Title: Availability and quality assessment of online nutrition information materials for pelvic cancer patients in the UK.

Running title: Online nutrition information in pelvic cancer

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Conflicts of interest

The authors have no financial conflict of interests related to the work described in the paper.

Acknowledgements

We would like to thank all PPI members who provided feedback for a number of PIMs. Their time and contribution is greatly appreciated.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Ethical statement

For the assessment of face validity – Public and Patient Involvement (Section 2.4)
Ethical approval was given by the University Research Ethics Committee (UREC), Oxford Brookes University (UREC 171150).

Abstract

Written information can be an essential source of support in the promotion of lifestyle changes after a cancer diagnosis. This study aimed to identify and assess the quality of available online Patient Information Materials (PIMs) in relation to diet and nutrition for pelvic cancer patients. The online sources of the National Health Service, cancer centres and charitable organisations throughout the UK were searched. Content was assessed using an evidence-based checklist, and readability with two validated formulas. Consumer feedback was sought through Patient and Public Involvement (PPI) groups. Forty PIMs were identified; four were designed specifically for pelvic cancers (bladder, bowel, prostate) and 36 were generic (relevant for all cancers). Most PIMs had a good content score, with PIMs from charities scoring higher overall than PIMs from cancer centres [32 (4) Vs 23 (11), $P<0.001$]. Seventy-three percent of PIMs had a readability score within acceptable levels (6^{th}-8^{th} grade; reading ability of 11-14 year-olds). PPI contributors found most PIMs useful and comprehensive but lacking specific information needed to meet individual needs. There is limited availability of online PIMs for cancer survivors and even fewer tailored to pelvic cancers. Most materials have comprehensive content and acceptable readability. Some PIMs may require improvement.

Keywords: pelvic cancers, nutrition, patient information, quality, readability, public and patient involvement

1. Introduction

Information and support are important components of health care, promoting active participation and patient self-management. Provision of oral and written information can increase awareness and enhance shared decision making (National Institute for Health and Care Excellence, 2012). Patient Information Materials (PIMs) complement verbal messages from healthcare professionals and are considered an essential source of additional support for patients. They can be stored and read several times at a patient's own convenience and, therefore, may contribute to knowledge in the long term (Wills & Holmes-Ronver, 2003; Wallace, et al., 2009).

A cancer diagnosis is perceived as a 'teachable moment' in people's lives when they may be more receptive to considering changes in lifestyle, such as diet (Fletcher, et al., 2017). The Department of Health (2013) has highlighted the importance of educating patients and promoting lifestyle changes in order to enhance recovery and health soon after cancer treatment. Development of services to support cancer survivors to live as healthy a life for as long as possible is a priority, with a focus on shared decision making and patient self-management to improve recovery and reduce demand and costs in the NHS (Department of Health, 2013). Patients diagnosed with cancer in the pelvis (anus, bladder, bowel and reproductive organs) may benefit from dietary modifications, which have shown to alleviate treatment side effects and increase patients' quality of life (Mohamad, et al., 2015; Smits, et al., 2015; Stacey, et al., 2015). There is also evidence that dietary patterns may have an impact on cancer recurrence and mortality (Van Blarigan and Meyerhardt, 2015; Jochems et al., 2018).

Provision of dietary advice in the healthcare setting has been shown to be sub-optimal, as many patients report unsatisfactory experiences of nutritional care in relation to cancer, thus highlighting a gap in survivorship care (National Institute for Health Research, 2015). Studies have shown that colorectal and prostate cancer patients would like to receive guidance in diet and nutrition post-diagnosis to improve health (Coa, et al., 2015; Anderson, Steele & Coyle, 2013; Bours, et al., 2015). Such guidance may influence behaviour change; however, information processing and, consequently, elaboration to behaviour change are complex procedures that rely on perceived relevance of the topic, quality of the message and credibility of the source that provides that message (Wilson, 2007). Information needs to be accessible and appropriate to all patients including "hard to reach" groups, such as older people, black, Asian and minority ethnic (BAME) groups and people who do not speak English (Iliffe, et al., 2017). PIMs that provide simple, targeted, evidence-based and culturally appropriate messages on diet and nutrition from credible sources such as clinical settings and charitable organisations, and are available to all cancer patients, could prompt behaviour change. Guidance on the development of comprehensive PIMs includes evidence-based preparation, readability assessment, content assessment and consumer testing (Lampert, Wien, Haefel & Seidling, 2016; Beaunoyer, Arsenault, Lomanowska & Guitton, 2017). Patient involvement has been reported as an essential part of the quality assessment of PIMs, as it reflects patients' perceived information needs (Smith et al., 2014).

Although health professionals are considered the most reliable providers of dietary information, inadequate support may turn patients to look for information on the internet (Playdon, et al., 2016; Hartoonian, et al., 2014). PIMs in diet and nutrition available online may be a useful aid both for symptom management and for the

prevention or management of other diseases, such as cardiovascular diseases, diabetes or a secondary cancer. The aim of this study was therefore to identify the availability and assess the quality of PIMs in relation to diet, nutrition and cancer survivorship suitable for patients with pelvic cancers.

