# **Macmillan ENRICH Project Report**

Engaging Nutrition Resources for Inclusive Cancer Health

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### Macmillan ENRICH Project

Engaging Nutrition Resources for Inclusive Cancer Health

### Acknowledgments

Thank you to all the people affected by cancer and health care professionals who participated in the online survey and interviews.

This project was kindly supported by Nutricia.

### **Executive summary**

The ENRICH (Engaging Nutrition Resources for Inclusive Cancer Health) project explored the availability of nutritional resources (i.e. written information, videos and websites) for diverse ethnic communities from the Black, Asian and mixed ethnicity groups, affected by cancer. Insights were gathered from individuals with a cancer experience as well as health care professionals providing dietary advice to people with cancer in their day-today work. Key findings and recommendations are summarised below which may provide helpful guidance for health care professionals, cancer charities, Cancer Alliances, NHS Trusts, Health Boards and Integrated care boards (ICBs):

#### Key findings

#### 1. There is a need for tailored nutritional guidance:

Diverse community members emphasised a strong need for culturally tailored nutrition support from diagnosis, during and after cancer treatment. A common theme was the lack of proactive, patient-centred advice and resources, as reflected in patient quotes:

"Advice should be offered at the point of diagnosis and workshops offered on-site at treatment locations. I feel totally let down by the lack of proactive support provided."

#### 2. Limited resources and cultural awareness:

Existing nutritional resources for diverse communities are insufficient. Health care professionals also recognised the gap, with 95% of those who responded to the online survey expressing interest in further training, particularly regarding cultural foods and adapting guidelines for various ethnic groups. Confidence in supporting diverse groups with their diet is also variable across professionals with 46% of all professionals 'not very confident' or 'not confident at all'



#### 3. Value of patient-centred care:

Online survey and interview feedback highlighted the importance of health care professionals understanding patients' cultural backgrounds and having the confidence to support diverse groups which can have a positive impact the care experience.

#### 4. Engagement Challenges:

Participation in the project was voluntary, potentially introducing bias, as those most interested in nutrition were more likely to engage. Survey numbers for individuals with a cancer experience, particularly from diverse backgrounds, were small, limiting how representative the sample was that was spoken to.

#### **Recommendations**

For Health Care Professionals:

**Cultural competency training is recommended for all healthcare staff-** Training such as Macmillan's training course 'Developing cultural competence n cancer care and support' should be widely implemented and linked to the ACCEND framework.

**Engage in conversations about nutrition and diet with all patients:** Improve confidence when working with diverse group so all patients are asked about nutrition and diet and provided with relevant resources or referrals if required.

Be aware of the local dietitian referral criteria, so patients can access specialist input when needed.

**Tailored/personalised conversations**: Engage patients in discussions about their cultural preferences and dietary needs to improve support.

#### **Resource development:**

Co-design culturally tailored resources with community groups, including:

**Develop culturally specific Eatwell guides:** Addressing needs of South Asian, African & Caribbean, vegetarian, and vegan diets.

**Develop nutrition support and food fortification advice** Simple, accessible information on healthful eating, managing weight, and recovery post-treatment.

**Develop meal plan and recipes** for different diverse community groups. These may be especially needed for groups who may need to alter their diet due to cancer treatment such as bowel cancer patients (e.g. patient requiring low fibre diets), patients requiring nutrition support, or experiencing side effects of treatment.

**Develop simple easy to read information** for diverse groups for after cancer treatment, focusing on health eating, managing weight and recovery.

**Develop videos which target different aspects of the treatment** pathway for example, diet and nutrition when getting ready for treatment, in treatment (exploring treatment side-effects), and after treatment.

Information should be **translated** in a range of languages.

Develop cancer **diet myth busting information** especially aimed at diverse communities.

#### Training and development for Health Care Professionals:

All training should be linked to the ACCEND pathway:

Provide **first line nutrition and cancer training and awareness of malnutrition** for community professionals such as pharmacists, optometrists, community nurses and allied health professionals.

Training for other HCP groups is indicated such as **doctors**, **oncology nurses and support workers** 

Training for health care professionals should focus on **'information about cultural foods for diverse groups'** and '**adapting guidelines for different ethnic groups'.** Exploring the topic of adapting guidelines may need some additional scoping work.

#### Conclusion

The ENRICH project highlights critical gaps in nutrition support for diverse communities with cancer. Addressing these gaps requires a combination of tailored resources, professional training, and further research to ensure equitable, patient-centred care.



### Background

Eating challenges and nutritional concerns are very common during cancer due to the treatments for cancer or the cancer itself, affecting up to 64% of all cancer patients at some point during their cancer pathway <sup>1</sup>. This may lead to weight loss and malnutrition which is highly prevalent in people with a cancer diagnosis and well reported in the literature. A recent UK survey found 52% of people with cancer were medium to high risk of malnutrition <sup>2</sup>.

Overall, there is limited research focusing on diverse communities with cancer and nutrition, but we do know people from ethnic minority groups often have a poorer cancer experience overall. In the latest National Cancer Patient Experience Survey (NCEP), Black, Asian and Mixed ethnicity people with cancer, reported a statistically significantly worse overall experience of NHS care in the 2023 survey<sup>3</sup>.

Currently, the nutrition and diet written information for cancer patients, are based on the UK British standard diet. This information does not reflect the variety of diets of our UK population where 18% of the population in England and Wales are from a Black, Asian or other mixed ethnic group <sup>4</sup>. This is an area of inequality for diverse communities.

Reducing health inequalities is an NHS England priority; part of the NHS Long Term Plan <sup>5-</sup> <sup>6</sup> and a strategic priority for Macmillan. The NHS Long Term Plan has led to the introduction of the Core20PLUS5 initiative: a targeted strategy by the NHS in England to reduce health inequalities, particularly focusing on the most deprived 20% of the population, known as the Core20<sup>7</sup>. The Core20 also includes marginalised populations, such as ethnic minorities and people with disabilities with an overall aim to ensure all people receive equitable cancer care. All nations have similar priorities for reducing inequalities in diverse groups such as the Race equality framework for Scotland 2016 to 2030<sup>8</sup>, and Race Equality Action Plan in Wales 9. Reducing inequalities for diverse communities in diet and nutrition information should also be part of this work.

This has led to developing the ENRICH project (Engaging Nutrition Resources for Inclusive Cancer Health) which explored cancer nutrition and diet information for people from ethnic minority communities.

