

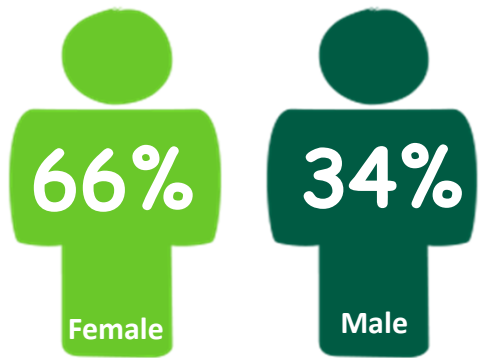
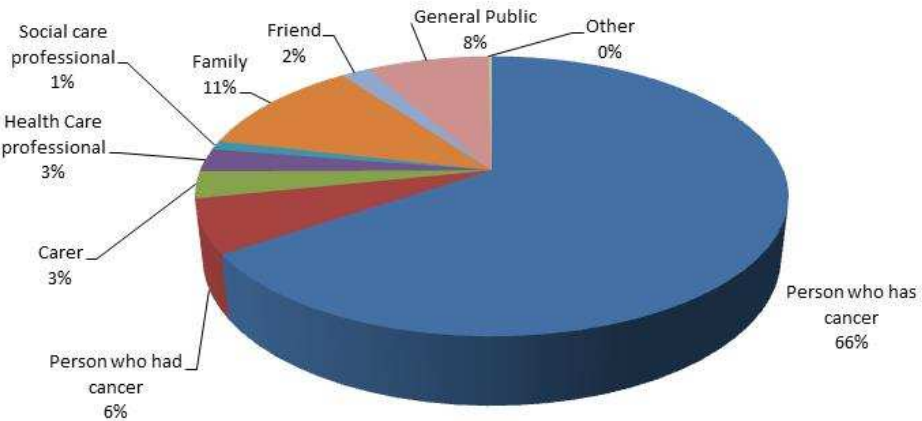
**MACMILLAN CANCER INFORMATION &  
SUPPORT CENTRE -  
THE WHITTINGTON HOSPITAL  
NHS TRUST**

Macmillan Core data collection from January – December 2016

# WHO ARE OUR ENQUIRERS?

Most of the enquirers to the centre came from those people who have cancer (66%), followed by family members of people with cancer (11%). The pie chart below illustrates the different number of people accessing services at the centre by their status (who they were in relation to having cancer or visiting because they know someone who has cancer). Using the rich data collected at the centre, we can analyse to further explore who enquirers are.

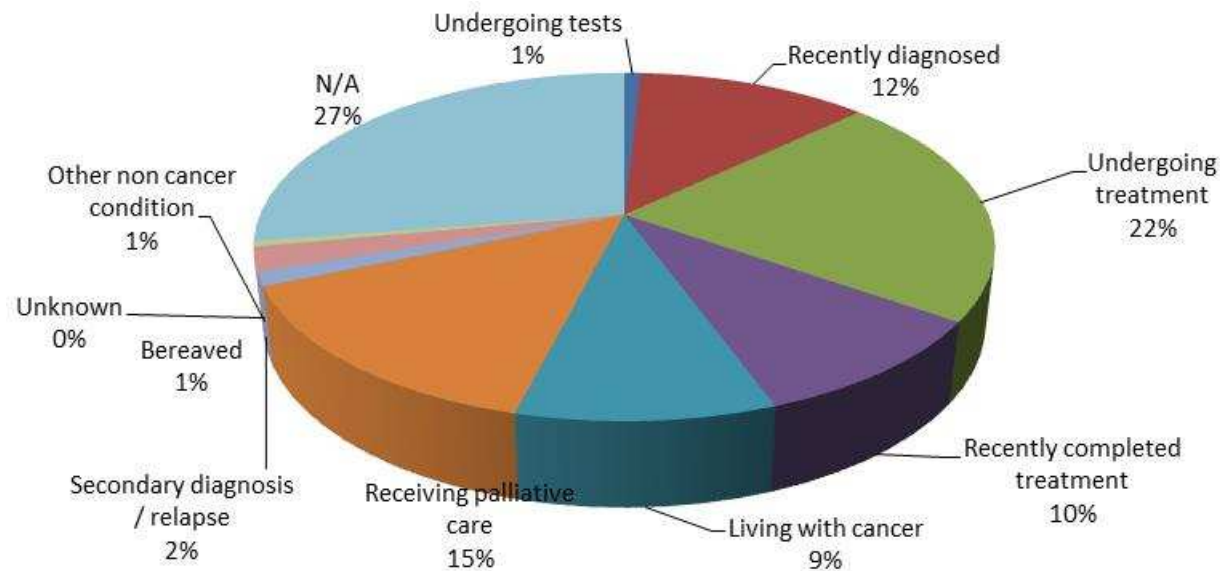
Service User	No:
Person who has cancer	634
Person who had cancer	60
Carer	30
Health Care professional	26
Social care professional	10
Family	110
Friend	18
General Public	77
Other	2



