

Cross Party Group on Cancer in the Scottish Parliament

Meeting, Wednesday 12 September 2012, 5.30pm

Present:

Nanette Milne MSP, Co-convener [Chair]
Malcolm Chisholm MSP, Co-convener
Richard Simpson MSP
Niall Taylor, Scottish Government
Maureen Black, Scottish Government
Lynne Huckerby, NHS24
Vicky Crichton, Cancer Research UK
Peter Hastie, Macmillan Cancer Support
Suzanne Spencer, Cancer Research UK Ambassador
Kerry Napuk, Edinburgh and Lothians Prostate Cancer Support Group
Stella MacPherson, SCAN patient rep
Richard Walker, MSD
Karen Bell, Cancer Research UK
Annie Anderson, University of Dundee
Gus Ironside, Brain Tumour UK
Leslie Horne, Edinburgh and Lothians Prostate Cancer Support Group
Lynne Barty, Brain Tumour Action
Frances Reid, Target Ovarian Cancer
Emma Anderson, Bowel Cancer UK
Martin Coombes, ABPI
Amanda Garden, SCAN
Stewart Dicker, Kent and Medway Cancer Network
Karen McNee, James Whale Fund
Elaine Nixon, Prostate Cancer UK
John Sleith, REHIS
Angus Ogilvy, SCAN patient rep
Robert Hill, ISD
Julie Uttridge, ISD
Alison Walker
Roseann Haig, Circle of Comfort
Lorraine Dallas, Roy Castle Lung Cancer Foundation
Sheena Dryden, NHS Lothian
Dr Alex Holme, NHS Lothian

Apologies:

Alison McInnes MSP
Jackie Baillie MSP
Audrey Birt, Breakthrough Breast Cancer
Michael Clancy
Elsbeth Atkinson, Macmillan
Leigh Smith, MASScot
Fiona Hamill, Janssen
Mhairi Simpson, RCN
Ellen Finlayson, CLIC Sargent
Prof Alan Rodger
Dr Colin Selby, NHS Fife

Val Lee, CIS Oncology
Mike Shaw, Edinburgh and Lothians Prostate Cancer Support Group
Dr Alison McCallum, NHS Lothian
Ailsa Patrizio, NHS Lothian
Bill Paton, Napp
Stewart Douglas, Skin Care Campaign Scotland
Iain Brotchie, Royal Pharmaceutical Society
Jacquie Forde, Health Inequalities Alliance
Suzanne Fernando, Cancer Research UK Ambassador
Elizabeth Preston, NHS Lothian
Dr Brian Montgomery, NHS Fife
Sheila Robertson, NHS Lothian
Shirley Fife, NHS Lothian
Adam Gaines, Prostate Scotland
Kathryn Quinn, NHS Fife
Mandy Forbes, NHS Fife
Prof. Bob Steele, Scottish Cancer Foundation
Liz Wilkinson, Division of Clinical Psychology

Agenda

Nanette Milne welcomed attendees to the meeting.

1 Minutes of last meeting

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

2 AGM

Malcolm Chisholm and Nanette Milne were proposed as Co-conveners, and duly elected. Cancer Research UK was re-elected as secretariat.

3 NHS Inform Cancer Zone

Maureen Black explained that the Cancer Zone website is part of NHS Inform, which developed from commitments in *Better Health, Better Care*, and a cancer-specific commitment in *Better Cancer Care* to provide a single health information point for Scotland. Ms Black explained that she had been seconded in from Macmillan Cancer Support to work with the Scottish Government on the project. The plan for the service was originally developed by a steering group chaired by Dr Bob Masterton, and via a visioning exercise, which proved very productive.

Ms Black explained that three key objectives had been identified – the Cancer Zone itself, the provision of face-to-face information and support, and the development of tailored information for patients at key parts of their journey.

Niall Taylor then explained the development of the Cancer Zone, which was very patient focused due in part to strong patient representation on the steering group. It also had to be aimed at a Scottish audience, since there was lots of information available on cancer, but not all of it directly relevant and accurate for patients in Scotland. There had also been a clear message not to recreate resources which already existed, so the team have been working with the cancer charities. The Cancer Zone has an emphasis on 'living with cancer' since this was felt to be a major gap, and the clear priority for patients. As Macmillan Cancer Support had a vast resource in this area, the decision was taken to work in partnership with them to adapt this for a Scottish audience.