The first stage of this work was to gather insights on the nutrition and diet information available for people from different communities and from health care professionals providing support and advice. The insights gathered have formed the recommendations in this report for further work.

### Methodology

Online surveys

#### Two separate online surveys were developed the details of which are set out below.

#### People with a cancer experience survey

People with a cancer experience (during cancer treatment and living with cancer) from diverse community groups were asked to complete a 25-question survey on Microsoft Forms to gather information about the nutrition and diet advice they received during their cancer experience, whether it was appropriate and relevant to their cultural background, and what resources on diet and cancer would have been helpful (Appendix 1).

The survey questions were reviewed by a multidisciplinary group including professionals working directly with diverse communities.

People with a cancer experience were invited to pilot the survey, some feedback was received, and the survey was updated

The surveys were shared directly to community groups supporting diverse communities, online through social media (Macmillan Instagram and Facebook pages), through Cancer Alliances, at the Macmillan Professionals Conference in November 2024, Nutricia Annual Congress in October 2024 and through the National Institute for Health Research (NIHR) charity partners group.

#### Health care professionals survey

A second survey was devised for health care professionals (HCP) working with people affected by cancer. The 21-question survey on Microsoft Forms (Appendix 2) aimed to gather insights from professionals on their experience of providing diet and nutrition information to diverse groups and whether they required any training or resources to support them providing this advice.

The survey questions were reviewed by different professionals and was piloted with 5 HCPs from a range of backgrounds (support worker, nurse, information manager).

The survey was shared online through social media (Macmillan Instagram, Facebook, LinkedIn pages), through Cancer Alliances, the Macmillan Professional network, Boots Pharmacy stores nationwide, Macmillan Professionals Conference in November 2024, Nutricia Annual Congress in October 2024 and the British Dietetic Association (BDA) Oncology group.

Both surveys were reviewed and approved by the Macmillan Information Governance and Compliance team and a Data Protection Impact Assessment (DPIA) was completed. Ethical approval was not required.

#### Professionals workshop and one-one user interviews

To gather more in-depth feedback and allow for semi-structured discussion a 1-hour online workshop meeting was arranged on Microsoft Teams with health care professionals who expressed interest in this project. Only HCPs who provided their email address on the survey and consented to being contacted were invited.

One to one interviews (30 minutes) were also set up with people affected by cancer either on Microsoft Teams or via the telephone. Only people who provide their email address on the survey and consented to be contacted were invited. Attending community group support meetings was also explored but not possible due to the time constraints of the project.

### Exploring resources currently available

#### Eat Well Guides

In addition to the data gathering work a scoping exercise was carried out to identify cancer nutritional information for diverse groups.

No resources specifically designed by diverse groups with cancer are currently available at Macmillan or other charity organisations. The British Dietetic Association Oncology group was contacted to identify if individual NHS Trusts produce their own guidance. One Trust NHS was reported to have a resource for African and Caribbean communities and created a draft document for South Asian communities.

Through the scoping exercise alternative versions of the NHS Eat well guide were identified. These have been produced for diverse groups created by individual nutritionists or dietitians such as the African & Caribbean Eatwell guide and South Asian Eatwell guide (Appendix 3 for a list of these) and there are also versions for vegetarian and vegan diets.

During this project meetings were arranged with the Macmillan cancer information content team and the alternative Eatwell guides creators to discuss how the Eat Well guides could be included in Macmillan's current information available in the recommendations section.

### Results

### Health care professionals survey

The survey respondents

The health care professionals survey was launched on 1<sup>st</sup> October 2025 for 5 weeks. All health care professionals working with people with a cancer diagnosis were invited to complete the survey.

202 HCPs completed the survey (one was excluded from the analysis due to incomplete information), (18%) dietitians, oncology dietitians (12%), nurses (9%), oncology nurses (12%), pharmacists (29%), support workers (6%) and others (9%) (Table 1). Professionals in the other category included other allied health care professionals (e.g. physiotherapist, occupational therapists, therapeutic radiographer, psychologists, and a nutritional scientist.

Number (%)
36 (18%)
24 (12%)
5 (2%)
4 (2%)
25 (12%)
18 (9%)
59 (29%)
12 (6%)
18 (9%)

*Table 1 Number of Health care professionals completing the survey* 

The majority of the respondents worked in London (40%) and the rest of the respondents worked across the United Kingdom (Northeast England 12%, South East England 8%, South West England, Scotland and West Midlands 7%, East of England 4%, East Midlands, Wales and Northern Ireland 3% and Yorkshire 2%).

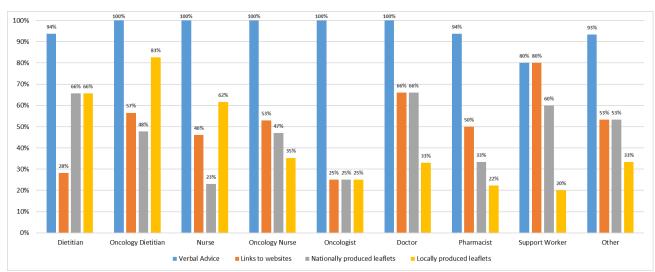
The HCP surveyed varied in their experience in working people affected by cancer; 37% (76) did not exclusively work in cancer, 38% (77) had more than 5 years' experience, 9% (19) 3-5 years, 10% (20) 1-3 years and 4% (9) less than 1 year.

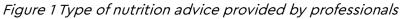
#### Providing nutritional information

Overall, 80% (161) of HCP provided nutritional information to cancer patients (yes and sometimes) but when asked if they provided advice to people from diverse ethnic backgrounds this dropped to 65% (130). Professionals working in North West England

(73%), London (56%), Yorkshire (50%) and East Midlands (50%) were more most likely to provide dietetic advice to diverse groups.

Professionals provided a range of advice to cancer patients, but verbal advice was most popular across all professionals (80-100%) (Figure 1).





#### Considering cultural background

Professionals were asked if they considered cultural/ethnic background when providing dietary advice. Doctors were the least likely to consider cultural background (33%) followed by pharmacists and oncologists (50% respectively). This was closely followed by 59% of oncology nurses.

