

Cross Party Group on Cancer in the Scottish Parliament

Meeting, Wednesday 12 December 2012, 5.30pm

Present:

Malcolm Chisholm MSP, Co-convenor [Chair]
Nanette Milne MSP, Co-convenor
Aileen McLeod MSP
Helen Eadie MSP
Margaret McCulloch MSP
Vicky Crichton, Cancer Research UK
Allan Cowie, Macmillan Cancer Support
Alan Clark
Dr Aileen Keel, Scottish Government
Peter Hastie, Macmillan Cancer Support
Gus Ironside, Brain Tumour UK
Heather Rankine, Boehringer Ingelheim
Adam Gaines, Prostate Scotland
Sheila Robertson, NHS Lothian
Shirley Fife, NHS Lothian
Dr Norman Pratt, NHS Tayside
Alison Walker
Lorraine Dallas, Roy Castle Lung Cancer Foundation
Sheena Dryden, NHS Lothian
Dr Alex Holme, NHS Lothian
Elspeth Atkinson, Macmillan Cancer Support
Mhairi Simpson, RCN
Kate MacDonald, SCAN
Sheena MacKenzie, SCAN
Prof John Wyke, Scottish Cancer Foundation
Dr David Linden, Scottish Government
Lynne Barty, Brain Tumour Action
Hilary Campbell, Breast Cancer Care
Chloe Cowan, Cancer Research UK
Stewart Douglas, Skin Care Campaign Scotland
Kate Seymour, Macmillan Cancer Support
John MacGill, GlaxoSmithKlein
Leslie Horne, Edinburgh and Lothians Prostate Cancer Support Group

Apologies:

Alison McInnes MSP
Stuart Macmillan MSP
Greg Stevenson, Roche
Prof David Cameron, University of Edinburgh
Lesley Howells, Maggie's Centre
Linda Summerhayes, Cancer Research UK
Kate Morgan, Myeloma UK
Prof Alan Rodger
Hannah Gagen, Boehringer Ingelheim
Val Lee, CIS Oncology
Bill Paton, Napp

Frances Reid, Target Ovarian Cancer
Angus Ogilvy, SCAN patient rep
Mike Shaw, Edinburgh and Lothians Prostate Cancer Support Group
Heather Cubie, SHINe
Dr Brian Montgomery, NHS Fife
Karen Bell, Cancer Research UK
Ellen Finlayson, CLIC Sargent
Liz Forbat, CCRC
John Sleith, REHIS
Peter Philips
Michael Clancy
Sander Henzing, Aridhia
Mia Rosenblatt, Breast Cancer Campaign
Karen McNee, James Whale Fund
Dr Colin Selby, NHS Fife
Kerry Napuk, Edinburgh and Lothians Prostate Cancer Support Group
Ailsa Patrizio, NHS Lothian
Suzanne Spencer, Cancer Research UK Ambassador
Dr Christine Campbell, University of Edinburgh
Prof. Bob Steele, Scottish Cancer Foundation
Prof Annie Anderson, University of Dundee
Lynne Barty, Brain Tumour Action

Agenda

Malcolm Chisholm welcomed attendees to the meeting.

1 Minutes of last meeting

The minutes were approved as a true record of the meeting.

2 Transforming Care After Treatment

Malcolm Chisholm introduced the speakers.

Dr Aileen Keel gave a presentation on the background to the programme. She noted that this is a priority for the Scottish Cancer Taskforce (SCT) and that one of the drivers is the increasing number of cancer survivors. This means that the current models of post treatment care and follow-up are no longer fit for purpose. It is also case that patients are not always happy with these services and that there are staffing resource pressures. It was noted that new cancer cases are expected to increase by approximately 8% every five years up to 2020 and that overall 2.5% of men and 3.4% of women in Scotland are living with or beyond cancer.