A total of 2,416 enquirers visited the Macmillan Information & Support Centre at the Whittington Hospital in 2016.

# STAGE OF PATHWAY

Enquirers were asked, where it was relevant what stage of the pathway the enquiry they were making was about. The chart below offers a breakdown (excluding unknowns and blank cells) of which stage of the pathway was being enquired about.

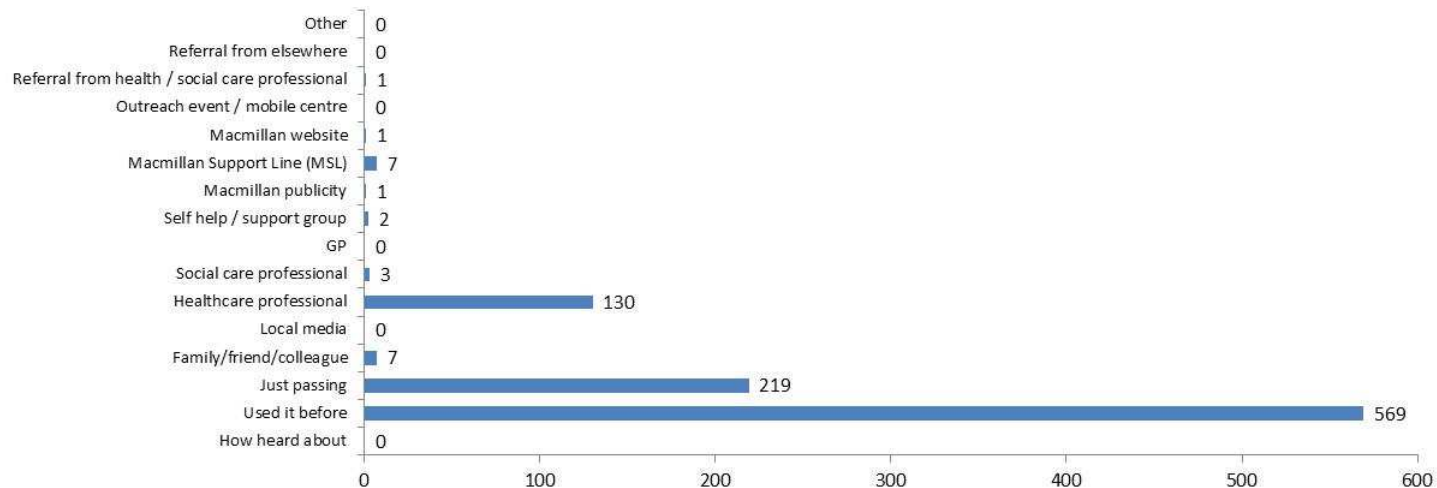


As you can see, over a third of the enquiries were made by someone who was recently diagnosed or undergoing cancer treatment. Followed by 15% of enquiries made by those who were receiving palliative care. The 27% NA applies to carers, family members and the general public who don't have cancer or who are supporting someone with cancer.