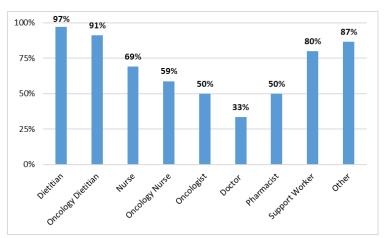
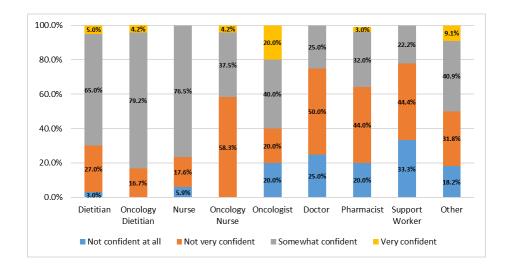


Figure 2 Is culture or ethnic background considered when providing dietary advice?

Confidence and challenges

Overall professionals felt very confident (4%) or somewhat confident (49%) when providing nutritional advice to cancer patients. It is interesting to look at how this differs across the different professionals as in Figure 2.



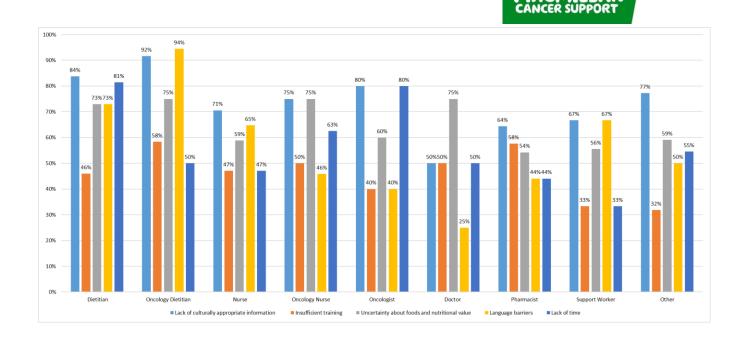
*Figure 3 Confidence in providing nutritional advice to diverse groups across professionals.* 

As anticipated oncology dietitians were more confident overall however more than half oncology nurses were not very confident (58.3%). Support workers were the least confident overall (33.3% not confident at all).

All professionals except doctors stated that lack of culturally appropriate information was the biggest barrier to providing nutritional information to cancer patients. (75% of doctors reported that 'uncertainty about foods and nutritional value' was the biggest challenge and oncology nurses thought this was an equal barrier to lack of information).

Oncologists were the only professional to report a lack of time as an equal barrier to lack of information. Support workers reported language barriers as an equal barrier to lack of information.

*Figure 4 Challenges professionals face when providing information to diverse groups* 



#### Nutrition training requirements

Overall, 95% (190) of professionals responded yes or maybe that they would like nutrition training for diverse groups. Across professionals this ranged between 50-80%, with 100% support workers reporting they needed training in this area.

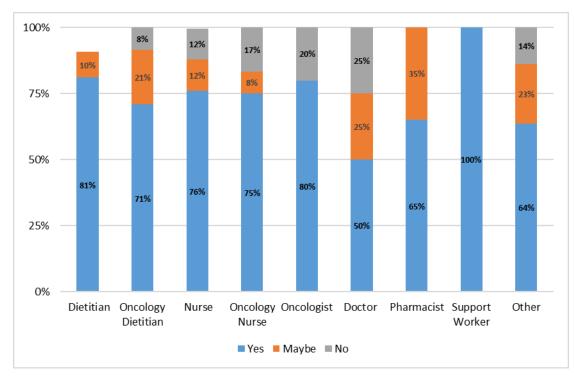


Figure 5 Training requirements by professional

There were three popular training styles preferred by professionals: online training modules, webinars and printed guideline or resources. Requirements were different in each professional group; oncology dietitians (75%) and oncologists (100%) preferring printed guideline or resources, webinars were most popular with dietitians and others

(89% and 68% respectively) and nurses, oncology nurses, pharmacists and support workers preferred online training modules respectively. (71%, 96%, 83%, 78%)

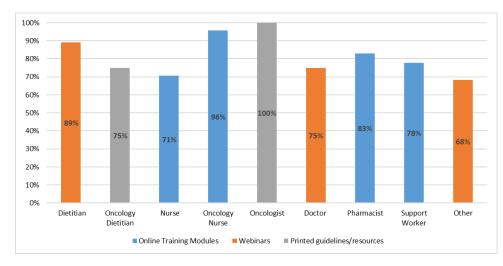


Figure 6 Preferred training style

Four training topic areas were most popular for HCPs: adapting guidelines to different ethnic groups, information about cultural foods for diverse groups and the effect of religious and cultural beliefs on diet and assessing nutritional status. The most popular topic across most HCPs was 'information about cultural foods for diverse groups'. This ranged from 75-92% across all HCPs except oncologists, pharmacists, and support workers who wanted support 'adapting guidelines for different ethnic groups'.

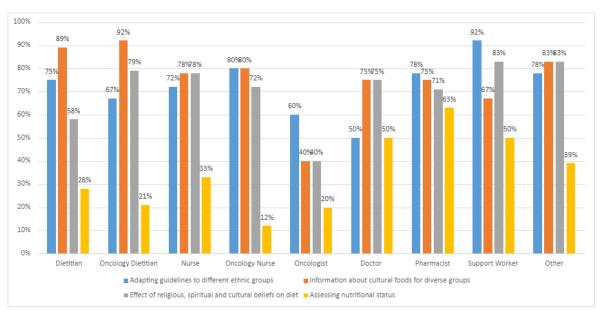


Figure 7 Training topics needs

#### Oral nutrition supplements

Professionals were asked if they recommended or prescribed oral nutritional supplements (ONS) to their patients 55% (110) said yes or sometimes. 87% (175) felt that diverse groups might experience barriers taking ONS.

The comments around area were mixed:

"Same barriers as other population groups but also flavour preferences not considered"

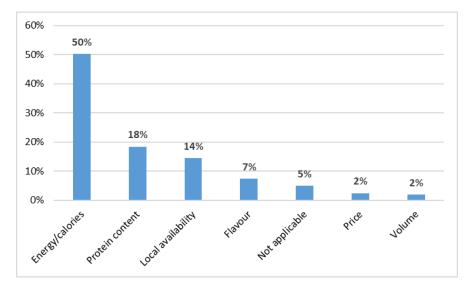
"In my experience people from diverse background are much more into nutritional driven interventions; juicing, herbs, intense ginger etc than white British people"

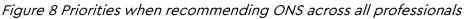
"I'm unsure - I feel like maybe more flavours would help with supporting diversity in the ethnic groups but I do not find this hugely challenging."

