Cross Party Group on Cancer in the Scottish Parliament

Meeting, Wednesday 14 December 2011, 5.30pm

Present:

Nanette Milne MSP, Co-convener [Chair]
Helen Eadie MSP

Vicky Crichton, Cancer Research UK
Peter Hastie, Macmillan Cancer Support
Lorraine Dallas, Breast Cancer Care
Alistair Haw, Prostate Cancer Charity
Phil Atkinson, Health Policy Scotland
Angus Ogilvy, SCAN Patient Representative
Lynne Barty, Brain Tumour Action
Suzanne Spencer, Cancer Research UK Ambassador
Sheena Dryden, NHS Lothian
Karen Bell, Cancer Research UK
Adam Gaines, Prostate Scotland
Jamie Erskine, Cancer Research UK
Ellen Finlayson, CLIC Sargent
Katie McDowell, CLIC Sargent
Barbara McLaughlan, Novartis Oncology
Leigh Smith, MASScot
John Wyke, Scottish Cancer Foundation
Carole Smith, SCAN
Alexander Henzing, Aridhia Informatics
Sarah Shepherd, Navigation Study
Fleur-Michelle Coiffait, NHS Lothian
Sarah Scott, NHS Lothian
Belinda Hacking, NHS Lothian

Apologies:

Malcolm Chisholm MSP
Jackie Baillie MSP
Stuart Macmillan MSP
Alison McInnes MSP
Prof. Bob Steele, Scottish Cancer Foundation
Prof. Annie Anderson, Scottish Cancer Prevention Network
Dr Katherine Quinn, Clinical Psychologist
Gus Ironside, Brain Tumour UK
Bill Paton, NAPP
Emma Brooks, Bowel Cancer UK
Val Lee, CIS Oncology
Dr Colin Selby, NHS Fife
Sarah Muir, Cancer Research UK
Audrey Birt, Breakthrough Breast Cancer
Anna Whyte, FSA
Hannah Gagen, Boehringer Ingelheim
Professor Alan Rodger, Chair, Scottish Radiotherapy Advisory Group

Sheila Robertson, NHS Fife
Mhairi Simpson, RCN
Suzanne Fernando, Cancer Research UK
Alison Harrow, Cancer Research UK
Gail Grant, BMA
Michael Clancy
Dan Wynn, GMC
Jane Cox, Genzyme
Pat McAulay, Scottish Government
Dr Paul Baughan, NHS Forth Valley
Liz Forbat, CCRC
Stewart Douglas, MASScot
Stella MacPherson, SCAN Patient Representative
Liz Wilkinson, NHS Dumfries and Galloway
Kerry Napuk, Edinburgh and Lothians Prostate Cancer Support Group
Christopher Garner, Edinburgh and Lothians Prostate Cancer Support Group
Dr Dermot Gorman, NHS Lothian
Kate Morgan, Myeloma UK
Julie Uttridge, ISD

Agenda

Nanette Milne welcomed attendees to the meeting. She passed on apologies from Malcolm Chisholm, who was unable to attend.

1 Minutes of last meeting

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

2 Helping cancer patients to navigate their healthcare: A randomised controlled trial of an intervention to facilitate shared decision making

Speaker: Dr Belinda Hacking, Consultant Clinical Psychologist and Lead Cancer Clinician, Clinical Health Psychology, Western General Hospital

Dr Hacking started by acknowledging funding and support from Macmillan Cancer Support for this research. She noted that Shared Decision Making is a term used a lot – it can be used to clarify treatment options, to share information a reach a mutual decision with a clinician. Patients bring their own expertise, for example regarding their social circumstances and their attitudes to risk, to these discussions. It was noted that when used effectively, it increases knowledge, engagement, outcomes treatment adherence and comfort with the decisions made.

SDM can be particularly useful when dealing with preference sensitive decisions, which have similar clinical outcomes but very different quality of life outcomes, for example those around prostate cancer treatment.

SDM is highlighted in numerous studies and policy documents, but has been little used in practice. There are barriers to its use; often clinicians believe they are doing it already, or that it will be time consuming. In addition, patients often

don't expect to be involved in this way. However, there are solutions, including the use of decision aids, which actively assist people to make a decision, rather than just giving information. Communication skills training for clinicians is also crucial.

