Responding to JLA priorities for Living With and Beyond Cancer
NCRI Psychosocial Oncology & Survivorship (POS) Clinical Studies Group

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Outline

• Brief history of work on LWBC
• NCRI POS CSG expertise with examples of ongoing portfolio projects
• NHS England QOL metric project
• Opportunities and challenges
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History of work in lwbc research

NCRI

SuPac Research in the UK report
Psychosocial Oncology, Primary Care, Palliative Care and Complementary Therapies CSGs

Other related work
Supportive and Palliative Care Research in the UK: Report of the NCRI Strategic Planning Group on Supportive & Palliative Care


Rapid Review of Research in Survivorship After Cancer and End of Life Care
Supportive and Palliative Care initiative (SuPac)

Impact of SuPac report
Impact of the NCRI Supportive and Palliative Care Initiative
NCRI scoping work

National Cancer Survivorship Initiative (NCSI)

Cancer Taskforce report

ACHIEVING WORLD-CLASS CANCER OUTCOMES
A STRATEGY FOR ENGLAND 2015-2020

Report of the NCRI Strategic Planning Group on Supportive & Palliative Care
NCRI POS CSG
18 members
3 subgroups
Created 2004
NCRI POS CSG Expertise and Strategy

• Mixed methods – qualitative and quantitative methodology
• Observational studies
• Design of complex interventions (models of care)
• Clinical trials of complex interventions
• Methodology of using Patient Reported Outcomes Measures (PROMs)
  – In clinical trials
  – In clinical practice
• Electronic methods for PROMs data collection and integration with medical records to support patient care
NCRI POS CSG Sub-groups:

**Impact and Consequences of Cancer & Treatment**
Chair: Dr Derek Kyte, University of Birmingham
- PROMs reporting in clinical trials
- ePROMs in cancer care – eRAPID, eSmart, ePRIME

**Lifestyle and Behaviour Interventions**
Chair: Dr Gill Hubbard, University of Highlands and Islands,
- Interventions to enhance physical activity, diet
- ASCOT trial

**Psychosocial Interventions**
Chair: Professor Mary Wells, Imperial College London
- Interventions to enhance psychological well being
- Fear of cancer recurrence

JLA priorities:

1. **best models for delivering long-term cancer care** including ...managing long-term side effects and late-effects of cancer.

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

9. What **lifestyle changes** (e.g. diet, exercise) will help

5. ...short-term and long-term **psychological impacts** ....and the most effective ways of supporting the psychological wellbeing
PRO-specific guidelines and support

Protocol Development  
Trial implementation  
Reporting

Methodological expertise

SPRIT-PRO  
PROlearn  
CONSORT-PRO

conference.ncri.org.uk  
@NCRI_partners  
#NCRI2018  
@NCRIpartners
Remote monitoring of symptoms and side-effects during cancer treatment

Mobile Technology

The eSMART study protocol: a randomised controlled trial to evaluate electronic symptom management using the advanced symptom management system (ASyMS) remote technology for patients with cancer

Results expected in 2020
Online monitoring of symptoms and side-effects during cancer treatment

Integration in Electronic Medical Records

Results expected in 2019
Large cohort studies of cancer survivors

2,562
Patients taking part in HORIZONS

1030
Breast cancer patients

517
Non-Hodgkin’s Lymphoma patients

1015
Gynaecological cancers patients

656
Endometrial cancer patients

164
Ovarian cancer patients

168
Cervical cancer patients

27
Vulval cancer patients

Quality of life in men living with advanced and localised prostate cancer: A United Kingdom population-wide patient-reported outcome study of 30,000 men
Lifestyle Interventions
For cancer survivors

ASCOT
N=1152 patients with:
Breast
Prostate
Colorectal cancer

Open Access

**BMJ Open** Study protocol for a randomised controlled trial of brief, habit-based, lifestyle advice for cancer survivors: exploring behavioural outcomes for the Advancing Survivorship Cancer Outcomes Trial (ASCOT)