"Unsure if nutrition companies include feedback from minority groups when testing products. Written information on use not always available in patients first language"

Also, religious or cultural preferences were mentioned such as following a Halal, Kosher, Vegan diet or lactose/dairy free diet which may limit supplement choice.

Professionals were also asked to rank in order their priorities when recommending supplements. Half the group felt energy (50%) was most important followed by protein content (18%) and local availability (14%) (figure 8)





### Health Care professionals' workshop

81 professionals provided their email address after completing the ENRICH professionals survey, expressing like would like to be involved in further work.

These professionals were then invited to a 1.5-hour workshop on Monday 2<sup>nd</sup> December 2024 which aimed to gather further insights and feedback.

28 professionals (34% of those invited) accepted the invitation, however only 9 (32%) attending the meeting on the day.

*Table 2: professionals who attended the workshop* 

Professional	Number attended
Oncology dietitian	3
Clinical nurse specialist (CNS)	2
Nutritional scientist	1
GP	1
Support worker (CSW)	1
Macmillan Centre & personalised care	1
manager	

The aim of the meeting was to probe deeper into the topic of nutritional information for diverse groups with cancer, explore their training needs and gather any other feedback. The meeting was organised to have 2 breakout sessions to allow small groups to discuss the questions raised.

The group raised issues with the lack of written information available. Oncology dietitians felts they had some knowledge of working with diverse groups (and knew how to seek more information) but they were limited in what they can provide to patients which supports this verbal advice.

The group was asked if anyone had received training to support them working with diverse groups and 8 out of 9 said they had not received any training. This led to discussion about cultural awareness training which the group thought should be available for everyone.

Generally, the groups felt more research in cancer and nutrition is needed in diverse groups and questions were raised about if the current guidelines for cancer prevention are applicable to diverse groups if they were not participating in the research.

Overall, the group felt information was needed at various levels; i.e. general information that could be provided by information managers or support workers then more detailed information that dietitians could use for example food fortification using cultural foods and recipes was a popular request in addition to having lower budget and low energy alternative cultural foods. Further details can be found in the Appendix 4.



### People with a cancer experience survey

#### Demographic Information

44 people completed the survey (6 were completing on behalf of a relative 38 were patients)

Interestingly 43.2% (19) who completed the survey were from a White background (English, Welsh, Scottish, Northern Irish, Irish, and other white background) despite promoting the survey to diverse communities.

Most people were aged 45 to 64 years (63%) and a third of people were from London (31.8%), and Southwest England (18.2%) and smaller numbers from various parts of the UK.

Almost half the survey responders had breast cancer (48%), prostate (16%) or gynaecological cancer (11%) others had lung, head and neck, bowel, blood, bladder or eye cancer.

Most users were diagnosed with cancer 1-3 years ago (Figure 9)

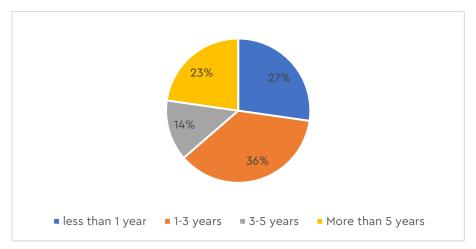


Figure 9 When users were diagnosed with cancer

#### Nutrition and Diet Advice

Notably, 50% (22) users did not receive any nutrition/dietary advice during treatment, which may be why 70% (31) of users sought information on their own. Most people looked online for help (54%- 20 people) or talked to friends and family (27%- 10 people)

For users that did receive advice, verbal advice was most popular at 20% (9) and provided by nurses (50% (5),or provided by an oncologist/doctor or a dietitian/nutritionist (both 20% respectively) and only 10% (1) by family/friends.

15% of people received leaflets and only 9% were referred to a dietitian

As show in Figure 10 most people surveyed found the information provided very or somewhat helpful (43%).

Not applicable 34% Not helpful 34%

Figure 10 How helpful was the nutrition and diet advice received

Most users also felt the information was easy or somewhat easy to understand (50%) and of the 9% (4 users) that felt it was difficult half the users where from an ethnic background (Asian or Asian British Indian).

#### Common themes the users felt was lacking from diet/nutrition information

The users were asked what information was lacking from the dietary information they received which was grouped into common themes. The following themes were common:

- Vegan/vegetarian diets (4)
- Foods for ethnic diets (3)
- Fasting diets (2)

There were also comments about diet advice for the menopause, specific diet information (e.g. low FODMAPs-fermentable oligosaccharides, disaccharides, monosaccharides and polyols diet in bowel cancer) and juicing advice.

Regarding information about ethnic or cultural diets users expressed the following:

" Culturally appropriate information. I asked for this but was told it was not available and was provided with generic information".

"I think also information on how to adapt traditional meals to make them a bit more suitable, such as less spices etc"

"... I understand if it's someone who doesn't have that knowledge of BAME cultures etc then it may make patient feel isolated even more and not eating properly".

#### Cultural Relevance

When asked if the nutrition advice provided was appropriate for users cultural or ethnic background 20% (9) stated yes completely but 23% (10) said not at all and as expected 9 of 10 users who reported this were from a diverse ethnic background (Black, Asian or mixed background)

The following quotes illustrates this:

"Cultural/Ethnic background should not be limited to 'content of the food intake' but also about the behavioural / societal factors which are so much more important to individuals on what (and when) they should consider or take their nutritional diets."

"I asked for advice based on my Caribbean ethnicity and told clearly that it could not be provided"

"I was not given any information, and my background was not considered"

"Nothing for Jain Asians"

"The service is designed to cater for white patients.

It is not inclusive of dietary requirements and health and wellness during and after cancer"

This is confirmed by 78% (34) of users stating they were yes or maybe interested in having resources designed for their cultural or ethnic group. 31% of users wanted online resources (26 users) closely followed by printed resources (27%; 23 users) as shown in Figure 11.

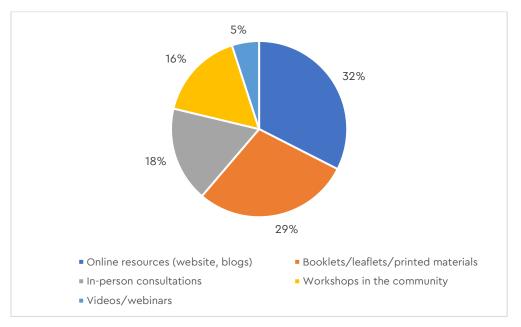


Figure 11 The users preferred format if new resources were developed

Most people in this survey did not require materials translated in their first language (not applicable, 34%), and only 3 (7%) said yes.

