It’s not just about survival: Equipping the primary care workforce to improve the quality of life of people living with and beyond cancer

‘Consequences of Cancer’ was a RCGP Spotlight Project for 2015-16. The project was led by Clinical Leads, Dr Pauline Love and Dr David Linden, and was a collaboration between the RCGP and Macmillan Cancer Support.

Background

In August 2015 the Independent Cancer Taskforce published its strategy for achieving ‘world class cancer outcomes’ in England, which for the first time emphasised the importance of quality of life after cancer, alongside diagnosis and length of survival.¹ Rising cancer incidence, earlier diagnosis and improved treatments mean that increasing numbers of people are living with or beyond cancer. Whereas in the 1970s overall median survival was one year, that has now climbed to almost six years². Half of people diagnosed with cancer today are predicted to survive their disease for at least ten years³. Across the UK there are around 2.5 million people living with cancer and this is projected to increase to over 4 million by 2030⁴.

However not all of these survivors are living well. Many have unmet needs arising from the physical, emotional, practical and financial impact of cancer⁵ including one in four who face poor long term health or disability⁶. Whilst oncologists will always aim to minimise treatment toxicities, it is inevitable that as people live longer they are more at risk of developing complications related to their treatment. Macmillan estimate that around 625,000 people in the UK are experiencing a significant health condition as a result of their cancer treatment – the equivalent of up to 15 patients on a GP list size of 1500. As hospital based cancer follow-up models become less sustainable this will inevitably place a responsibility on primary care professionals to help cancer survivors to live well, through: identifying ongoing support needs; providing information to support self management where appropriate; giving healthy lifestyle advice; and managing the consequences of cancer treatment.

The RCGP/Macmillan Cancer Support Consequences of Cancer Spotlight project builds on work carried out by Macmillan and partners as part of the National Cancer Survivorship Initiative (2008-13), to raise awareness of the needs of cancer survivors among health professionals, and provide resources and guidance to support high quality patient care.

Beneficiaries

The aim of the Consequences of Cancer Spotlight project has been to raise awareness among GPs and other primary care professionals of the needs of patient following treatment for cancer; to support them to identify and manage these needs appropriately; and help patients to live well.

² Macmillan Cancer Support, Living after diagnosis: Median cancer survival times (2012)
⁶ Macmillan Cancer Support, Throwing light on the consequences of cancer and its treatment (2013)
180 GPs completed a survey indicating current practice and confidence in managing problems caused by cancer treatment. The findings showed a wide variation in confidence levels but demonstrated a clear demand for guidance on specific consequences of treatment, and the need for improved communication between primary and secondary care. The resources in the Consequences of Cancer toolkit are intended to address these needs.

The implementation of a joint communications plan between Macmillan and the RCGP has meant that we have been able to highlight these issues to many thousands of primary care professionals through a range of channels. For example:

- 3 articles in RCGP Clinical News enewsletter – approx. reach 48,000 RCGP members
- Regular promotion of the toolkit, survey and workshops in RCGP Chair’s update – approx. reach 50,000
- Toolkit promoted in Macmillan Update enewsletter – approx. reach 7,000 health professionals
- 2 articles in Macmillan Primary Care newsletter – approx. reach 500 GPs and Practice Nurses
- Toolkit and resources feature on Macmillan’s Doctors.net microsite – approx. reach 6,000 GPs
- Promotion through social media by both Macmillan and RCGP

The toolkit was launched at the Macmillan Primary Care Conference in Manchester in November 2015 and we delivered three workshops to introduce the content to delegates. 74 primary care professionals including Macmillan GPs and Practice Nurses attended.

Five workshops have been delivered across England and Wales to a total of 164 primary care professionals, with two further events planned in Scotland and Northern Ireland.

**Measurable Difference**

The main output of the project has been the Consequences of Cancer Toolkit. Working in partnership with the Macmillan Consequences of Treatment team, the Spotlight Project Clinical Leads developed an easy to navigate toolkit providing for the first time a single point of access to a wide range of resources on the support of patients who’ve been treated for cancer. The toolkit brings together clinical guidance for primary care on identifying and managing long term consequences of treatment such as GI problems and cardiotoxicity; introduces the Cancer Recovery Package; and provides a range of patient information and resources to support self management. The toolkit received 1660 views in the first three months following its launch with an average 3.06 minutes spent at each visit, indicating good engagement with the content.