2. Methods

2.1 Identification of Patient Information Materials (PIMs)

Online PIMs related to diet and nutrition for pelvic cancers (anal, bladder, bowel and reproductive organs) were identified through systematic searches of the National Health Service (NHS), NHS cancer centres and charitable organisations websites in the UK. PIMs were included if they provided information about diet and nutrition for general health, weight management or management of treatment-related side effects for pelvic cancer. PIMs which provide dietary information for generic cancer were also included, as they were deemed relevant for pelvic cancer patients.

2.1.1 NHS

A search of PIMs was conducted by checking the NHS websites in England, Scotland, Wales and Northern Ireland. Focus was given to the NHS Choices, section “Cancer” (2017), NHS Inform Scotland, section “Cancer” (2017), NHS Direct Wales, section “Cancer” (2017) and Health and Social Care Online Northern Ireland (2017) websites. All sections relevant to cancer were searched. The keywords ‘cancer’, ‘diet’ and ‘nutrition’ were also used in each website’s search box.

2.1.2 Cancer centres

There is currently no comprehensive list of cancer centres in England available. Cancer centres were identified from NHS Choices, section “Services” (2017), the Organisation of European Cancer Institutes (2017) and a Google search.

The key phrase ‘cancer centre’ was used in the NHS England and Google search boxes. Cancer centres in Scotland, Wales and Northern Ireland were identified from the National Cancer Patient Experience Surveys for Scotland (Quality Health, 2015), Wales (Quality Health, 2014) and Northern Ireland (Quality Health, 2015) respectively. In every centre’s website, information under the sections “patient information leaflets” and “dietetics and nutrition” were searched.

2.1.3 Charitable organisations

Identification of charities was through the Charity Commission for England and Wales (2017), the Charity Commission for Northern Ireland (2017) and the Office for the Scottish Charity Regulator (2017). Charities that relate to each pelvic cancer type, as well as generic cancer, were searched. Using the advanced search option, each of the following keywords was typed in the keyword box: cancer (when looking for generic cancer charities), prostate cancer, testicular cancer, ovarian cancer, bladder cancer, urological cancer, cervical cancer, bowel cancer, colorectal cancer, rectal cancer, anal cancer, endometrial cancer, uterine cancer, vulvar cancer, womb cancer, male cancer, gynaecological cancer and female cancer. To identify PIMs relevant to the aim of this study, only charities with a remit relating to the advancement of health and/ or the provision of advice, advocacy or information were included. Due to the large number of generic charities in England and Wales, only the ones with an income over £25,000 (financial year 2016-2017) were included. Any materials available up to December 2017 were included.

2.2 Assessment of content

An adapted version (Coulter 2006) of “The International Patient Decision Aids Standards instrument” (IPDASi) (Elwyn, et al., 2006) was used for the assessment of

content. IPDASi is a validated assessment tool, which was originally developed to assess decision aids about treatment or screening options. Coulter et al. (2006) slightly adapted the IPDASi with elements from the DISCERN instrument (Charnock, Shepperd, Needham & Gann, 1999) to reflect differences in the assessment of the content of health-related materials, including healthy eating and obesity. The adapted checklist underwent three rounds of pilot testing before use. It consists of eight categories (Table 1). In each category, a minimum of one point and a maximum of five can be given, depending on the clarity of information provided. One point was given when the material did not meet the criteria in any way and five points when the material completely fulfilled the quality criteria. Scores of 2, 3 and 4 were awarded for materials which partially met the criteria with the actual score depending on the assessor's evaluation. The higher the score, the better the quality of the content is. An additional point is given if the material provides information on social care issues. The first reviewer (GS) assessed the content of all PIMs and a subsample was checked by a second reviewer (JB). Any uncertainties were discussed among all authors, until an agreement was reached.

[Table 1 here]

2.3 Assessment of readability

The readability of PIMs was determined using the Flesch-Kincaid Grade Level (FKGL) (Kincaid, Fishburne, Rogers & Chissom, 1975) and the Simplified Measure of Gobbledygook (SMOG) Grade (McLaughlin, 1969). FKGL is a widely used readability tool, and the SMOG grade is considered the gold standard in health-related information and education materials (Ley & Florio, 1996). All tools have been previously validated and shown good reliability (Ley & Florio, 1996). FKGL uses the

number of words per sentence and the number of syllables per word in an equation to calculate the US school grade level necessary to understand the text (Kincaid, Fishburne, Rogers & Chissom, 1975). The SMOG grade also reflects to the US school grade and is based on the square root of the number of words with three or more syllables on a total of thirty sentences (McLaughlin, 1969).

