

ICPV Summer School
Stirling Court Hotel, University of Stirling
Thursday 15 to Friday 16 June 2017

A two day Summer School with a focus on Survivorship was scheduled for June 2017. This was a collaboration between ICPV and the University of Stirling, organised by Elspeth Banks (ICPV) and Professor Mary Wells (NMAPH-RU Research Unit, University of Stirling).

Most course participants arrived on Wednesday, 14 June, ahead of the formal start the following morning. Accommodation was in the Stirling Court Hotel which was also the venue for the Summer School.

Day one: **Key issues in Cancer Survivorship and Living well after cancer.**

Following a welcome by Elspeth Banks, the programme got underway with the speakers and presentations:

Professor Mary Wells - Introduction to Survivorship



- Why survivorship matters and what it means
- Current challenges in survivorship
- Changing practice and research

Dr Lynn Calman from the University of Southampton - Patient Reported Outcomes



- What are PROs
- Strengths and limitations
- How are PROs used in research and practice
- Can PROs make a difference?

Participant comment: *'This session was really informative and of value' and 'I thought this and all sessions were memorable'*

Dr Gozde Ozakinci, University of St Andrews - Fear of Recurrence



- Fear of cancer recurrence as a major experience by those living with and beyond cancer
- What is the role of health care communication in managing these fears? How do we facilitate conversation about fear of cancer recurrence?

Participant comment: *'Fear of recurrence is a fear that impacts on living and the joy of being alive – needs to be addressed by Health Care Professionals'*

Dr Ruth Isherwood from Strathcarron Hospice - *Symptom Management in Recurrent and Advanced Disease*



- Palliative care support can be very helpful early in the disease journey for some people
- Palliative care should be available to everyone – based on need not diagnosis
- Palliative care enables people to live until they die

Participant comment: *'This was an excellent session as I knew so little about this work of a hospice'*

Professor Annie Anderson from the University of Dundee - *Diet and lifestyle change*



- Forget the guilt about diet– moving forward
- Current scientific understanding of the role of diet and lifestyle in survivorship
- Starting steps to changing eating behaviours
- Success and achievements

Participant comment: *'I'll also worry less about nutrition after Annie Anderson's talk – I will continue to eat well and healthily, but not fret that if I don't it will make my cancer progress'* and *'This was particularly useful as I'm involved in a number of studies and groups looking into these areas'*

Dr Anna Campbell, Edinburgh Napier University - *Physical activity (including practical session)*



- Benefits of physical activity
- International guidelines and recommendations
- Putting it into practice

Participant comment: *'Well presented. The session on exercise following diagnosis - A subject close to my heart and one which I talked about years ago following my own diagnosis and one which was not ever discussed at that time'* and *'Plan to hook up with Anna re exercise and the part it plays in cancer recurrence, and may exercise even more now'* and *'My efforts so far, as a patient representative on a TSSG (H&N) and a Radiotherapy Group, to have exercise as part of treatment and recovery have had limited success, but the Summer School has given me more ammunition to push for this enhancement. It will also allow me to influence the Macmillan Aftercare and Rehabilitation Service and provide factual information to the Second Chancers'*

Before the Summer School dinner ICPV members were invited to join members of the University of Stirling for a Drinks Reception and an opportunity for researchers to learn more about ICPV and for participants to hear about current research projects.

Day two: The Costs and Consequences of Survivorship.

Dr Peter Hall of the Edinburgh Cancer Centre, NHS Lothian / University of Edinburgh
Health Economics and Cost of Survivorship



- Health economics core concepts
- NICE/SMC and how they do cost effectiveness analysis
- Examples

Participant comment: *'I especially found the talk by Peter Hall on Health Economics fascinating and made the whole subject of funding so simple - I think funding of treatments etc. is such a huge topic in the present economic climate that the general public need to understand how it all works. Dr Hall's presentation was very thought provoking' and 'A topic that has never, in my experience, been referred to in any study proposal and it obviously should be'*

Ms Gillian Knowles, Edinburgh Cancer Centre, NHS Lothian - *Late effects following pelvic treatment for anal cancer*



