning that things can often be left unsaid.

What needs to change?

- Better identification of patients who need palliative care.
- Communication- more open and honest conversations
- Education and training of healthcare professionals
- Clearer routes between different specialists and palliative care
- Better data and monitoring to ensure improvement

The impact of palliative care is that patients get the care that they want where they want it. Furthermore, it can save the acute sector money by doing more in the community, provided sufficient resources are there. The London School of Economics has estimated that delivering effective palliative care to all those who need it could generate savings of more than £4 million. He notes that this is a rare situation in which doing what people prefer could actually save the NHS money.

What next?

The Health and Sport Committee recently held an enquiry into palliative care which made a number of recommendations which will go on to influence the replacement of the Scottish Government's current policy document Living and Dying Well, published in 2008. The new Carers Bill is looking at providing support for those caring with a terminally ill loved one.

6) Questions to RM

Questions were taken from the floor, and discussion touched on liaising with support groups, on pancreatic cancer, on advertising information and support services (RM noted that every GP in Scotland receives information and the charity also has an advertising budget). It was also noted that the Palliative Care Register is not necessarily just 'box-ticking' as is sometimes supposed. It was noted that palliative vs. curative treatment is a false binary, as palliative care in the true sense can be delivered alongside curative treatment and care. Finally, it was noted that more training is needed for healthcare staff on the issue, as well as more palliative care specialists.

7) The Chair then opened a group discussion on the National Conversation on Health and Social Care

The discussion opened on the topic of **prevention**, with a group member noting that prevention needs to involve a greater understanding of risk as a whole: including family history, lifestyle and screening. She noted that a personalised understanding of risk allows individuals to make informed choices, moving away from "bombarding" people with single topic agendas.

Continuing on the topic of prevention it was noted that health care centres and facilities have to set an example and the poor quality of hospital food as well as the presence of vending machines selling fizzy drinks and unhealthy snacks was discussed. The NHS should set a better example to both patients and staff.

Another attendee noted the psychology of behaviour change, and noted that there is a gap between knowing and doing. The role of personal responsibility must be taken into account too, though it was also noted that a healthy lifestyle needs to be empowered in people through a skilled workforce.

Finally on the topic of prevention, the strong link between deprivation and cancer was noted, and that this needs to be tackled at source.

The group discussion then turned to look at the topic of **early diagnosis,** and the closely linked issue of genetic testing. This has been a significant development in cancer research and treatment in recent years, with a pronounced phenotype to genotype shift in the way cancer is looked at, although it was noted that cancer is still generally described according to its location in the body. It was noted that a greater awareness of genetic risk allows people to make better lifestyle choices.

Pancreatic cancer was mentioned, which has a strong link to genetics. It was noted that genetic testing for cancer can lead to earlier diagnosis. Genetic screening gives a picture of general risk, which can be monitored through screening. This is more targeted and also helps to save money for the NHS. It was noted that once a greater evidence base has built up for genetic testing it will be able to be used much more effectively.

On the topic of screening another attendee felt that universal mammography screening of the over 50s is not effective, while others felt that we need to do smarter screening. Some of the risks of screening were discussed, with one speaker estimating that for every cancer caught through screening several more people will have undergone painful and damaging treatment to remove a tumour which would never have done them any harm. It was noted that we need to look at the big picture to see the benefits of screening, and we need to be honest with patients about the risks.

Unfortunately due to lack of time the discussion had to be cut off before other topics could be considered. However, **it was decided to resume looking at the National Conversation at the next meeting.**

8) A.O.B.

It was noted that the next meeting of the CPG Cancer will take place on 24th February 2016.

The Chair then closed the meeting.

Next meeting: 17:30-19:00, Wed 24th February 2016

Attendees

Lynne	Barty	Brain Tumour Action
Natalia	Calanzani	University of Edinburgh
Dr Neil	Pryde	NHS Fife
Moira	Adams	Challenge Breast Cancer Scotland
Mary	Allison	Breast Cancer Now
Dr Christine	Campbell	The University of Edinburgh
Lindsay	Campbell	WoSCAN
Malcolm	Chisholm	MSP
Mary	Dunlop	Cancer Research UK
Jeannie	Erskine	
Prof Tonks	Fawcett	University of Edinburgh
Ellen	Finlayson	CLIC Sargent
Heather	Goodare	Edinburgh Health Forum
Peter	Hastie	Macmillan Cancer Support
Dr Peter	Hutchison	Scottish Primary Care Cancer Group
Colin	McFarlane	Beating Bowel Cancer
Karen	McNee	James Whale Fund
Gregor	McNie	Cancer Research UK
Richard	Meade	Marie Curie
Nanette	Milne	MSP
Francis	Norton	Heads Up Cancer Support
Katie	Robertson	NHS Forth Valley
Kim	Rowan	
Ewan	Shannon	
Lesley	Shannon	
Greg	Stevenson	Roche
Mona	Vaghefian	Cancer Research UK
Nicolas	White	Breast Cancer Care
Jo	Williamson	Cancer Research UK

Apologies

Annie	Anderson	University of Dundee
Dr Colette	Backwell	CLAN Cancer Support
Karen	Bell	NHS Greater Glasgow & Clyde
Tracey	Bowden	Pfizer
Prof David	Cameron	University of Edinburgh
Alison	Campbell	NHS Greater Glasgow & Clyde
Ian	Campbell	
Martin	Coombes	Novartis
Dr Emilia	Crighton	NHS Greater Glasgow & Clyde
Andrew	Dempsey	Celgene
Sheena	Dryden	NHS Lothian
Valerie	Doherty	SCAN
Jennifer	Fingland	SHAAP
Marie	Gardiner	SCAN
Nigel	Graham	Merck Group
Roseann	Haig	Circle of Comfort
Andrew	Harris	Bowel Cancer UK
Alistair	Haw	Prostate Cancer UK
Robert	Hill	NHS National Services Scotland
Dr Alex	Holme	NHS Lothian
Lesley	Kidd	SCAN
Robert	Lester	Edinburgh & Lothians Prostate Cancer Support Group
David	Linden	Scottish Government
Stella	MacPherson	SCAN
Donald	Marshall	Cancer Research UK
Dr Marie	Mathers	NHS Lothian
Alison	McInnes	MSP
Angus	Ogilvy	SCAN
Peter	Phillips	Edinburgh & Lothians Prostate Cancer Support Group
Rachel	Pont	Cancer Research UK
Helen	Reilly	BMA
Katie	Robb	University of Glasgow
Prof Alan	Rodger	
Rebecca	Scott	Cancer Research UK
Mhairi	Simpson	NHS Lanarkshire
Prof Robert	Steele	Scottish Cancer Foundation
Julie	Uttridge	NHS National Services Scotland