# HOW HEARD ABOUT & LOCATION

When asked how visitors to the centre heard about the centre 59% had used the centre before and were making a return visit. This was followed by 23% who stated they were just passing and saw the service, and then 13.5% said they were told about the centre by a healthcare professional. The chart on the right shows where the enquiries were made with the majority of them (97%) at the Centre.

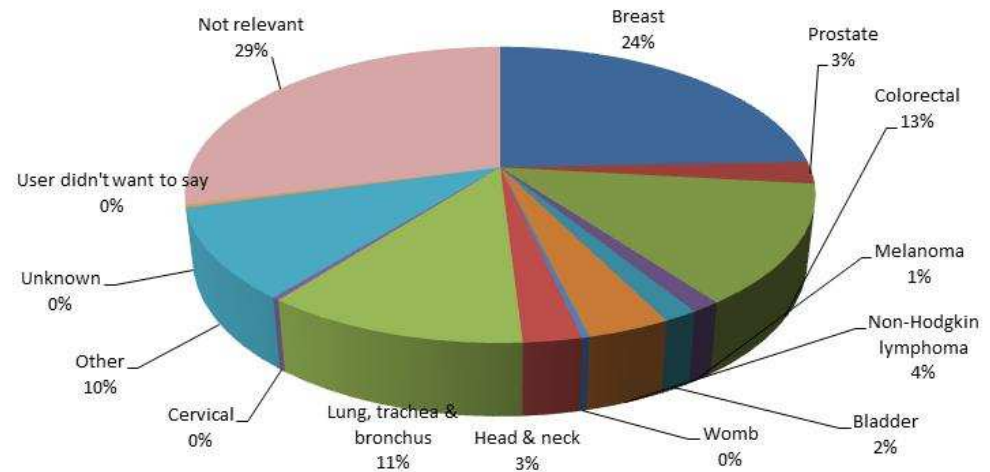
Location	No:
Information and support centre	942
Anywhere in hospital	7
Library	0
Outreach event	0
Community location	0
Other	17
<b>Total number of people</b>	<b>2416</b>



# CANCER SITE

The data collected at the centre also allows us to analyse the types of primary cancer sites visitors were enquiring about.

Primary Cancer Site	
Breast	231
Prostate	23
Colorectal	124
Melanoma	12
Bladder	14
Non-Hodgkin lymphoma	34
Womb	3
Head & neck	24
Lung, trachea & bronchus	108
Cervical	3
Other	94
User didn't want to say	3
Unknown	1
Not relevant	274



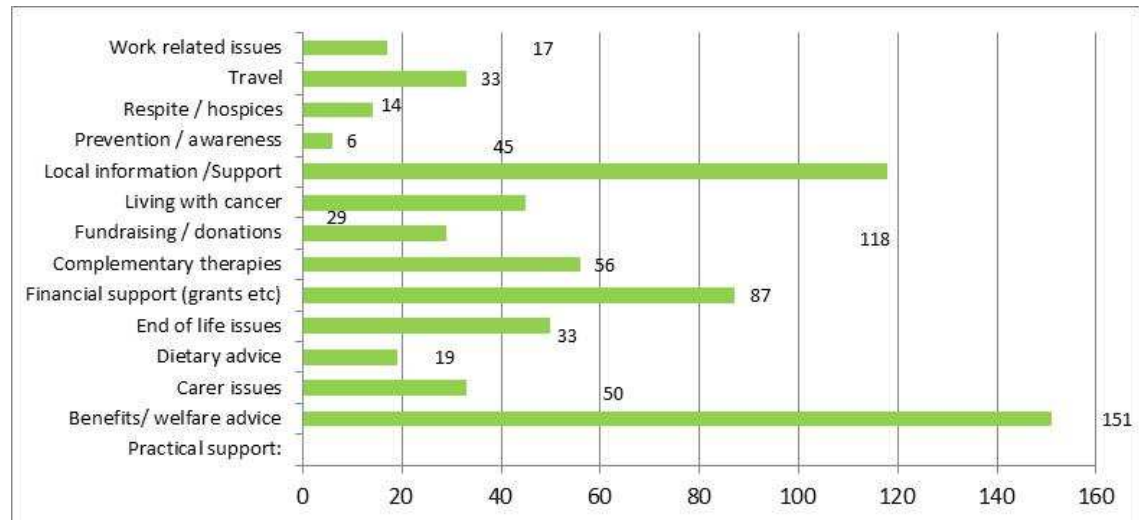
The table and chart show that the top 3 cancer sites enquired about at the centre in this period of time were:

