NCRI and NHS England
Living With and Beyond Cancer 2019

Parallel workshop session:
Models of care
NCRI: The UK Top living with and beyond cancer research priorities

Research question 1
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)?

(https://www.ncri.org.uk/lwbc_question/question-1/)
Workshop outline:

• Short presentation (Agz Lemanska, University of Surrey, 10mins)
  – TrueNTH Exercise and Diet project
  – The role of community pharmacy in supporting people LWBC
• 1\textsuperscript{st} discussion session – group work with feedback (30 mins):
  – MODELS OF CARE & PATIENT JOURNEY
• 2\textsuperscript{nd} discussion session (30 mins)
  – THE ROLE OF RESEARCH
TrueNTH Exercise and Diet UK Project

(www.redi.help)

Dr Agz Lemanska
Lecturer in Integrated Care
University of Surrey

This work was funded by the Movember Foundation, in partnership with Prostate Cancer UK, as part of the True NTH programme, grant number 250-20
TrueNTH global

Improving survivorship outcomes for men, their carers and family members after prostate cancer

World’s largest single investment in prostate cancer care programmes
$41USD million over 3 years

Multi-national collaboration linking initiatives in Canada, Australia, New Zealand, UK & USA
TrueNTH UK
£5.4 million

Projects
- Understanding Consequences
- Needs Assessment
- Supported Self Management
- Exercise & Diet
- Post-surgery Follow up
- Post-radiation Follow up
- Continence Management
- Sexual Wellbeing

https://prostatecanceruk.org/about-us/projects-and-policies/truenth
• 250,000 men living with prostate cancer
  – 40,000 diagnosed per year

• Cancer now a chronic illness

• 84% predicted to live 10 years or more
  – More health problems than other men of a similar age
  – More than 30% will die of cardiovascular disease
Growing evidence beneficial effects of exercise
Moderate intensity 30 minutes for 5 days a week (10 min bouts)

Vigorous intensity 20 minutes for 3 days a week
Activities to build muscle, increase balance, improve flexibility on 2 or more days a week
Why does what you eat matter?
DOES WHEN YOU EAT MATTER?
Lifestyle Prescription Resource pack

The Manual
LOOKING AFTER YOUR HEALTH AFTER TREATMENT FOR PROSTATE CANCER

CHANGES DRIVEN BY YOU

UNIQUE PROGRAM FOR EACH INDIVIDUAL

WE ALL KNOW THAT WE SHOULD EAT MORE HEALTHILY AND EXERCISE. THIS STUDY AIMS TO HELP YOU MAKE A DIFFERENCE AND ENJOY IT ALONG THE WAY.

Stack the odds in your favour

kcal
km
miles
Baseline
• Physical Activity (7-day Actiwatch)
• Questionnaires:
  • Diet habits & quality (MEDAS +6)
  • Activation (PAM)
  • Quality of Life (EPIC-26)
  • QALYS (EQ5D-5L)

Post-intervention: 3 months
• Physical Activity (7-day Actiwatch)
• Questionnaires:
  • Diet habits & quality (MEDAS +6)
  • Activation (PAM)

Post-intervention: 6 months
• Physical Activity (7-day Actiwatch)
• Questionnaires:
  • Diet habits & quality (MEDAS +6)
  • Activation (PAM)
  • Focus groups with Pharmacies
  • Semi-structured interviews with men
  • Quality of Life (EPIC-26)
  • QALYS (EQ5D-5L)
  • Service use
Results: 116 participants

Mean age 70.4 (9 men under 60 to 11 over 80)

87.9% married/partner

76.7% retired

Mean time since diagnosis (1.5 years)

Socioeconomic groupings
- Group 1-3 13.8%
- Group 4-6 20.8%
- Group 7-8 31.9%
- Group 9-10 33.6%

Treatment received:
- Surgery 42.2%
- Radiotherapy 59.5%
- Brachytherapy 3.5%
- Hormone therapy 56.9%

QRisk® 2: 71% scored high risk (>20%)
What did the participants think?
Telephone based interviews (33)

• Change is not relevant, necessary or possible (3)
• None of the changes worked for me (7)
• Some of the changes work for me (16)
• This is the new me! (7)
Five themes (Poole et al. Psycho-Oncology 2019)

• Being “ripe” for lifestyle intervention

I’m just glad that I had the opportunity to do it because it has kick started me[...] I jumped at the chance because I thought well, I’ve either got to do this or just bin it and carry on with how I’m going. It has been the thing that’s been missing for several years, I haven’t looked after myself.