When asked what could have improved the nutrition and diet advice received, the two most popular answers were 'recipe suggestions based on traditional foods' (26%; 16 users) and 'meals plans based on traditional diets' (25%; 15 users). People also wanted 'more images and diagrams' (10%; 6 users) and 'easy to read language' (8%; 5 users). There were also a range of other comments such as 'anything at all' and referral to a dietitian (2 users).

#### Oral supplement drinks

Users were asked whether they were recommended or prescribed any nutritional supplement drinks; only 27% (12 users) said yes and one third were able to drink 100% of these, 42% managed 25-75%, and 25% managed less than 25% of the supplement drinks.

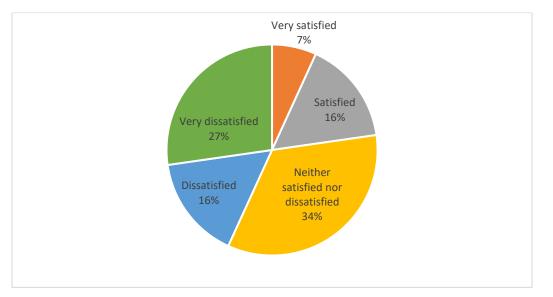
#### Eatwell Guide

Public Health England has produced the Eatwell Guide which 'defines the government's advice on healthy eating and is a visual representation of how different foods contribute towards a healthy balanced diet' <sup>10</sup>. It is a common resource used when describing the main food groups that form a healthy, balanced diet but is not designed to provide advice for specific conditions such as cancer.

The current version is very much based on a British diet and does not contain any ethnic or cultural foods. We were keen to explore whether this impacted people from diverse groups. In the survey most people had seen the guide before (68%) and when asked what food were missing, cultural foods from an Indian, Caribbean and African diets were mentioned e.g. yam, dumpling, plantain. A user wrote *"lack of visuals or mention of cultural foods could alienate some people."* 

#### Overall satisfaction with nutrition and diet advice during cancer

Unfortunately, 43% of users were dissatisfied or very dissatisfied with the nutrition advice they received during their cancer treatment as per figure 12.



*Figure 12 Satisfaction with nutrition and diet advice during cancer treatment* 

Some of the additional comments provides insights into why this may be the case. One user mentioned the confusing information and lack of 'high quality evidence':

"Patients are subjected to a lot of confusing non evidence based rumour about certain foods that may potentially benefit or be adverse in their cancer journey. Dairy products and prostate cancer for example. It would be helpful for this and other cancers to identify these themes and address with high quality evidence"

There was also a theme from users that they felt nutrition was not the focus for health care professionals:

"More emphasis on diet as there wasn't much"

"It should be a big part of the recovery plan and I was given nothing."

### One to one user interviews

To collect more qualitative data from diverse groups with a cancer experience one-toone interviews were arranged either on Microsoft Teams or by telephone. The aim was to allow more free discussion and capture individual experiences.

One to one interviews (30 minutes) were arranged with five people affected by cancer either on Microsoft Teams calls or via the telephone.

A set of questions prompts were developed to help guide the conversations and ensure some consistency across all calls this available in Appendix 5.

Transcripts of calls were reviewed, and common themes were developed from the data influenced by the thematic analysis approach <sup>11</sup>.

#### Themes

#### Not being asked about eating/diet

Nearly all the users had nutritional questions about diet but were not asked about nutrition by health care professionals. Only one person mentioned their mum was referred to a community dietitian.

#### Advice provided was not tailored to cultural preferences

One person spoke about her mother's cancer diagnosis said she was referred to community dietitians but felt their advice unsuitable as it was based on a 'European diet'.

#### Seeking help from the community

One lady mentioned that she attended a local support group and was able to talk to women from a similar background which she found most helpful. Another person mentioned that there were no local groups in her area, so they attended online groups aimed at Black women which she found helpful.

#### Mistrust of health care professionals

This was mentioned by some users, who felt that could Trust people in their community more than health care professionals.

#### Following alternative diets and not sure how it fits with western medicine

A few people shared that they were following their own alternative practices based on advice given in the community and some mentioned that they were scared to discuss this with health care professionals for fear of being dismissed.

Another woman mentioned feeling conflicted with cultural practices recommended from family and standard advice being given by health care professionals.

#### Feeling unable to ask questions about treatment or share cultural practices

There was an overall theme that people felt unable or scared to ask questions about their treatment or talk about how they are feeling. "*I didn't ask that question and I regretted not asking the question"* 

#### Suggestions or improvements

When asked about improvements that could be made the responses were varied. Some people would have liked blog posts with simple easy to understand information while others were keen to have short videos, peer support and in person groups in the community.

There was also lots of discussion about the variety that exists within the same cultural groups for example South Asian groups from different countries diets vary. This suggest that generalisations with regards to different diets should not be made.

#### The ethnic diet Eatwell guides

At the interviews the users were shown either a South Asian version or African & Caribbean Eatwell and asked if they had seen it before. No one had seen these versions before, however they had very positive feedback. Generally, most people were pleased to see familiar foods and thought this would be very useful (and one person asked for a copy to share). However, one comment was that it was quite complicated *"everything on one plate is confusing, it's like you should eat all of these things"* and would need some simple explanations alongside the guide to be most useful.

### Discussion

This project aimed to review current resources available for diverse community groups and capture insights from people with a cancer experience from these groups and from professional providing dietary advice.

A very clear message from diverse communities is that they want information on nutrition during their cancer experience and an area where they need tailored support and guidance is identified below:

"Advice should be offered at point of diagnosis and workshops offered on site at treatment locations. I feel totally let down by the lack of pro active support provided. This was the area I struggled most with and received the least support"

Information relating to diverse communities with cancer around their nutritional needs is very limited, so despite the small sample size this work provides some valuable insights and identifies where further work is needed.

Resources for health care professionals to provide to diverse communities about nutrition, is lacking. Professionals are clearly aware of this as illustrated by the interest in this work, the feedback provided and the fact that 95% of professionals identified the need for training in this area.

The importance of providing patient-centred care has been evident through the user survey and interviews. The benefit of health care professionals understanding their patients' cultural backgrounds can have a positive effect on patient's experience of care as illustrated in this quote:

"My oncologist is from a BAME background so therefore they understood that we eat different foods and would give me recommendations of food that I would eat, I was given a leaflet with food I can and can't eat during stem cell transplant and although it was helpful I had to constantly contact my doctor as I felt the food on their is not what I eat and it's more complicated like curries etc...my specialist nurse had also just had a BAME patient so my team personally we're very trained in this aspect and could provide advice that was suitable for me."