Models of cancer follow-up are changing and in the future more patients are likely to be discharged from hospital-led medical follow-up to a mix of supported self management, shared care and complex case management models, in an effort to more adequately address patient needs in an efficient and cost-effective manner. Primary care professionals therefore need to be aware of the local and national support available to cancer patients, such as health and wellbeing events and exercise referral schemes. The Consequences of Cancer workshops introduced these and signposted attendees to sources of further information, including their local Macmillan GP.

The evaluation of the workshops showed that 100% participants felt the event had increased their knowledge of i) the needs of people living with cancer, and ii) the possible long term effects of cancer treatment. 100% also reported that their confidence to manage common
consequences of cancer treatment had increased. The sessions perceived to be the most useful were the patient accounts of living with consequences of their cancer treatment, and the practical management case studies.

Selection of comments from the evaluation:
- “Enjoyable day, informative, interactive, interesting & extremely relevant to primary care”
- “The consequences of treatment should be included in the RCGP curriculum if not already”
- “This should be a session for all GP trainees as GP’s of the future when there will be even more long term cancer patients”
- “Did not think about this topic before and did not realise there were so many consequences. Also did not realise that keeping physically active was so useful.”

Among the actions delegates pledged at the end of the workshops were to:
- Send out information ahead of the cancer care review to support effective discussion
- Conduct an audit of cancer patients to identify those that may be at risk of consequences of their treatment
- Ask patients about potentially embarrassing symptoms such as bowel problems or sexual difficulties that they may not feel confident to raise themselves
- Signpost primary care colleagues to the resources on the Consequences of Cancer toolkit
- Encourage cancer patients to be physically active during and after treatment

Supporting Information

“Engaging GP's to recognize and treat late pelvic effects of cancer treatment is important generally, but especially for those patients who do not start suffering late effects until they are out of the remit of their hospital. Quality of life for sufferers can be poor, but may be improved quite easily if it is realised the symptoms are treatable. The RCGP Macmillan Consequences of Cancer Spotlight project has brought much needed attention to this under-recognised issue and provides a good basis for future work to ensure late effects are identified and managed appropriately in primary care.”

Pelvic Radiation Disease Association (patient organisation)

Quotes from Macmillan GPs following the launch of the toolkit:
- “Excellent, interactive and engaging as well as educational and giving food for thought- looking forward to using the new toolkit”

- “Really good, will be using info I learned to spread to other GPs & determine educational sessions.”

- “Useful workshop which was done well and thought provoking. I have utilised the resources for sharing with GP colleagues already.”

- “Excellent example of huge gap in knowledge even amongst Mac GPs so imagine the rest!!”

Legacy
Both Macmillan and the RCGP will continue to promote the Consequences of Cancer toolkit as part of their wider programmes of work. The toolkit will remain on the College website indefinitely, to be updated on a regular basis with new resources and guidance for primary care professionals. Further regional workshops in collaboration with College faculties in the Celtic Nations are also planned to disseminate the work and Macmillan’s existing network of GPs and practice nurses will support this.

As part of Macmillan’s ongoing Consequences of Treatment programme we will be reviewing the learning from the Spotlight project and make recommendations for future work to sustain the momentum and relationships developed. Endorsement from the College will be sought where it will add value and areas for further collaboration may be identified.

Consultation with GPs throughout the project has identified future areas for development such as one-page summary information for patients that can be printed off in surgery. The survey also provided useful data around specific consequences of cancer treatment that GPs felt less confident to manage such as endocrine problems (62% not confident). Macmillan will be taking forward work in these areas in 2016, continuing to work in partnership with other charities and professional bodies to produce high quality evidence based guidance for patients and professionals. We are also working on a training pack for GPs to support them to cascade the resources and guidance to local primary care colleagues.

The Clinical Leads have been feeding into plans for a conference on the Late Medical Effects of Cancer Treatment on 11th November 2016, a joint meeting of RCP, RCGP, RCPATH, RCR & Late Effects Group Sheffield (LEGS). This is an area of healthcare that by necessity crosses a number of different specialties and this event will be the first of its kind in bringing together UK colleagues from the different Colleges to recognise this issue and explore ways to address it and improve work across boundaries.

Macmillan are committed to an ongoing programme of work to ensure that the identification and management of cancer related consequences is a recognised issue within primary care, and that health professionals, patients and their carers are supported to identify and manage problems appropriately.

Collaborating with the College on this Spotlight project has enabled us to raise awareness of this important and under recognised issue among a wider GP audience at both a national and regional level.