1. Breast (24%)
2. Colorectal (13%)
3. Lung, trachea and bronchus (11%) This data is more or less the same as in 2015. We will be targeting more prostate cancer patients as this group are under represented . We will be working with the new Prostate cancer CNS to look at ways of improving uptake.

# REASON FOR VISIT

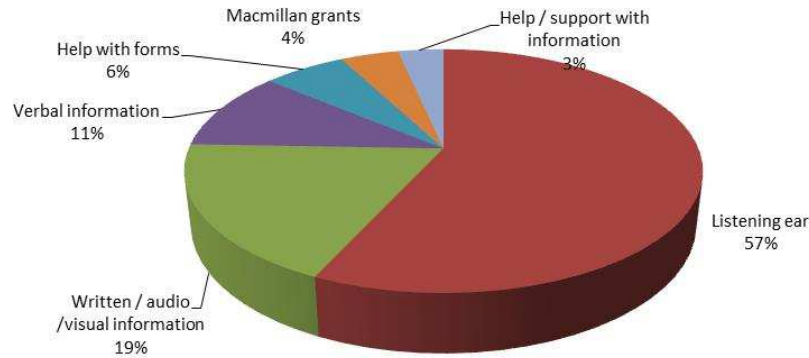
A wide range of subjects of enquiry were recorded during this time. The most frequent reasons for visiting were people seeking emotional & psychological support. This was closely followed by people seeking advice on benefits and financial support.

<b>Emotional support:</b>	
Counselling / psychological support	178
Wants to talk	834
Relationship issues	6
<b>Practical support:</b>	
Benefits/ welfare advice	151
Carer issues	33
Dietary advice	19
End of life issues	50
Financial support (grants etc)	87
Complementary therapies	56
Fundraising / donations	29
Living with cancer	45
Local information /Support	118
Prevention / awareness	6
Respite / hospices	14
Travel	33
Work related issues	17
<b>Clinical support:</b>	
Genetic concerns	5
Screening	24
Symptoms	13
Treatment / side effects	54
Palliative care	12
End of Life	9
Other	3