A random sample of approximately 500 words from each PIM was examined using software that includes both instruments described above (Automatic Readability Checker, 2017). In this paper we present the reading grade level and corresponding age range and reading difficulty as indicated in Table 2. A readability level of US grade 8 corresponds to the reading ability of 13-14 years old and is generally considered the upper acceptable level for the US population. The Joint Commission suggests PIMs should read on a grade 5 level or lower, which corresponds to the reading ability of 10-11 years old (The Joint Commission, 2010).
[Table 2 here]

2.4 Assessment of face validity

Patient and Public Involvement (PPI) contributors were invited through advisory groups, support groups and PPI web forums, to assess the face validity of a sample of the materials. Those who expressed an interest were asked to provide feedback anonymously by answering four open-ended questions regarding the quality of the content, the ease of reading and whether the information they contained was helpful for them.

- How would you rate the information provided in this leaflet?
- How easy was it for you to understand the information?
- How helpful was the leaflet for you?

- Would you change anything?

PPI contributors were provided with PIMs with a range of scores in terms of content and readability. Each contributor was given up to three PIMs. Where possible, members reviewed PIMs that were related to their own type of cancer diagnosis. For example, a prostate cancer survivor would review a PIM from a prostate cancer charity.

2.5 Analysis

Content and readability scores were analysed descriptively using the SPSS Statistical Package, version 23.0 (SPSS INC., Chicago, IL, USA). Normality of the content and readability data distribution for was assessed with the Shapiro-Wilk test. Mann-Whitney U test was used for the analysis of the content and readability of PIMs from different sources. Results are presented as median and Interquartile Range [Median (IQR)]. Statistical significance was set at $P<0.05$. Feedback from PPI is presented as a summary.

3. Results

3.1 Identification of PIMs

3.1.1 NHS

No information regarding diet or nutrition for any cancer type was found in NHS Choices, NHS Direct Wales or Health and Social Care Northern Ireland. The NHS Inform Scotland website had information under the sections “Exercise, diet and healthy living” and “Eating and digestion”. In all NHS websites, there were links to various charities’ website pages. Macmillan Cancer Support and Cancer Research UK were the most frequently mentioned sources for information on diet and nutrition after a cancer diagnosis.

3.1.2 NHS Cancer Centres

Fifteen cancer centres were identified, eight of which provided information about diet (Table 3). Across these eight centres, a total of 26 PIMs were identified online, all of which were generic cancer PIMs and in the form of leaflets or booklets (Table 4). PIMs covered mainly topics related to diet during treatment, such as management of treatment-related symptoms and use of soft/liquidised food. PIMs from all cancer centres were available to download and print.

3.1.3 Charitable Sector Organisations

An initial search yielded 319 results. After removing duplicates (*n*=37) and checking all websites, eight charities were found to provide information about diet after cancer diagnosis. Four charities provided cancer-specific PIMs and four charities provided generic PIMs (Table 3). Thirteen online PIMs were identified and assessed (Table 4). Topics covered in the materials include healthy eating, management of treatment-related symptoms and weight management. All charities provided information about diet in the form of booklets available to download and

print, with the exception of Cancer Research UK, which had online information organised in sections.

[Table 3 here]

3.2 Assessment of content

A total of 40 PIMs were assessed. There was a wide range of scores for content (16 – 37/40). Overall, materials from charities scored higher [32 (4); *n*=13] than those from cancer centres [23 (11), P<0.001; *n*=26]. Comparison of PIMs from NHS sources with PIMs from other sources could not be performed, due to the small number of PIMs from the NHS (*n*=1). Most materials scored high in the categories "Clarity of aims" and "Clear structure and layout" (4 – 5/5). PIMs from six charities and four cancer centres (*n*=17) had the Information Standard logo, indicating that the organisations "have been certified as a producer of reliable health and social care information".

The range in scores is primarily a result of the content quality of PIMs provided by cancer centres. Materials from five cancer centres had an overall high content score whereas materials from three centres scored low in most categories of the checklist (Table 4).

3.3 Assessment of readability:

Table 4 shows the grade reading level of all PIMs. The median reading grade level was 7.5 (2.1) for FKGL and 7.4 (1.7) for SMOG (p>0.05). No PIM scored as low as the recommended level of 5th grade (reading ability of 10-11 years old). Eight PIMs from charities (61.5%) and 21 PIMs from NHS/cancer centres (77.8%) had a readability score within acceptable reading grades (6th to 8th grade level; reading

ability of 11-14 years old). Eleven PIMs (27.5%) scored higher than 8th grade level (reading ability of 13-14 years old). Materials from charities had a similar average readability level [8.1 (2.1)] to materials from cancer centres [7.2 (1.8); p=0.076].

3.4 Assessment of face validity

Sixteen PPI members (7 females, 9 males) evaluated eleven PIMs; seven were developed by charities (four pelvic-cancer specific and three generic) and four by cancer centres. PIMs had a variety of scores in content (18-37/40) and readability (6.2-11). PPI contributors generally praised the quality of these PIMs, as information was generally considered up-to-date with the latest evidence. Information was presented in a simple, direct and straightforward way, especially for smaller PIMs. Also, some PIMs had references for external sources of information and support, which was perceived as positive. However, two PPI contributors questioned the accuracy of information related to consumption of sugar, fizzy drinks and alcohol in some PIMs. Also, according to feedback, pictures did not reflect the educational purpose of the PIMs, as it was not clear what they were trying to portray. For example, an older cancer patient would not perceive a picture of a young person exercising as a realistic motive to increase physical activity to 30 minutes per day. Most PIMs were easy to read and structure was appropriate to navigate easily and find relevant information. Language was considered simple in most PIMs and layout was clear. In larger PIMs, consumers noted that a more concise version would be easier to read.