#### Further research opportunities

Given the findings of the ENRICH project and through discussions with stakeholders there are several areas which would be useful to explore including:

- Improving engagement in diet and health research in diverse communities
- Understanding cultural diets and food beliefs in diverse communities with cancer
- Exploring confidence and self-advocacy in diverse communities and its impact on cancer outcomes



#### Limitations of this project

People were invited and self-selected to complete the surveys or attend workshops and one-to-one meetings on voluntary basis so it is likely that the people most interested in nutrition would volunteer to contribute to this work.

The survey numbers for people with a cancer experience were small. There were less people from diverse backgrounds completing the survey which may not represent the views of all people with a cancer experience.

### **Macmillan ENRICH Project recommendations**

Based on the insights gathered in this project the following recommendations are suggested for further work.

#### General recommendations for health care professionals working in cancer care:

**Cultural competency training is recommended for all healthcare staff-** Training such as Macmillan's training course 'Developing cultural competence n cancer care and support' ('Developing cultural competence in cancer care and support') should be widely implemented and linked to the ACCEND framework.

**Engage in conversations about nutrition and diet with all patients:** Improve confidence when working with diverse group so all patients are asked about nutrition and diet and provided with relevant resources or referrals if required.

Be aware of the local dietitian referral criteria, so patients can access specialist input when needed.

**Tailored/personalised conversations**: Engage patients in discussions about their cultural preferences and dietary needs to improve support.

#### Suggested resources for development for people affected by cancer

Any resources should be co-designed with community groups from the start to ensure that is meets their unique requirements. The following are some suggestions from this work:

**Develop culturally specific Eatwell guides:** Addressing needs of South Asian, African & Caribbean, vegetarian, and vegan diets.

Including the other Eatwell guides available for different groups e.g. South Asian, African & Caribbean, vegetarian and vegan diets as alternative options. Guidance on how to use these guides during and after cancer treatment would be helpful and ideally co-designed with community groups.

**Develop nutrition support and food fortification advice** Simple, accessible information on healthy eating, managing weight, and recovery post-treatment co-deigned with the community and dietitians working with diverse groups.

**Develop meal plan and recipes** for different diverse community groups. These may be especially needed for groups who may need to alter their diet due to cancer treatment such as bowel cancer patients (e.g. patient requiring low fibre diets), patients requiring nutrition support, or experiencing side effects of treatment.

**Develop simple easy to read information** for diverse groups for after cancer treatment, focusing on health eating, managing weight and recovery.

**Develop videos which target different aspects of the treatment** pathway for example, diet and nutrition when getting ready for treatment, in treatment (exploring treatment side-effects), and after treatment.

Information should be **translated** in a range of languages.

Develop cancer **diet myth busting information** especially aimed at diverse communities.

#### Training and development for Health Care Professionals:

All training should be linked to the ACCEND pathway:

Provide **first line nutrition and cancer training and awareness of malnutrition** for community professionals such as pharmacist, optometrists, community nurses and allied health care professionals.

Training for other HCP groups is indicated such as **doctors**, **oncology nurses and support workers** 

Training for health care professionals should focus on **'information about cultural foods for diverse groups'** and **'adapting guidelines for different ethnic groups'.** Exploring the topic of adapting guidelines may need some additional scoping work.

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### APPENDIX 1: SURVEY QUESTIONS FOR PEOPLE AFFECTED BY CANCER FROM DIVERSE GROUPS

This survey from Macmillan Cancer Support, aims to gather information about the nutrition and diet advice you received during your cancer experience, specifically whether it was appropriate and relevant to your cultural background.

We anticipate the survey taking no more than 10 minutes to complete.

If you share your email address and sensitive information about yourself and your cancer diagnosis it may be possible to identify you. Information you provide will be treated confidentially and responses to questions will be combined and analysed/reported in aggregate, and not attributed to you personally. The data will be deleted after 2 years.

Your feedback will help us identify gaps and improve resources to better support the diverse needs of people from different ethnic groups. This information will be shared anonymously within Macmillan and as a research paper or poster.

We greatly appreciate your time and input.

<tick> Please tick if you are happy for us to use your information in this way

Thank you for completing this survey. Your feedback is important to us. We promise to keep your details safe and never sell or swap them with anyone. This includes any sensitive personal data you may provide. Our privacy policy on our website at www.macmillan.org.uk explains how we keep this promise.

This survey will close on Friday 8<sup>th</sup> November 2024.

#### 1. What is your ethnic background?

White

English, Welsh, Scottish, Northern Irish or British

Irish

Gypsy or Irish Traveller

Roma

any other white background

Mixed or multiple ethnic groups

White and black Caribbean

White and black African

White and Asian

any other mixed or multiple ethnic background

Asian or Asian British

Indian

Pakistani

Bangladeshi



Chinese

any other Asian background

Black, black British, Caribbean or African Caribbean African any other black, black British, or Caribbean background Other ethnic group

#### Arab

any other ethnic group (please list) Prefer not to say

#### 2. How old are you?

Under 18

18-24

25-34

35-44

45-54

55-64

65 and older

#### 3. Where do you live?

Wales

Scotland

Northern Ireland

England:

London

North East England



- North West England
- Yorkshire England
- East Midlands
- West Midlands
- South East England
- East of England
- South West England

#### 4. If you had cancer, what type of cancer were you diagnosed with?

- Breast cancer Lung cancer
- Prostate cancer
- Bowel cancer
- Liver cancer
- Head and neck cancer
- Blood cancer
- Skin cancer
- Brain cancer
- Other (please list)

#### 5. How long ago were you diagnosed with cancer?

- Less than 1 year,
- 1-3 years
- 3-5 years
- More than 5 years

# 6. If you have not had cancer, but supported someone with cancer and completing this on their behalf please tick the below:

Family

Friend

Other (specify)



# 7. Were you given any nutrition or dietary advice at any point your cancer experience (e.g. before treatment, during treatment, and after treatment)?