The team has worked with NHS 24 from a practical perspective to create the Cancer Zone site.

The Cancer Zone was launched on 23rd August 2012 and has six sections:

- about cancer
- treatment and side effects
- living with cancer
- emotions and relationships
- life after cancer
- cancer support in Scotland.

It includes links to relevant other organisations and the services they provide. Mr Taylor noted that there are additional levels of detail, but that people don't always want to see it all at once so they can access the level they choose. He also asked for feedback on areas that members feel could benefit from further information.

Ms Black then outlined plans for the second phase – Tailored Information for the people of Scotland (TIPS). There had been feedback that generic information is helpful, but that patients also want to be able to access tailored information, as it can often be overwhelming. This project aims to allow them to access relevant information when and how they choose. There will be information on each tumour group across the pathway, links to information on emotional and financial needs and it will be simple and easy to access. This will provide meaningful information for patients, and will support health care professionals to provide information and support face-to-face. A prototype has been developed and is currently being consulted on with user groups. The TIPS tool will be available from January 2013 and will be piloted across cancer sites. There will be ongoing evaluation.

Nanette Milne thanked Maureen Black and Niall Taylor and stated that it sounded like an important and well needed tool. The discussion was then opened to the floor for questions. Many positive comments were made about the need for this sort of information, and the collaborative way it had been developed.

It was noted that there is a section on recurrence within the 'advanced cancer section'. However, members felt that this might not be the most appropriate place.

It was confirmed that the Cancer Zone is a publicly available website, not just hospital based, but teams will be working directly with health care professionals to make sure they're aware of it and to encourage them to use it with their patients.

The methods for making people aware of the site were discussed. It was noted that this will be an ongoing challenge, but that the Detect Cancer Early campaign adverts are using the NHS Inform website and this will help to publicise it. It was also stated that a small team is going into partner venues such as libraries and pharmacies to enable them to direct members of the public to the site.

The learnings regarding making generic information relevant to Scotland were discussed, and it was noted that this is something which many UK-wide charities

struggle with. The main areas needing specific information related to NHS structures and the complexities of financial information and support. It was noted that the TIPS information is being reviewed by clinical teams to ensure that it is relevant and correct.

It was noted that while the Cancer Zone focuses primarily on living with cancer, there is a need for other information, for example on cancer prevention. This can be found elsewhere on the NHS Inform site, but it wasn't felt to be easy to find.

The limitations of a website in providing information were discussed, but it was noted that this should help provide a basis for health care professionals to have a dialogue with patients on issue, using the information to support this. This might include discussions around, for example, informed choice on treatment options. This should also help to support those without access to a computer, although it was also noted that charities and cancer centres also provide good quality printed information.

The group discussed how the project had learned from the development of information prescriptions in England, but had decided to use a different approach as there have been issues with duplication of information and difficult to navigate formats. It was also felt that there was an advantage of scale in Scotland in terms of developing relevant information within the timescales.

A hand-held device compatible version of the site is also being developed so people can access it from their smartphones.

Nanette Milne closed the discussion, thanking the speakers, and noting that the group would be keen to hear from them again in future to see how the project has developed.

4 Scotland Against Cancer

Nanette Milne noted that the conference had been very successful. Vicky Crichton stated that the report had now been circulated to delegates and to CPG members. The report has also been sent to the Scottish Government. A number of issues had been raised at the conference which the group may wish to address in forthcoming meetings. The group identified two further issues for future discussion – taking forward the agenda on cancer prevention, and the relationship between stress and cancer.

5 Apologies (Scotland) Bill

The group noted the proposed Bill, but agreed not to submit a group response to the consultation. However, individual members may wish to respond.

6 AOB

Suggestions were made for future meeting topics including informed consent, palliative care and brain tumours.

7 Date of next meeting

The next meeting of the group will be Wednesday 12th December at 5:30pm. The agenda will be circulated to members once it is confirmed.