PPI members thought that the content of most PIMs contained useful information and they would make an informed decision about diet based on it. Most of them did not find the information relevant to their current health status (which was expected),

but noted that most PIMs would be useful to newly diagnosed cancer patients, patients who have not considered changing their lifestyle before, or patients who experience specific side effects. Some PIMs would benefit from information about special diets (e.g. vegetarian), according to feedback. In some PIMs, purpose and target audience needed to be explicitly mentioned at the beginning of the material. Consumers found that PIMs related to healthy eating after cancer treatment did not include advice for nutrition issues during treatment and vice versa. Finally, feedback for generic leaflets highlighted the need to address individual needs and provide some information for specific cancers, particularly the common ones (e.g. prostate). PPI feedback was generally positive for all given PIMs, irrespective of their content or readability scores.

[Table 4 here]

4. Discussion

Our study identified 40 online PIMs available from nine NHS sources (NHS Inform Scotland and eight NHS cancer centres) and eight charitable organisations. Considering the importance of providing sound nutritional advice after a cancer diagnosis in relation to weight management, nutritional management of side effects and healthy eating for future wellbeing (Demark-Wahnefried, et al., 2015; Richman, Carroll & Chan, 2012; Koutoukidis, Knobf & Lanceley, 2015; Van Blarigan & Meyerhardt, 2015), it is important that such information is widely available. Development of materials from cancer centres indicates that information may be provided in some geographical regions of the UK. However, not all cancer centres had information about diet and nutrition online. Similarly, the NHS Scotland website had information about diet and nutrition in cancer survivorship, whereas the NHS England, Wales or Northern Ireland websites did not. Williams et al. (2015) has highlighted the lack of any information about lifestyle (diet, physical activity, alcohol or smoking) in cancer survivorship in the NHS England website, despite it being the most preferred source of information for many patients in England (Rozmovits & Ziebland, 2004).

Patients may choose to look for nutritional information from a charity specific to their cancer, as they may expect to find information tailored to their individual needs. This study showed that only four cancer specific charities provided such information. Few charities websites had external links of information to generic cancer charities (this was not further assessed) but most websites did not include any information on diet and nutrition. Consumer feedback highlighted the need for tailored nutritional information from reliable sources, especially post-treatment. Results from qualitative studies have shown that when cancer patients receive

dietary advice, it is often broad and does not meet their current needs and expectations (Anderson, Steele & Coyle, 2013; Hardcastle, et al., 2017; Sutton, et al., 2017; Kwok, Palermo & Boltong, 2015).

The variety in content scores from the checklist was not reflected in PPI consumers' feedback. According to the checklist, most PIMs had a clear structure and layout and included information based on the available (limited) scientific evidence; however, some PIMs would benefit from modifications. On the other hand, consumers' comments focussed mostly on the quality and the practicality of the information, which was considered adequate to make an informed decision in most cases. The IPDASi checklist contains some elements which may not be perceived as essential for cancer survivors, such as presentation of a reference list or the authors' credentials. Nevertheless, provision of PIMs from reliable sources, such as cancer centres and charities, may lead survivors to believe that PIMs have been created from experts who use the latest available evidence; hence the reason why no comments on credentials or references were made where this information was missing.

In terms of readability, although most of the PIMs in this study had an overall acceptable readability score, 28% of them may be perceived as hard to read. Given that 43% of the working population in the UK has low health literacy (Protheroe, et al., 2017), it may be difficult for all cancer patients to fully understand the content of the current PIMs and this could contribute to health inequalities (Protheroe, et al., 2017; Public Health England, 2015). Even though health literacy may not predict adherence to nutritional guidelines, especially among patients with chronic non-communicable diseases (Carrara & Schulz, 2018), PIMs should score within acceptable readability levels to enhance understanding.

The importance of patient and public involvement (PPI) in health and social care research has been highlighted in a recent systematic review (Brett, et al., 2014). Feedback from PPI contributors in our study highlighted a number of positive and negative points about the PIMs that could not have been identified from the evaluation of content or readability. Involvement of service users is strongly recommended in the design of new PIMs and upgrade of existing ones and could possibly contribute to greater understanding and adherence (Smith, et al., 2014; Dellson, Nilbert & Carlsson, 2016).

This study has both strengths and limitations. Assessment of quality was performed using three parameters; content, readability and face validity, as suggested by Beaunoyer et al. (2017) for the evaluation of online health information. It was not possible to assess the evidence base for the preparation of these materials. The content assessment tool was previously used in the assessment of health-related PIMs produced by UK organisations. One section of the checklist (presentation of probabilities of outcomes) was not relevant to PIMs about diet and nutrition but may be useful for the assessment of other health-related information materials. Also, involvement of patients provided in-depth information about the usefulness of the PIMs; patients or consumers active in research are often highly educated and more knowledgeable about healthcare issues and their views may not reflect the views of all pelvic cancer patients. PPI contributors' level of participation was limited to the provision of feedback based on four open ended questions.