Yes (tick all that apply)

Verbal advice

Leaflets

Links to websites

Referral to dietitian

Other

No

# 8. Who provided you with nutrition and diet advice during your cancer treatment? (Select all that apply)

- Dietitian/Nutritionist
- Oncologist/Doctor
- General Practitioner (GP)
- o Nurse
- Family/Friends
- Online information
- Other (please specify)
- o Not applicable

9. How helpful did you find the nutrition and diet advice you received?

- o Very helpful
- o Somewhat helpful
- o Not helpful
- o Not applicable

# 10. Was the nutrition and diet information provided to you easy to understand and follow?

- o Yes, completely
- o Somewhat
- o No, it was difficult to understand
- o Not applicable



11. What information, if any, do you feel was lacking from the nutrition and diet advice you received during your treatment?

For example, would information about eating during fasting/religious festivals, or information related to cooking methods, or information on how to adapt traditional meals, vegetarian diets be helpful ?

Any comments

12. Were you recommended and or prescribed any nutritional supplements drinks (e.g. milkshakes or ready to drink supplements) during your cancer experience?

Yes/no/not sure

13. On average, how much of these drinks were you able to finish each day?

- 100%
- 75%
- 50%
- 25%
- Less than 25%

Other

Not applicable

14. Do you feel the nutrition and diet advice you received was appropriate for your cultural or ethnic background (e.g. did it include advice on the usual foods you eat, your religious practices or preferences)?

- o Yes, completely
- o Somewhat
- o No, not at all
- o Not applicable

Please give any examples of the ways your cultural/ethnic background was or was not considered

# 15. Have you seen any versions of the Eatwell guide for healthy eating (image as below)?



#### Yes/No/ not sure



# 16. Are there any foods that you usually eat that are missing from this? (please list below)

#### 17. Did you look for additional information about diet and nutrition on your own?

 $\circ$  Yes / No

If yes, where did you find this information?

- Talking to family and friends
- Local charities
- Religious groups
- Online including social media
- $\circ$  Other (please state)

# 18. Were you offered any translated materials or dietary resources in your first language?

- o Yes / No/not applicable
- o any comments

#### 19. What could have improved the nutrition and diet advice you received?

Easy to read language More images and diagrams

Meal plans based on your traditional diet

Recipe suggestions based on your traditional foods

Any other comments

# 20. Would you be interested in resources about cancer nutrition designed for your cultural/ethnic group?

Yes / No/ maybe

If yes, what format would you prefer? (Select all that apply)

- Booklets/leaflets/Printed material
- Online resources (website, blogs)
- Videos/Webinars
- o In-person consultations
- Workshops in your community
- $\circ$  Other

# 21. Overall, how satisfied were you with the nutrition and diet advice you received during your cancer experience?

- o Very satisfied
- o Satisfied
- o Neither satisfied nor dissatisfied
- o Dissatisfied
- o Very dissatisfied

# 22. Do you have any additional comments or suggestions regarding the nutrition and diet advice you received during cancer experience?

#### Any comments

If you are interested in being involved in this work or sharing your ideas, please leave your email address and I will be in touch.

Email address\_\_\_\_\_

If you don't want to hear from us, or change your mind about how we contact you, email jinjore@macmillan.org.uk or call 0300 1000 200



### APPENDIX 2: SURVEY QUESTIONS FOR HCP (HEALTH CARE PROFESSIONALS) WORKING WITH DIVERSE GROUPS

This survey aims to gather insights on the nutrition and dietary information available for people from diverse ethnic groups. Your input will help us develop new, culturally appropriate resources to better support the needs of these communities. This information will be shared anonymously within Macmillan and as a research publication and poster.



The survey will take no more than 10 minutes to complete.

We appreciate your time and valuable feedback.

This is an anonymous survey unless you choose to provide your email address at the end.

Thank you for completing this survey. Your feedback is important to us. We promise to keep your details safe and never sell or swap them with anyone. This includes any sensitive personal data you may provide. Our privacy policy on our website at www.macmillan.org.uk explains how we keep this promise.

This survey will close on Friday 8<sup>th</sup> November 2024.

#### 1. What is your job role?

Oncologist

Dietitian

Oncology dietitian

Oncology nurse

Pharmacist

Support worker

Nurse

General Practitioner

Other (please specify)

#### 2. Where do you work?

Wales

Scotland

Northern Ireland

England:

London

North East England

North West England

Yorkshire

East Midlands



West Midlands South East England East of England South West England

#### 3. How long have you been working in cancer care?

Less than 1 year

1-3 years

3-5 years

More than 5 years

I do not exclusively in cancer care

#### 4. Do you provide information on nutrition to cancer patients?

Yes/no/ sometimes

# 5. Do you provide nutritional information for cancer patients from diverse ethnic background?

Yes/no/sometimes

If yes please list which ethnic groups from you worked with:

#### 6. What information do you provide? (select all that apply)

Verbal advice

Locally produced leaflets

Nationally produced leaflets

Links to websites

Not aplicable

Other (please specify)

# 7. When giving nutritional advice, do you consider the patient's cultural or ethnic background?



- o Always
- o Often
- o Sometimes
- o Rarely
- o Never

#### 8. Do you feel that the general nutrition guidelines provided to cancer patients are adaptable to the cultural and dietary preferences of diverse groups (e.g., Black African, British Asian, Polish groups etc)?

- o Yes, they are adaptable
- o Somewhat, but improvements are needed
- o No, they are not adaptable
- o I am unsure

Any comments

# 9. How confident do you feel in providing nutrition advice to patients from diverse ethnic backgrounds?

- o Very confident
- o Somewhat confident
- o Not very confident
- o Not confident at all

# 10. What are the main challenges you face when providing nutritional advice to cancer patients from diverse ethnic groups? (Select all that apply)

Lack of culturally appropriate dietary information

Language barriers

Lack of time to explore cultural preferences

Insufficient training on cultural sensitivity

Uncertainty about traditional foods and their nutritional value

Other (please specify)

# 11. Do you feel that you need further training to support you providing culturally appropriate nutrition advice to cancer patients from diverse ethnic groups?