This particular intervention was trialled in the US in breast cancer patients, and showed an improvement in comfort with the decisions made. Using the 'navigation' technique, a consultation plan is created jointly by the navigator (in this case, the researcher) and the patient and reviewed by them in advance of the consultation. The medical consultation takes place with the navigator present. The patient then receives an audio recording and personal summary of the consultation. This summary also goes to the clinician and patient's GP.

During this process patients are asked to think about what is most important to them, which means that the consultation is personalised, addressing their key concerns and their context. Dr Hacking gave an example of a patient considering brachytherapy treatment but with some specific concerns about its effect on children as he cared for his granddaughter on a daily basis.

The study carried out by Dr Hacking and her team was run as a randomised clinical trial, with 115 prostate and 65 breast cancer patients taking part. Qualitative and quantitative methods were used and there were four key questions for researchers:

- Is Navigation translatable from the US to the Scottish population?
- Does Navigation increase patients' confidence in making decisions?
- Does Navigation reduce patients' decision uncertainty and regret?
- Will Navigation impact patients' mood or adjustment to cancer?

For the prostate cancer patients there were significant findings favouring the navigation group in terms of increased confidence, reduced uncertainty and regret, but no impact on mood or adjustment. The breast cancer study did not show the same results, however Dr Hacking did note the smaller study size. In the qualitative results, both sets of patients experiences benefits. Clinicians participating in the study also saw the benefits of this approach.

Dr Hacking concluded by asking whether audio recordings could be provided to all patients; whether the use of decision support tools should be promoted in clinical practice and whether existing healthcare staff could be trained to deliver navigation.

Nanette Milne thanked Dr Hacking for her presentation.

It was noted that this could also be a useful tool for patients with a second diagnosis, who often have baggage from previous experience and would benefit from decision support.

Dr Hacking noted that the second phase of the trial is now underway in brain and colorectal cancer patients. The study in brain tumour patients will include work with carers and family members as patient groups have highlighted the need to involve them, particularly where patients may have cognitive impairment.

The group discussed the difference between the breast and prostate results and whether this could be related to gender. Dr Hacking stated that the men had been very keen to participate, but that her feeling is that while decisions about

prostate cancer treatments could benefit from this sort of approach, the breast cancer pathway is very fast, with little time for consideration of options, which could lead to regret later for patients.

The group also discussed the applicability of this sort of tool for young people with cancer, who often feel talked about and not consulted on their treatment options. Dr Hacking noted that the research team had met with members of the Scottish Youth Parliament to discuss the applicability of this tool for young people with health issues, and stated that in the US there are now mobile phone apps to support this work.

Patients attending the group felt strongly that the recording of their consultation would have been very helpful, and that an opportunity to identify which information was applicable and targeting that to each patient would help to avoid overload.

It was also noted that clinician or centre preferences can drive decision making. For example, mastectomy rates vary significantly across Scotland, which suggests that in some centres there is a clinical preference for one type of treatment over another.

The role of clinical nurse specialists in supporting patient information and understanding was highlighted, and also examples where volunteers, including ex-patients, were able to support those being given a diagnosis. It was agreed that these were very helpful, but noted that the navigator provided a different and type of specific support.

Dr Hacking stated that the second phase of the study will also look at a health economic analysis, which will be vital in convincing the NHS to take this up. It will look at self management, coping skills etc. and the various options for recruiting navigators or training existing staff etc.

It was also noted that the navigators signposted participants to good quality information and support, where these were felt to be helpful.

3 Scotland Against Cancer

Vicky Crichton advised that the next conference will be on Monday 30th April 2012, in Edinburgh. Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon, will be speaking, and the keynote address will be given by Professor David Cameron. Registration will open in the New Year.

4 AOB

The Scottish School of Primary Care, Scottish Government and Royal College of General Practitioners are hosting a conference, *Improving cancer outcomes in Scotland: the role of primary care* on Wednesday 1st February 2012 in Edinburgh. Full details are available from the secretariat.

5 Date of next meeting

The next meeting of the group will be Wednesday 14th March at 5:30pm. The agenda will be circulated to members once it is confirmed.