This is not an exhaustive study of resources, as only materials available online were evaluated. For cancer centres, PIMs provided at the healthcare settings may be different to the ones currently available on the websites, as the websites may have not been updated with the latest versions. Access to online information may still

be a challenge for older populations, who may have low digital literacy. Finally, the authors acknowledge that new PIMs may have been created and current PIMs may have been updated since the end of the evaluation (December 2017).

5. Conclusion

The current study found a limited number of online PIMs in diet and nutrition suitable for pelvic cancer populations. Most PIMs had a comprehensive content; however, some PIMs may benefit from modifications. PPI contributors were more interested in the practical information within the PIMs and provided overall positive feedback, irrespective of content or readability score. They also highlighted the need for tailored and evidence-based information in diet and nutrition for symptoms management and improving health. In future, accessible, evidence-based diet and nutrition information should be made more widely available on NHS and charity sites.

REFERENCES

Anderson, A. S., Steele, R., & Coyle, J. (2013). Lifestyle issues for colorectal cancer survivors—perceived needs, beliefs and opportunities. *Supportive Care in Cancer,21*(1), 35-42. doi:10.1007/s00520-012-1487-7

Automatic Readability Checker. (2017). Available at: http://www.readabilityformulas.com/free-readability-formula-tests.php. (accessed November 2017).

Beaunoyer, E., Arsenault, M., Lomanowska, A. M., & Guitton, M. J. (2017). Understanding online health information: Evaluation, tools, and strategies. *Patient Education and Counseling,100*(2), 183-189. doi:10.1016/j.pec.2016.08.028

Bours, M. J., Beijer, S., Winkels, R. M., Duijnhoven, F. J., Mols, F., Breedveld-Peters, J. J., . . . Poll-Franse, L. V. (2015). Dietary changes and dietary supplement use, and underlying motives for these habits reported by colorectal cancer survivors of the Patient Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship (PROFILES) registry. *British Journal of Nutrition,114*(02), 286-296. doi:10.1017/s0007114515001798

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014). Mapping the impact of patient and public involvement on health and social care research: A systematic review. *Health Expectations,17*(5), 637-650. doi:10.1111/j.1369-7625.2012.00795.x

Carrara, A., & Schulz, P. J. (2018). The role of health literacy in predicting adherence to nutritional recommendations: A systematic review. *Patient Education and Counseling,101*(1), 16-24. doi:10.1016/j.pec.2017.07.005

Charity Commission for England and Wales. (2017) Available at: http://apps.charitycommission.gov.uk/showcharity/registerofcharities/RegisterHomePage.aspx. (accessed November 2017).

Charity Commission for Northern Ireland (2017) https://www.charitycommissionni.org.uk/ (accessed November 2017).

Charnock, D., Shepperd, S., Needham, G., & Gann, R. (1999). DISCERN: An instrument for judging the quality of written consumer health information on treatment

choices. *Journal of Epidemiology & Community Health,53*(2), 105-111. doi:10.1136/jech.53.2.105

Coa, K. I., Smith, K. C., Klassen, A. C., Thorpe, R. J., & Caulfield, L. E. (2015). Exploring Important Influences on the Healthfulness of Prostate Cancer Survivors' Diets. *Qualitative Health Research,25*(6), 857-870. doi:10.1177/1049732315580108

Coulter, A., Ellins, J., Swain, D., Clarke, A., Heron, P., Rasul, F., Magee, H. & Sheldon, H. (2006) *Assessing the quality of information to support people in making decisions about their health and healthcare*. Picker Institute Europe. ISBN 978-1905945030

Dellson, P., Nilbert, M., & Carlsson, C. (2016). Patient representatives' views on patient information in clinical cancer trials. *BMC Health Services Research,16*(1). doi:10.1186/s12913-016-1272-2

Demark-Wahnefried, W., Rogers, L. Q., Alfano, C. M., Thomson, C. A., Courneya, K. S., Meyerhardt, J. A., . . . Ligibel, J. A. (2015). Practical clinical interventions for diet, physical activity, and weight control in cancer survivors. *CA: A Cancer Journal for Clinicians,65*(3), 167-189. doi:10.3322/caac.21265

Department of Health and Social Care (2015) NHS Outcomes Framework 2015-2016. Retrieved from https://www.gov.uk/government/publications/nhs-outcomes-framework-2015-to-2016.

Department of Health. (2013). Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision). Retrieved from https://www.gov.uk/government/publications/living-with-and-beyond-cancer-taking-action-to-improve-outcomes.