Yes /No/ maybe

#### 12. What training topics would be helpful? (select all that apply)

Information about cultural/traditional foods from diverse groups How to adapt nutritional guidelines for different ethnic groups Assessing nutritional status Understanding how religious, spiritual or cultural beliefs effect nutrition/diet choices Other (please specify)

#### 13. What training method would be helpful? (select all that apply)

Conference/study day Online training modules Webinars Printed guidelines/resources Working directly with local community groups Other (please specify)

# 14. Are there any resources that you think are lacking on nutrition and cancer for people from ethnic groups? Please specify

# 15. Do you prescribe or recommend oral nutritional supplement (ONS) drinks to patients?

Yes, no, sometimes

If yes how do you decide which patients require ONS? (please specify)

# 16. Do you think people from diverse groups experience any barriers to taking oral nutritional supplements?

Yes/ no/ maybe

Any comments

# 17. Which factors do you prioritise when recommending an oral nutritional supplement drink to your patients? Please rank these 1-5 (1 being highest priority, 5 being lowest priority)

Energy/calories provided Protein provided Volume Flavour Price What is available locally Not applicable

18. Do you have any additional comments or suggestions regarding the provision of nutrition and dietary advice to diverse ethnic groups in cancer care?

If you are interested in being involved in this work or sharing additional ideas please leave your email address and I will be in touch.

Email address\_\_\_\_\_

If you don't want to hear from us, or change your mind about how we contact you, email jinjore@macmillan.org.uk or call 0300 1000 200

# APPENDIX 3: Other versions of the Eatwell guide for healthy eating

#### African and Caribbean Eatwell guide

Available at: African & Caribbean Eatwell Guide — The Diverse Nutrition Association



#### South Asian Eatwell guide

Available at: <u>Untitled (700 x 700 px) (mynutriweb.com)</u>

#### **Vegetarian Eatwell**

Available at: Eatwell guide veggie DR EDIT MAR2018 (vegsoc.org)

#### Vegan Eatwell

Available at: The Vegan Eatwell Guide (vegansociety.com)

### **APPENDIX 4: NRICH Professionals workshop report**

#### Introduction

81 professionals provided their email address after completing the ENRICH professionals survey, expressing like would like to be involved in further work.

These professionals were then invited to a 1.5 hour workshop on Monday 2<sup>nd</sup> December which aimed to gather further insights and feedback.

28 professionals (34% of those invited) accepted the invitation, however only 9 (32%) attending the meeting.

Table 1: professionals who attended the workshop

Professional	Number attended
Oncology Dietitians	3
Clinical Nurse Specialist (CNS)	2
Nutritional scientist	1
GP	1
Support worker (CSW)	1
Macmillan Centre & personalise care	1
manager	

The aim of the meeting was to probe deeper into the topic of nutritional information for diverse groups with cancer, explore their training needs and gather any other feedback.

The meeting was organised to have a 2 breakout sessions to allow small groups of 3 to discuss the questions raised.

#### **Breakout question 1**

#### What verbal advice do you provide to people with cancer?

Non-dietitian/nutritional scientist mentioned they provide Macmillan booklets, bowel cancer booklet, doesn't really get involved (GP)

#### Does cultural background feature in the advice you provide?

"there is room for a diversity and we and I think that they could be extra pages added into the information that we give out"

Translations are difficult to get, information is copy and pasted in Google translate (CSW)

Macmillan translated booklets are used

Dietitians- verbal advice backed up by written and cultural background is always considered

Dietitian R Clinic run for embassy patients from overseas- struggle with written information. Can't get in house stuff, cant be translated as it costs a lot of money so use apps. Patient library translate verbal and written info from electronic forms.

Asked patients for info about their diets and learn about their cultural difference (from Qatar and Kuwait)

In house advocates to support patients

Another dietitian- time spent advising patients on nutrition support, optimise intake pre treatment and in treatment, micronutrient monitoring. Group sessions for weight loss and healthy eating

The Trust has one booklet for African Caribbean patients and draft South Asian diet

Nutritional scientist – doing this work for a long time already (survey didn't include nutritionists?). Translations are not enough, info is high level and doesn't make sense to how people are actually living, videos are more useful. BDA, WCRF recommendations are not the same

#### Mentimete Join at menti.com | use code 4116 8699 What nutritional guidelines do you refer to when talking to people with cancer? (e.g. The Eatwell guide (plate model), ESPEN guidelines, etc) 16 responses eatwell and espen my own wcrf eat well guides bomms nhs macmillan espen eat well eat well guide eatwell eatwell plate espen cancer 2021 talwar 2016 0

CNS- maninly advievoiding

CSW stoma patients - want recipes, will be working on getting some recipes and asking people and producing something ourselves. Stoma booklet from Berkshire nurses

#### Summary

Verbal advice provided by dietitians- cultural background considered but struggle without having written info to back this up. Eatwell guides adapted for other cultural backgrounds are also used

1 nutritionist working in this area developed own resources

CNS providing generic advice on bacterial foods, provide standard booklets like Macmillan

Cultural awareness training isn't very common- should be mandatory training as it applies to any discipline

Training needed: better estimated of energy and protein on the wards, budget version of lower energy alternative, fortification of cultural foods, recipes and composition

Need different levels of information, basic/general and more personlised, tailored advice from someone with cultural training to support this group, info on energy and protein quantity within different food, budget versions of culturally appropriate foods, handy checklists of snacks and puddings that are cultural appropriate food, good swaps or healthy options or lower energy alternative

Cookery class to help people with cooking



#### Key points:

Important not to group people as a homogenous group i.e. south Asian, Black Caribbean as lots of variety exist within a group

Information is needed at different levels-

Some of the information used in booklets is high level

Sources of information from the WCRF, BDA, are different?

neutropenic diets, nutrition support, health eating, living with and beyond cancer.

#### Diabetes and cancer

Information on energy and protein quantity within different foods



budget versions of culturally appropriate food

quick handy checklists or list of things like food fortification, snacks and puddings that are culturally appropriate

quick swaps or healthier options or lower energy alternatives

### **APPENDIX 5: User interview questions**

Thank you so much for giving up your time to discuss your thoughts about cancer nutrition information for diverse groups.

# I will be transcribing our call just so I have a written account of what we discuss and I can listen to you completely. The account will only be used to take notes from your answers which will be used anonymously

What is your ethnic background?

Is this regarding your own cancer experience or a friend/family member?

Q1 As you know were here to talk about nutrition and cancer information. You kindly completed the questions so may have an idea of the things we are interested in finding out. Can you start by telling me a bit about yourself?

Q2 can you tell me what was your diagnosis and treatment?

Q3 Did you experience any nutritional problems?

Q4 where did you get support?

Q5 if you got nutrition support was it everything you needed?

Q6 what would you have liked?

Q7 I am going to show you a image this is the Eatwell plate guide it is available in for UK , for Asian and Black Caribbean diets

Q8 Would this be helpful for you?

Q9 what form of information would have been helpful- booklet, video, online?