The Government's Healthcare Quality Strategy identified person centred care as a key strand, and there is a pressing need to manage the downstream consequences of cancer and its treatment. Dr Keel noted that doing more of the same will not deliver the outcome improvements required for cancer survivors, nor will it be affordable for the NHS in Scotland. Plotting the demographics forward, we expect to see growing numbers of cancer survivors - this is partly due to more people being diagnosed per year, but mostly due to increased survival and life expectancy.

Dr Keel then outlined the structure of the programme, which has a Programme Board and reports into the SCT. The Board has strong patient involvement, has developed a workplan and has good clinical engagement, which is vitally important. It builds on the previous work of the Living with Cancer group, and work already underway in the cancer networks. The Board will also seek to learn lessons from England's National Cancer Survivorship Initiative and from similar work in Northern Ireland.

The programme will consider methods of holistic needs assessment, risk stratification models, alternative models of care, personalised care plans and end of treatment care summaries.

Allan Cowie then presented on the programme, noting that it chimed with what patients and families tell them, which is that they'd like more information and advice, that they often have multiple unmet needs, and that very few have a care plan. He noted the growing understanding that needs don't end at the end of active treatment. These issues were also raised at the Big Cancer Conversation event held in 2009.

Mr Cowie then outlined the main areas of focus for TCAT: risk stratification which relies on undertaking a holistic needs assessment; assessment and care planning which helps people to prepare for life post treatment; co-ordination across care settings; information to meet individual needs; and rapid access to appropriate health or care professionals. He noted that the Scottish Primary Care Cancer Group is working on end of treatment summaries to help with the handover from secondary to primary care.

Mr Cowie highlighted some of the delivery challenges facing the group, including the prevailing culture, whether to augment existing solutions or create new ones, and how to define outcomes and measure impact. There are multiple stakeholders involved, and the programme will need to be delivered in partnership. The focus in the first year will be on the redesign of current models of follow-up and will include test pilots.

Alan Clark then spoke of his own experience. Mr Clark felt he had benefited from swift treatment and had had a good experience of the clinical part of the journey. During his active treatment he was well supported, but his need for support continued beyond that. He spoke of the challenge of moving from a situation where there was always someone there to a more normalised lifestyle. He stated that he felt lucky, not only because of the success of his treatment, but that he had insurance that helped him and his family to remain in their home, despite him not being able to return to work. The after effects of the treatment are such that he cannot return to his previous profession. Mr Clark described some of the effects which he still lives with and the impact these have on his daily life. He stated that while he had been able to find support, this was hard to do. He also acknowledged the impact on family members and their need for support.

Malcolm Chisholm thanked all the speakers and opened the discussion to the floor.

The issue of the needs of family members was discussed with attendees agreeing that they also need tailored support, and that people need to be aware of the services that are available. It was also noted that nurse specialists play a crucial role in supporting both the patient and the family, for example, in helping

to explain the news to children. There are also local authority projects in some parts of the country which help support children. It was noted that in some cancers, for example brain tumours, there is an even greater need to work collaboratively with families.

It was noted that work is underway to map services across Scotland for patients and their families to ensure that all providers are included in this work. The importance of patient, carer and voluntary sector involvement was also highlighted.

The balance between genuinely personalised services and the restrictions of time and expense were discussed. It was felt that there is a genuine opportunity to develop an individualised system, and that variation in the current delivery of follow-up shows that there is waste which can be removed. It was noted that while there is some funding to support this work, there is also a need to do better with existing resources.

The importance of rehabilitation as a 'teachable moment' to deliver lifestyle advice, to both the patients and their family, was flagged up.

There was a discussion about the use of peer support and using cancer survivors to support others, which patients felt would be beneficial.

The group agreed that there are some areas of very good service, but this programme will be important in reducing variation and rolling out best practice.

3 AOB

Vicky Crichton updated the group on issues relating to tobacco control, including the ruling by the Supreme Court against Imperial Tobacco's appeal on point of sale displays and vending machines, and the forthcoming Scottish Government Tobacco Control strategy.

4 Date of next meeting

The next meeting of the group will be Wednesday 27th March at 5:30pm. The agenda will be circulated to members once it is confirmed.