Elwyn, G. (2006). Developing a quality criteria framework for patient decision aids: Online international Delphi consensus process. *Bmj,333*(7565), 417-0. doi:10.1136/bmj.38926.629329.ae

Fletcher, C., Flight, I., Chapman, J., Fennell, K., & Wilson, C. (2017). The information needs of adult cancer survivors across the cancer continuum: A scoping review. *Patient Education and Counseling,100*(3), 383-410. doi:10.1016/j.pec.2016.10.008

Jochems, S. H. J., Van Osch, F. H. M., Bryan, R. T., Wesselius, A., van Schooten, F. J. Cheng, K. K., Zeegers, M. P. (2018). Impact of dietary patterns and the main food

groups on mortality and recurrence in cancer survivors: a systematic review of current epidemiological literature. *BMJ Open, 8*(2), e014530. doi:10.1136/bmjopen-2016-014530

Hartoonian, N., Ormseth, S. R., Hanson, E. R., Bantum, E. O., & Owen, J. E. (2014). Information-Seeking in Cancer Survivors: Application of the Comprehensive Model of Information Seeking to HINTS 2007 Data. *Journal of Health Communication,19*(11), 1308-1325. doi:10.1080/10810730.2013.872730

Health and Social Care Northern Ireland. (2017) Retrieved from http://online.hscni.net/. (accessed December 2017).

Iliffe, S., Walters, K., Manthorpe, J., Goodman, C., & Kharicha, K. (2017). Health and well-being promotion strategies for 'hard to reach' older people in England: A mapping exercise. *Primary Health Care Research & Development, 18*(6), 563-573. doi:10.1017/S1463423617000378

Kincaid, J. P., Fishburne, R. J., Rogers, R. L., & Chissom, B. S. (1975). Derivation of New Readability Formulas (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for Navy Enlisted Personnel. doi:10.21236/ada006655

Koutoukidis, D. A., Knobf, M. T., & Lanceley, A. (2015). Obesity, Diet, Physical Activity, and Health-Related Quality of Life in Endometrial Cancer Survivors. *Nutrition Reviews,73*(6), 399-408. doi:10.1093/nutrit/nuu063

Kwok, A., Palermo, C., & Boltong, A. (2014). Dietary experiences and support needs of women who gain weight following chemotherapy for breast cancer. *Supportive Care in Cancer,23*(6), 1561-1568. doi:10.1007/s00520-014-2496-5

Lampert, A., Wien, K., Haefeli, W. E., & Seidling, H. M. (2016). Guidance on how to achieve comprehensible patient information leaflets in four steps. *International Journal for Quality in Health Care,28*(5), 634-638. doi:10.1093/intqhc/mzw077

Ley, P., & Florio, T. (1996). The use of readability formulas in health care. *Psychology, Health & Medicine,1*(1), 7-28. doi:10.1080/13548509608400003

McLaughlin, G. H. (1969). SMOG grading: a new readability formula. *Journal of Reading*, *12*, 639-646.

Mohamad, H., Mcneill, G., Haseen, F., N'Dow, J., Craig, L. C., & Heys, S. D. (2015). The Effect of Dietary and Exercise Interventions on Body Weight in Prostate Cancer

Patients: A Systematic Review. *Nutrition and Cancer,67*(1), 43-60. doi:10.1080/01635581.2015.976313

National Institute for Health Research. (2015). Cancer and Nutrition NIHR infrastructure collaboration: Report of Phase One., University of Southampton & University Hospital Southampton NHS Foundation Trust. Retrieved from http://cancerandnutrition.nihr.ac.uk/wp-content/uploads/2016/06/Cancer-Nutrition-Full-Report-FINAL_03-06-16.pdf

NHS Choices (section Cancer) (2017). Retieved from https://www.nhs.uk/conditions/Cancer/. (accessed December 2017).

NHS Choices, (section Services; cancer centres). (2017). Retrieved from https://www.nhs.uk/service-search/Disambiguation/Organisation?serviceName=cancer%20centre. (accessed December 2017).

NHS Direct Wales (section Cancer). (2017). Retrieved from https://www.nhsdirect.wales.nhs.uk/encyclopaedia/c/article/cancer. (accessed December 2017).

NHS Inform Scotland (section Cancer). (2017). Retrieved from https://www.nhsinform.scot/illnesses-and-conditions/cancer. (accessed December 2017).

Office for the Scottish Charity Regulator (2017) https://www.oscr.org.uk/. (accessed November 2017).

Organisation of European Cancer Institutes, Membership: United Kingdom. (2017). Retrieved from http://www.oeci.eu/Membership_I.aspx?Id_Country=21. (accessed December 2017)

Playdon, M., Ferrucci, L. M., Mccorkle, R., Stein, K. D., Cannady, R., Sanft, T., & Cartmel, B. (2016). Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society's Study of Cancer Survivors-I. *Journal of Cancer Survivorship,10*(4), 674-685. doi:10.1007/s11764-015-0513-4

Protheroe, J., Whittle, R., Bartlam, B., Estacio, E. V., Clark, L., & Kurth, J. (2016). Health literacy, associated lifestyle and demographic factors in adult population of an

English city: A cross-sectional survey. *Health Expectations,20*(1), 112-119. doi:10.1111/hex.12440

Public Health England. (2015). Local action on health inequalities: Improving health literacy to reduce health inequalities. Retrieved from https://www.gov.uk/government/publications/local-action-on-health-inequalities-improving-health-literacy.