Rebecca J Beeken,¹ Helen Croker,¹ Maggie Heinrich,¹ Lee Smith,² Kate Williams,¹ Allan Hackshaw,³ John Hines,⁴ Michael Machesney,⁴ Madhavan Krishnaswamy,⁵ Sharon Cavanagh,⁵ Rebecca Roylance,⁷ Alison Hill,⁷ Kathy Pritchard-Jones,⁶ Jane Wardle,⁸ Abigail Fisher¹
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2015 NHS England Independent Cancer Taskforce report
Achieving World-Class Cancer Outcomes

- **Recommendation 64**
- To develop a **national metric on quality of life by 2017** which would enable better **evaluation of long-term quality of life after treatment**.
- PROMs should be rolled out across breast, colorectal and prostate cancer by 2020, with evaluation and further rollout across other cancer types.
Cancer Dashboard
Expectation for aggregate-level metric

https://www.cancerdata.nhs.uk/dashboard#?tab=Overview&ccg=02N

To act as a flag and prompt improvement discussions at a Cancer Alliance, commissioner and provider level.

To show the importance of quality of life outcomes, alongside survival and patient experience, encouraging the NHS to place a greater focus on enabling people living with and beyond cancer to live as well as possible.

Other expectation for the future:

• (System) Evaluate economic costs
• (Patient) Inform treatment choices
• (Patient) Understand likely QOL trajectory
Phase 1- Recommended EQ5D-5L and EORTC QLQ-C30

- Considerations
  - Psychometrics
  - Single score
  - Cancer relevance
  - Normative data
  - Level of experience

“In my ideal world, I’d say absolutely, every patient needs the opportunity to have it tailored to them but, with my work hat on, if you’re trying to get this rolled out, there needs to be a big degree of uniformity to get anything useful.”

Lead Research Nurse, Cancer charity

“EQ-5D only has five questions and, generally speaking, for cancer, it’s meaningless. It’s too generic.”

Expert patient, Male
Agreeing the metric – many different expectations (3 of 3)

**Type of data**

**Aggregate data**
- Informing patient choices
- Understanding likely QOL trajectory

**Patient-level data**
- Monitor own progress over time
- Receive support for individual needs

**Understanding level of need by area/patient group**
- Benchmarking against other providers
- Evaluating economic cost of treatment
- Educating clinicians

**Enhanced understanding of individual needs**
- Early identification and treatment of issues

Image above adapted from Ipsos Mori

www.england.nhs.uk/expo | @ExpoNHS | #Expo17NHS
Ongoing Phase 2 - Pilot phase data collection (Sept 2017-mid-2019)

• **Five pilot sites** collect QOL data
• **Digital collection** through existing patient portals (paper allowed)
• **Embedded along patient pathway** – contact points for Recovery Package and stratified follow-up.
• Currently – **by September 2018**
• 444 patients invited
• 293 patients returned
• Equal spread between breast, colorectal and prostate cancer

• **Data linkage with NCRAS**
• **Data analysis** - recommendations for presentation of the metric.
• An independent formative **process evaluation** to assess the practical aspects of data collection during the pilot and generate a **toolkit for the national roll-out**.
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Challenges

• Moving beyond pilot studies to large multi-centre studies - needed but hard to do
• Need for funding schemes that allow large grants (well above the current £250-£300K)
• Study designs – best approaches to study complex care interventions and patient experiences
• Moving towards implementation science studies - NIHR
• Real world data including PROMs
• Understanding the biological/molecular mechanisms of symptoms and adverse events – collaborations with basic scientists, industry, genomics, mathematicians

Opportunities

• Public & society recognition and focus on cancer survivorship
• Dedicated funding schemes
• NHS England QOL metric project will open wider opportunities
• Analysis of routinely collected clinical and PROMs data
• Digital & mobile technology, ‘Big Data’, use of Artificial Intelligence approaches
• Existing wide range of expertise in the NCRI cross-cutting CSG and sub-groups
• Patient and public engagement
• International Collaborations