• Functional assessment as a “listening” moment

The steps were a bit of an eye-opener [...] I thought I could do them all day long but I couldn’t.

...it jolted, it sort of reminded you of things that you already knew in my case but being told about it made me do something about it, rather than it's just something you, you know, intellectually knew but weren't doing anything about.

It did really motivate you, thinking blimey, I hadn’t realised the drop out so much since I've had the injections [...] because before that I was, well reasonably fit, I was... surprised.
• Trying out new behaviours

…the muscle mass had gone so badly in my legs and yet funny enough, in that short period of time with the increased walking, the muscle mass has actually come back massively.

• Turning new behaviours into habits

We think we always eat pretty healthily you know, I mean no fry-ups and all that sort of thing and we love fresh vegetables and all that, fruit and that but it’s changed our habits by eating at lunchtimes [...] that’s made a big difference to us I think.

• Social context

…she keeps me on the straight and narrow and I think that’s important because I think if she wasn’t there I would probably... Yeah, I think I probably would fail.
What did the pharmacy staff think?
Different to other community pharmacy service

- Required new skills, more intense, more intimate
- Enjoyed holistic aspect and relationship with men
- Importance of building experience
- Length of consultation
- Integration into other pharmacy work
- Support from University research team

“...grab this opportunity with both hands, it's a real learning experience for you as a pharmacist and it's a real positive way to really show and help, you know, the community, somebody in the community, and it's a real positive thing. We do so many things where... you're just checking and you're just so bogged down with the day-to-day running of the pharmacy, that something like this that comes along, you can really give back and show that you've really made a difference to somebody, and that's what you always want to do.”

Poole et al. Psycho-Oncology 2019: doi.org/10.1002/pon.4983
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Graham Phillips (Pharmacist)
Dr Karen Poole (Surrey)
Prof John Saxton (UEA & Northumbria)
Role of community pharmacy
The specific research question: Can a community pharmacy-led personalised risk assessment and lifestyle prescription for men living with and beyond prostate cancer increase physical activity and improve health?

Given that cancer is frequently accompanied by older age, comorbid conditions and increased risk of cardiovascular disease, community pharmacy-led provision of lifestyle advice could have far-reaching implications for future health and quality of life in this patient group.
Challenges for community pharmacy

- Poor information exchange between primary and secondary care sectors
- The effectiveness of **this model is dependant on better communication** between community pharmacy, primary and secondary care
- Limited ability to provide a continuum of care
- The lack of a coordinated approach to managing comorbidities
- Patients still report unmet information and support needs during and after treatment

This community pharmacy model could be used as a platform for **reducing unmet health needs**, supporting **transition from oncology services to primary care** and supporting people during and beyond cancer treatment.
Community Pharmacies – opportunities and future role

• Model of cancer follow up moving into primary care
• High street, walk-in access to information and support
• Pharmacists skilled to deliver a wide range of NHS services
• Skills and training to understand health risks of cancer and its treatment
• Pharmacies integrated into primary care and public health services
• Signposting and specialist referrals
• National agenda for community pharmacies to work in:
  o Optimising the use of medicines and treatments
  o Supporting people to self-care and live independently
  o Supporting people to make healthier lifestyle choices
  o Reducing risks for diabetes and cardiovascular disease
What next?
1\textsuperscript{st} discussion session – group work (30 mins)

**MODELS OF CARE and PATIENT JOURNEY**

- What is our understanding of models of care?
- How does the ‘full’ patient journey currently look like?
- How could the journey of people LWBC be improved? What are the Barriers, Facilitators and Opportunities to support people LWBC with (e.g.):
  - Healthy lifestyle changes (examples of effective interventions?)
  - Psychological support?
  - Complex care needs?
  - Long-term effects? (any other important support care areas)?

One person feedbacks from each group on the main points
2nd discussion session (30 mins)

THE ROLE OF RESEARCH

• What current research are people already involved in this priority area?

• What are the Opportunities, Gaps and Challenges to generating specific research questions and funding proposals in this priority area?

• The patient voice - how do we best facilitate patient involvement?

• How can we maximise translation and implementation of research into practice?

• What are the gaps in impact? Are we reaching the right people (e.g. those with unmet needs)? How can we maximise impact?