Quality Health. (2015) Northern Ireland Cancer Patient Experience Survey. Retrieved from https://www.quality-health.co.uk/resources/surveys/northern-ireland-cancer-patient-experience-survey/northern-ireland-cancer-patient-experience-survey-1

Quality Health. (2016) Scottish Cancer Patient Experience Survey 2015/16. Retrieved from http://www.gov.scot/Topics/Statistics/Browse/Health/cancersurvey/SCPES2015

Quality Health. (2014). Wales Cancer Patient Experience Survey National Report. Retrieved from https://www.quality-health.co.uk/resources/surveys/welsh-cancer-experience-survey

Richman, E. L., Carroll, P. R., & Chan, J. M. (2012). Vegetable and fruit intake after diagnosis and risk of prostate cancer progression. *International Journal of Cancer,131*(1), 201-210. doi:10.1002/ijc.26348

Smith, F., Carlsson, E., Kokkinakis, D., Forsberg, M., Kodeda, K., Sawatzky, R., . . . Öhlén, J. (2014). Readability, suitability and comprehensibility in patient education materials for Swedish patients with colorectal cancer undergoing elective surgery: A mixed method design. *Patient Education and Counseling,94*(2), 202-209. doi:10.1016/j.pec.2013.10.009

Smits, A., Lopes, A., Das, N., Bekkers, R., Massuger, L., & Galaal, K. (2015). The effect of lifestyle interventions on the quality of life of gynaecological cancer survivors. *Gynecologic Oncology,139*(3), 546-552. doi:10.1016/j.ygyno.2015.10.002

Stacey, F. G., James, E. L., Chapman, K., Courneya, K. S., & Lubans, D. R. (2015). A systematic review and meta-analysis of social cognitive theory-based physical activity and/or nutrition behavior change interventions for cancer survivors. *Journal of Cancer Survivorship,9*(2), 305-338. doi:10.1007/s11764-014-0413-z

Sutton, E., Hackshaw-Mcgeagh, L. E., Aning, J., Bahl, A., Koupparis, A., Persad, R., . . . Lane, J. A. (2017). The provision of dietary and physical activity advice for men

diagnosed with prostate cancer: A qualitative study of the experiences and views of health care professionals, patients and partners. *Cancer Causes & Control,28*(4), 319-329. doi:10.1007/s10552-017-0861-7

The Joint Commission. (2010) *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals* Oakbrook Terrace, IL: The Joint Commission.

Van Blarigan, E. L., & Meyerhardt, J. A. (2015). Role of Physical Activity and Diet After Colorectal Cancer Diagnosis. Journal of Clinical Oncology,33(16), 1825-1834. doi:10.1200/jco.2014.59.7799

Wallace, A. S., Seligman, H. K., Davis, T. C., Schillinger, D., Arnold, C. L., Bryant-Shilliday, B., . . . Dewalt, D. A. (2009). Literacy-appropriate educational materials and brief counseling improve diabetes self-management. *Patient Education and Counseling,75*(3), 328-333. doi:10.1016/j.pec.2008.12.017

Williams, K., Fisher, A., Beeken, R. J., & Wardle, J. (2015). Availability of Information About Lifestyle for Cancer Survivors in England: A Review of Statutory and Charitable Sector Organizations and Cancer Centers. *JMIR Cancer,1*(1). doi:10.2196/cancer.3521

Wills, C. E., & Holmes-Rovner, M. (2003). Patient comprehension of information for shared treatment decision making: State of the art and future directions. *Patient Education and Counseling,50*(3), 285-290. doi:10.1016/s0738-3991(03)00051-x

Wilson, B. J. (2007). Designing Media Messages About Health and Nutrition: What Strategies Are Most Effective? *Journal of Nutrition Education and Behavior, 39*(2 Suppl), S13-S19. doi: 10.1016/j.jneb.2006.09.001

Table 1: Checklist for content assessment [36].

Does the information leaflet/website…	***Maximum points***
Start with a clear statement of aims?	/5
Provide unbiased and detailed information about options?	/5
Present probabilities of outcomes in an understandable way?	/5
Contain accurate information?	/5
Help patients to make appropriate decisions	/5
Disclose conflicts of interest?	/5
Have a clear structure and layout?	/5
Help the reader judge its reliability?	/5
Total	***/40***

Table 2: Reading grade level (US) and corresponding age range and reading difficulty.

Reading grade level (US)	Age range (years)	Reading difficulty
5	10-11	Very easy
6	11-12	Easy
7	12-13	Fairly easy
8-9	13-15	Standard
10-12	15-18	Fairly difficult
>13	>18	Difficult or very difficult

Table 3: Cancer Centres and Charitable Organisations providing online PIMs for diet and nutrition.