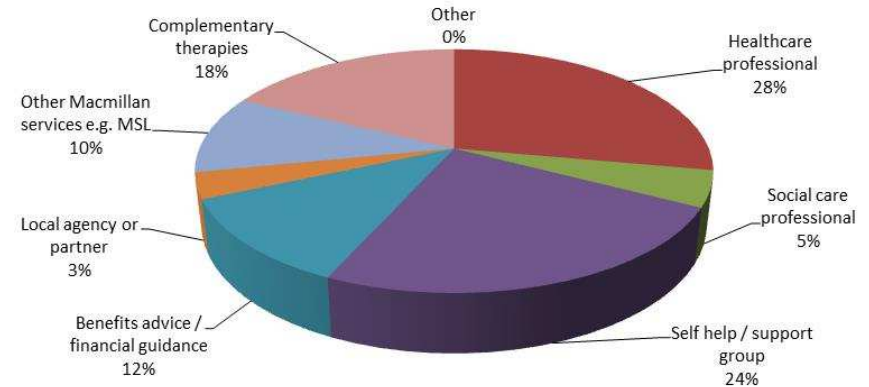


# ACTIONS, SIGNPOSTED & REFERRALS

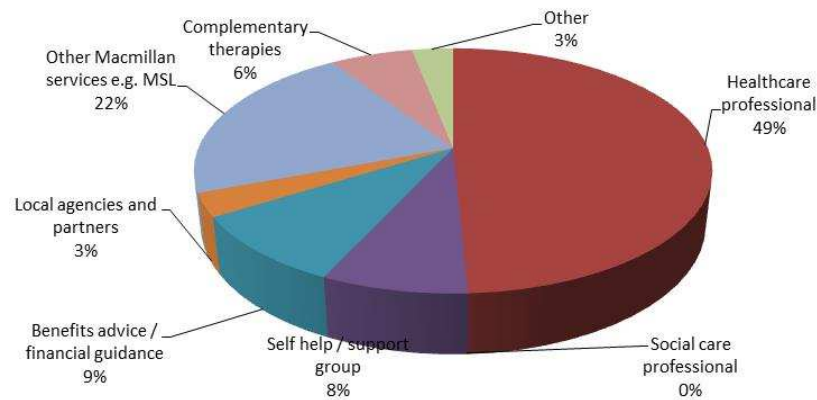
## Actions or Outputs



## Signposted



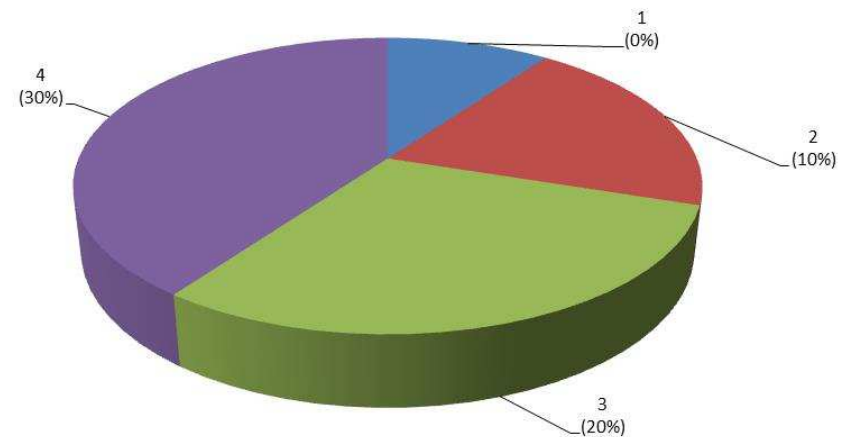
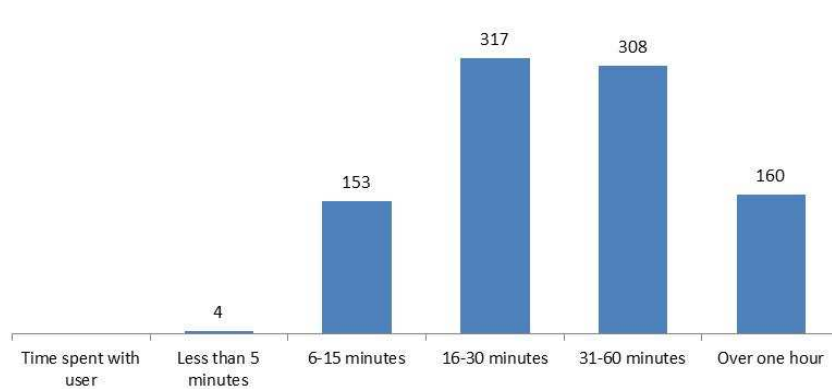
## Referred user to



The charts show the actions required to help the enquirer, where enquirers were signposted to and referred on to if required.

# LENGTH & COMPLEXITY OF ENQUIRY

These two charts show the length of enquiry per enquiry and the level of complexity for all enquiries made to the centre during 2016.



