Responding to the NCRI JLA PSP on Living With and Beyond Cancer

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First, what does ‘Supportive Care’ cover?

Supportive Care is

“The prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side effects across the entire continuum of the cancer experience including the enhancement of rehabilitation and survivorship.”

Multinational Association for Supportive Care in Cancer
Model of supportive and palliative care

Model:

1. **Diagnosis**
   - Direct therapy
   - Patient-directed therapy
   - Family-directed therapy

2. **Remission-----Cure-----Relapse**
   - Late effects and recurrence

3. **Death**
   - Symptoms of progressive and advanced disease
   - Issues at end of life

Supportive care:

- Symptoms and concerns at presentation
- Acute treatment-related toxicities
- Information
- Side-effects
- Psychological support
- Financial help
- Rehabilitation
- Patient-directed therapy
- Family-directed therapy
- Co-morbidity

**Survivorship**

**Conference.ncri.org.uk**

**@NCRI_partners**

**#NCRI2018**
Structure of the SPC CSG

Subgroup: Diagnosis
- Grief / Bereavement
- Disease-directed therapy
- Patient-directed therapy
- Family-directed therapy

Subgroup: Death
- Remission
- Cure
- Relapse

Subgroup: Survivorship
- Information
- Side-effects
- Rehabilitation

Subgroup: Early stage disease and Acute treatment toxicities

Subgroup: Advanced disease and End of life

Subgroup: Survivors and Late consequences
## Breakdown of SPC CSG members

<table>
<thead>
<tr>
<th>DISCIPLINE</th>
<th>2018</th>
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<tbody>
<tr>
<td>Oncology</td>
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<tr>
<td>Palliative medicine</td>
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<tr>
<td>Health service researcher</td>
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<td>Nurse</td>
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<td>Allied health professional</td>
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<tr>
<td>Statistics/CTU</td>
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</tr>
<tr>
<td>Patient/carer representative</td>
<td>2</td>
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</table>
Expertise within the SPC CSG

Supportive & Palliative Care CSG members have expertise in –

- Clinical trials – phase 1/2/3
- Qualitative studies – interviews / focus groups
- Quantitative studies – questionnaire design, surveys
- Translational research
Priorities of SPC CSG for future research

- **Exercise, nutrition and rehabilitation** before, during and after cancer treatment:
  - roles of AHPs, community teams and charity sector

- **Treatment toxicities** – especially immunotherapy:
  - physical effects, patient experience, community care implications

- **Pain and other symptoms** especially in advanced disease and at end of life:
  - hospital, community and hospice contributions
How do the JLA PSP priorities fit with the NC strategy?

What causes *fatigue* in people living with and beyond cancer and what are the best ways to manage it?

What are the best ways to manage *chronic pain* caused by cancer or cancer treatments?
How do the JLA PSP priorities fit with the strategy?

What specific lifestyle changes (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life?

What are the most effective ways to stop cancer coming back (combining treatments and life-style changes)?
What are the biological bases of side-effects of cancer treatment and how can a better understanding lead to improved ways to manage side-effects?

How can the short-term, long-term and late effects of cancer treatments be (a) prevented, and/or (b) best treated/managed?

How can we predict which people living with and beyond cancer will experience long-term side-effects (side-effects which last for years after treatment) and which people will experience late effects (side-effects which do not appear until years after treatment)?
What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?

How can care be better co-ordinated for people living with cancer and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)?

These priorities will need coordination with Primary Care CSG as well as site-specific CSGs.
Examples of current SPC studies that respond to JLA PSP questions

- **Pain** – assessment; new technologies for reducing longterm side-effects such as constipation
- **Fatigue** – prehab and post-treatment rehab
- **Nutrition** – support for patients and carers during treatment
- **Post-treatment needs assessment** and supported self-management
How will SPC CSG take the JLA PSP priorities forward?

• **Talk with patients and carers!** – at beginning and during development of each new project

• **Work with site-specific CSGs** to ensure that we are targeting the correct questions (impact of disease, types of treatments)

• **Work with other cross-cutting CSGs** – Psychosocial Oncology, Primary Care
Challenges in taking JLA PSP questions forward

1. **Funding** – supportive care research has largely been ignored by the ‘big’ research funders

2. **Awareness** - engaging with charities and CSGs for specific cancers to ensure supportive care priorities are being addressed

3. **Funding!**
Conclusions

• LWBC JLA PSP has shown us what the important issues and priorities are for people living with and beyond cancer

• Supportive and Palliative care CSG is well equipped and ready to develop these priorities into new research studies

• NCRI partners need to open doors for funding!