My Journey Kit survey 2014

Executive Summary

In June 2014, BCNA conducted a survey of women who had received My Journey Kit in the previous 18 months. This survey was undertaken to inform a comprehensive review of My Journey Kit that will be carried out during 2014. Production of the third edition of My Journey Kit is expected to be completed in early 2015.

Survey aim

The aim of the survey was to hear women’s thoughts on:

- the quality, relevance, content, and look-and-feel of the current My Journey Kit
- whether there are any information gaps, or emerging needs
- their opinions on what online / digital delivery of information would be of value.

Distribution

The survey was sent to 558 women who had received a My Journey Kit in the previous 18 months -- 358 members of BCNA’s Review & Survey Group were invited to complete an online survey, and 200 My Journey Kit recipients without an email address were sent a hard copy of the survey by mail. In total, 138 anonymous responses were received (107 completed online, 38 hard copy responses).

“It [My Journey Kit] was very helpful. It gave me the feeling that there are people who care and that I’m in good hands. It made me more optimistic.”

Results

The results presented here represent the key findings of the survey, however all feedback has been reviewed and will be taken into account in the ongoing development of My Journey Kit.

Demographics

Of those who completed the survey:

- 60% indicated they were from a major city, and 39% were from regional or rural areas.
- The majority of respondents were in the 50-59 age group (32%). 26% were in the 40-49 age group and 28% in the 60-69 age group. 9% indicated they were over 70 years of age.
- 12% of respondents indicated they spoke a language other than English at home.
- 83% indicated they live with their partner/spouse or family, and 13% said they live alone.

Information sources

Survey respondents were asked where they go to find health information, and what technologies they use.

Responses indicated:

- the majority of respondents (96%) use a health professional to find health information. 79% also use the internet, and 34% use friends.
- When using technology, tablets or other hand held devices are more likely to be used ‘a lot’ (34%), followed by desktop computers (25%), laptops (24%) and smartphones (13%).
- However, when reading a lot of information (like a fact sheet, chapter of a book or information guide) printed format is preferred (78%).

“I liked the fact that it was paper (not on info tech) as this is the most practical for me, I can pick it up at any time, take it anywhere, is less harsh on the eyes “
My Journey Kit overall

Satisfaction with the amount of information

- 93% of respondents indicated they were either ‘very satisfied’ (70%) or ‘satisfied’ (23%) with the amount of information in *My Journey Kit*.

- **Very satisfied with the amount of information**: 70% (81)
- **Satisfied with the amount of information**: 23% (27)
- **Dissatisfied - I'd like MORE information**: 2% (2)
- **Dissatisfied - I'd like LESS information**: 3% (3)
- **I don't remember / I'm unsure**: 3% (3)

“It [My Journey Kit] is a tremendous resource & it’s a great idea to have it boxed up. It also should be ordered for you on diagnosis so you receive it ASAP."

Usefulness

When asked **how useful** they found the *My Journey Kit* components:

- 95% indicated they found the *Cancer Australia Guide for women with early breast cancer* ‘very useful’ or ‘somewhat useful’. 
- 90% found the *My Journey Kit Information guide* ‘very useful’ or ‘somewhat useful’. 
- 85% found the *Beacon* magazine included in the pack ‘very useful’ or ‘somewhat useful’. 
- The *Personal record* was considered ‘very useful’ or ‘somewhat useful’ by 63% of respondents, and not useful at all by 21% of respondents. 
- The *Cancer Australia DVD ‘When the woman you love has breast cancer’* for partners was considered ‘very useful’ or ‘somewhat useful’ by 36% of respondents and ‘not useful at all’ by 13% of respondents.

“I found it [My Journey Kit] extremely useful. If I didn't feel I had enough information on some part, I looked for it. It helped to keep me informed and I didn't feel I was doing this on my own.”

Look and feel of My Journey Kit

Respondents indicated they **liked** the following aspects of *My Journey Kit*, ‘a lot’ or ‘a little’:

- The organisation of the content of the Information Guide (sections) (87%)
- The size of the Information Guide (83%)
- The photos in the Information Guide (81%)
- The colour of the kit (76%)

The highest responses of ‘didn’t like it much’ or ‘didn’t like it at all’ were:

- The amount of space available to write in the Personal Record (13%)
- The size of the Personal Record (13%) – (includes those who thought it is too big as well as those who consider it too small)
Information Guide

- The majority of respondents considered that the amount of information in the different parts of the Information Guide was ‘just right’ for all sections of the Guide (63-84%).
- The sections most commonly deemed to include ‘not enough’ information were Section 5: Life after treatment (18%), and Section 3: Breast cancer and treatment (13%), although the number of women who thought that there was not enough information was fairly small.

The main topics where respondents indicated that they had received enough information were:
- Emotional wellbeing (76%)
- The impact of breast cancer on relationships (74%)
- Healthy eating and breast cancer (73%)
- Physical activity and breast cancer (72%)
- Anxiety and depression (70%)
- Practical assistance during treatment (65%)

The main topics where respondents would have liked more information were:
- Side effects associated with treatment (29%)
- Lymphoedema (24%)
- Complementary therapies (e.g. massage, acupuncture, meditation) (23%)
- Recurrence of early breast cancer (21%)
- Breast reconstruction (19%)

“The kit is extensive and covers a lot more than I needed, but that isn't a bad thing. Overall I found it very helpful and you don't know before what areas you need info on, so good to have it all there to choose from.”

Personal Record (Diary)

When asked did you use the Personal Record at all, 53% said yes and 46% said no. Of those who used the Personal Record, the sections they used ‘a lot’ or ‘occasionally’ were:
- Personal information (83%)
- Appointments (81%)
- Treatment (79%)
- Journal (72%)
- Contacts (73%)

Sections that respondents indicated they ‘did not use at all’ were:
- Donation form (67%)
- A5 plastic sleeves (57%)
- Expenses tracking form (46%)

Delivery via technology

When asked whether they would be likely to use a range of technologies to read or access the My Journey Kit, the highest support was for the Information Guide to be provided in digital format, either online via the BCNA website (54%), or via an app for phone or tablet (17%).

There was also support for a digital ‘symptom tracker’ delivered online via the BCNA website (34%) or as an app for phone or tablet (28%), and for the Personal Record as an app for phone or tablet (24%). Some support was also expressed for providing an ‘expenses tracker’ via the BCNA website (23%) or as an app for phone or tablet (16%).

The lowest support was for resources provided in eBook format and on CD/DVD/USB stick. In addition, 49% said they would not use audio files ‘at all’ and 42% said they would not use video files ‘at all’.

Feedback or questions relating to this survey or the survey results should be directed to BCNA. Phone: 1800 500 258 or policy@bcna.org.au.