Cancer Centres
Christie Foundation NHS Trust, England
Clatterbridge Cancer Centre NHS Trust, England
The Royal Marsden NHS Foundation Trust, England
Leeds Teaching Hospitals NHS Trust, England
St Luke's Cancer Centre, Royal Surrey County Hospital NHS Foundation Trust, England
South East Scotland Cancer Network (Edinburgh Cancer Centre), Scotland
Velindre Cancer Centre, Wales
Belfast Cancer Centre, Northern Ireland
Charitable Organisations
Prostate Cancer UK
Fight Bladder Cancer
Beating Bowel Cancer
Bowel Cancer UK
World Research Cancer Fund/UK
Cancer Research UK
Macmillan Cancer Support
Penny Brohn UK

Table 4: Content and Readability Scores of available online PIMs (n 40).

Source	Title of publication (year)	Content score (/40)	Readability score (in U.S. grades)		Mean (SD)	Age range equivalent (years)
			FKGL	SMOG		
NHS (Scotland)	Eating and digestion/Exercise, diet and healthy living (2017)	23	7.5	7.4	7.5 (0.1)	13-14
Cancer Centre	Eating – Help yourself (2015)	30	10.8	8.7	9.8 (1.5)	15-16
	Advice about soft/liquidised food (2016)	29	6.6	7.0	6.8 (0.3)	12-13
	Eating well following treatment and recovery from cancer (2013)	30	6.8	7.2	7.0 (0.3)	12-13
	Eating well and coping with side effects (2016)	35	6.8	7.0	6.9 (0.1)	12-13
	Eating well when you have cancer (2016)	33	9.0	8.0	8.5 (0.7)	14-15
	Eating well during treatment (2017)	33	5.8	6.1	6.0 (0.2)	11-12
	Eating well during cancer treatment (2017)	34	7.2	7.3	7.3 (0.1)	12-13
	Healthy eating (2013)	23	7.7	7.6	7.7 (0.1)	13-14
	Eating well through your treatment (2013)	23	8.6	8.6	8.6 (0.0)	14-15
	Taste changes (2013)	23	5.3	6.0	5.7 (0.5)	11-12
	Soft diet (2013)	23	7.5	7.7	7.6 (0.1)	13-14
	Nausea and vomiting (2013)	23	8.7	8.0	8.4 (0.5)	13-14
	Loss of appetite (2013)	22	13.6	11.5	12.6 (1.5)	>18
	Diarrhoea (2013)	24	10.8	10.1	10.5 (0.5)	16-17
	Constipation (2013)	21	7.0	7.4	7.2 (0.3)	12-13
	Soft diet (2014)	20	7.0	7.5	7.3 (0.4)	12-13
	Dry mouth (2014)	18	5.9	6.4	6.2 (0.4)	11-12
	Nausea and vomiting (2014)	21	6.3	6.1	6.2 (0.1)	11-12
	Poor appetite (2014)	18	5.9	6.4	6.2 (0.4)	11-12

	Taste changes (2014)	19	6.7	6.4	6.6 (0.2)	12-13
	Low fibre diet (2013)	19	6.6	6.8	6.7 (0.1)	12-13
	Poor appetite (2013)	23	7.4	7.2	7.3 (0.1)	12-13
	Constipation (2013)	17	6.5	7.0	6.8 (0.4)	12-13
	Diarrhoea (2013)	16	7.7	8.1	7.9 (0.3)	13-14
	Taste changes (2013)	16	6.5	6.7	6.6 (0.1)	12-13
	Soft diet (2013)	18	9.8	8.7	9.3 (0.8)	14-15
Charity	Eating well – Living with bowel cancer (2017)	26	11.9	10.0	11.0 (1.3)	16-17
	Your diet and lifestyle – Living with and beyond cancer (2017)	34	8.7	7.9	8.3 (0.6)	13-14
	Diet and physical activity for men with prostate cancer (2015)	31	6.9	7.0	7.0 (0.1)	12-13
	Diet and Nutrition (N/A)	26	8.4	8.5	8.5 (0.1)	14-15
	Healthy Living After Cancer (2016)	33	10.1	9.0	9.6 (0.8)	15-16
	Eating well during cancer (2017)	32	10.0	8.9	9.5 (0.8)	15-16
	Healthy Eating Guidelines (2017)	31	9.5	9.0	9.3 (0.4)	14-15
	Healthy Eating and Cancer (2017)	37	7.6	6.7	7.2 (0.6)	12-13
	Managing weight gain after cancer treatment (2016)	34	7.6	7.1	7.4 (0.4)	12-13
	Recipes for people affected by cancer (2015)	32	6.3	6.3	6.3 (0.0)	11-12
	The Building-up diet (2017)	35	7.2	7.3	7.3 (0.1)	12-13
	Eating problems (2017)	35	8.2	7.9	8.1 (0.2)	13-14
	Coping with cancer/Coping physically/Diet problems (2014-2017)	31	8.4	7.8	8.1 (0.4)	13-14

FKGL, Flesch-Kincaid Grade Level; SMOG, Simplified Measure of Gobbledygook; SD, Standard Deviation; NHS, National Health Service; N/A Not Available.