- Prevalence of late effects following pelvic treatment in anal cancer: experience from the Edinburgh Cancer Centre
- Changing practice to support recovery
- New treatment technology that may influence the extent of late effects in the future

Participant comment: *'I had not realised the extent of the impact on quality of life and perhaps not fully appreciated by clinicians in relation to long term side effects of treatment'*

Professor Diana Greenfield from Sheffield Teaching Hospitals NHS Foundation Trust / University of Sheffield - *Endocrinopathies after cancer treatment: a quality of life concern*



- A resume of the endocrine system
- Examples of how cancer treatment may cause 'endocrinopathies'
- How men are incredibly sensitive
- Thinking hormonally and changing practice

Participant comment: *'There was a lot to take back that we can use when we are on TMGs especially the late effects data and the endocrinopathies'*

Professor Mary Wells, NMAHP Research Unit, University of Stirling – *Addressing the consequences of head and neck cancer treatment*



- The changing nature of head and neck cancer and its treatment
- The survivorship needs of people with head and neck cancer
- Interventions to improve health and wellbeing

Participant comment: *'This gave me so much that I can take back to the Macmillan Aftercare and Rehabilitation Service for Head and Neck steering group that I'm a member of' and 'I will highlight issues around recurrence and long term side effects when partnering with researchers at the design and information stage, also at trial adoption meetings for the Network raise questions around these points'*

Dr Iain Macpherson, Greater Glasgow / University of Glasgow - *Developments in Oncology Research and Practice*



- Current landscape of Cancer Research in the UK
- Where have we come from and where are we going?
- What are the challenges on the way?

Participant comment: *'Iain MacPherson's session was particularly useful, and more of that in the future would be good. I was interested in his brief look at the future issues – role of exercise and of gut bacteria'*

Dr Adrienne Morgan of Independent Cancer Patients' Voice - *Minor side effects!!!*



- Menopausal symptoms and breast cancer treatment
- Raising levels of awareness in the breast cancer community
- The Symptom Management Working Party

Participant comment: *'I will highlight issues around recurrence and long term side effects when partnering with researchers at the design and information stage, also at trial adoption meetings for the Network raise questions around these points'*

ICPV member Mairead McKenzie offered her reflections on the event before Elspeth Banks thanked everyone for their participation and wished all a safe journey home.



Mairead



Elspeth

Participant Comments:

- Excellent programme and all the topics fitted together well, so the days flowed seamlessly.
- I will certainly keep the presentations on the computer and refer to them in relation to survivorship whenever this subject comes up. Thanks for having this opportunity to learn from professionals.
- I believe that colleagues have made new contacts in the speakers who were all very interested in the work of ICPV. This works both ways and those who gave their time to support our Summer School will benefit from ICPV advice and support in future
- It was a most enjoyable 2 days and I would like to thank Elspeth and Mary Wells for organising such a great conference. I really appreciate their time and know just how much work is involved in organising these events.
- I came away from the conference with renewed enthusiasm for the work that we do as PPI representatives and for the work and dedication of the researchers who are looking into better ways to treat and support us as cancer patients.
- Thank you for the privilege of attending and helping to expand my knowledge which I plan to use within the wide area of my research involvement for the benefit of other patients.
- The venue and catering could not be faulted. My special dietary needs were perfectly catered for and the best I've had at a hotel.
- We need a week rather than 2 days. There is just so much to learn....

Speaker Comments:

- It was a delight to participate in this summer school event. A great group of colleagues who were genuinely interested in learning as much as possible about exercise and cancer survivorship. I actually learned a lot from them too!
- I will definitely consider approaching ICPV in the future
- I'd like to keep in touch with the group with respect to Scottish Cancer Prevention Network (SCPN) and get to know what kind of issue they might like to read about in the newsletter or share with the wider cancer community re reducing risk of recurrence
- I swithered on accepting the invitation as I am ultra-busy with getting ActWELL up and running and now delighted that I decided to come. I feel Elspeth has helped me in many ways re SCPN and ActWELL etc I owe a few favours. In fact I think I probably gained more than I gave – so thank you once again for the invitation