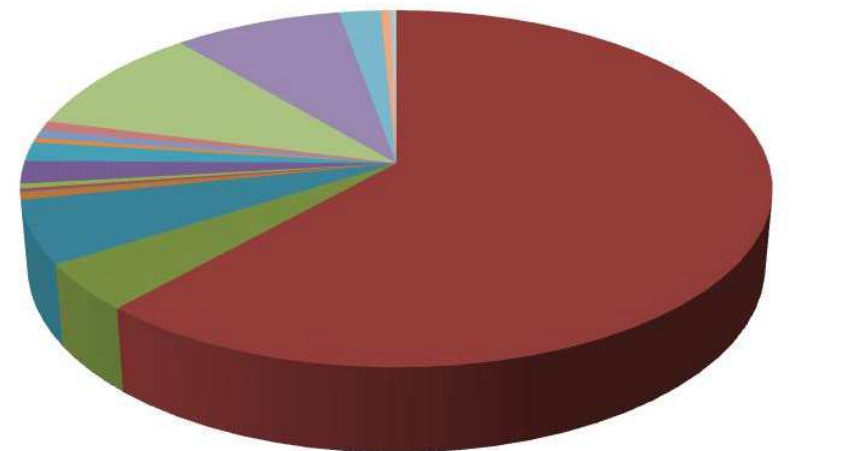
Please see the appendix for definitions of levels of complexity that were used. As we can see the majority of users were level 3 & 4. This means that people had complex multiple issues and would be likely to return for more support.



# ETHNICITY

The table and chart below shows the data collected about the breakdown of ethnicity. The majority of visitors were White British 570 (388 in 2015). We have seen an increase in Black African visitors from 57 in 2015 to 91 in 2016 and also in Black Caribbean from 48 in 2015 to 77 in 2016.

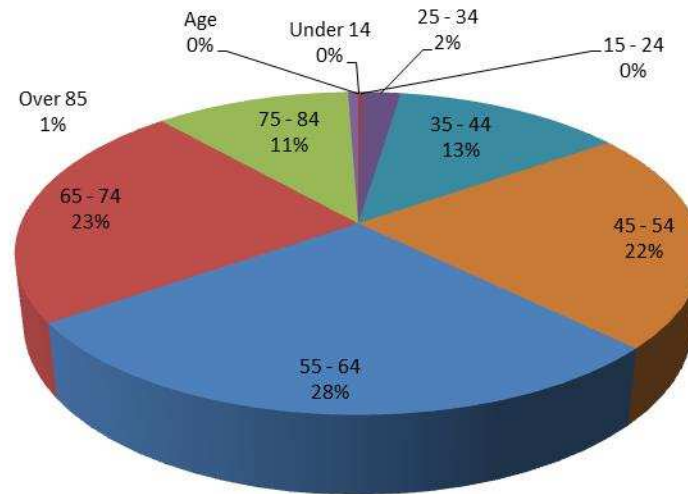
Ethnicity	No:
White: English / Welsh / Scottish / Northern Irish / British	570
Irish	40
Gypsy traveller or Irish traveller	0
Any other white background	53
Mixed / multiple ethnic groups: White and Black Caribbean	6
White and Black African	1
White and Asian	2
Any other mixed / Multiple ethnic background	4
Asian / Asian British: Indian	19
Pakistani	16
Bangladeshi	4
Chinese	7
Any other Asian background	8
Black / African / Caribbean / Black British: African	91
Caribbean	77
Any other black / African / Caribbean background	19
Other ethnic group: Arab	4
Any other ethnic group	2
User preferred not to say	0
Not asked	1



# AGE

The table shows the data collected about age groups, showing that most enquiries were made from those who were between 45 and 74 years old

Age	No:
Under 14	2
15 - 24	0
25 - 34	19
35 - 44	114
45 - 54	194
55 - 64	247
65 - 74	204
75 - 84	97
Over 85	5
Didn't ask	0
User preferred not to say	0



**At the centre we have helped people to apply for Macmillan grants totalling £26,669 in 2016 with the total amount applied for from July 2014 to December 2016 £64,212 (the average grant is £400).**

# LEVELS OF COMPLEXITY

## LEVEL 1

1. The user has a specific enquiry (likely to be single topic)
2. The worker/volunteer answers the enquiry verbally, provides one or two items of information, or signposts to another service
3. The worker/volunteer needs to take no further action on behalf of the user
4. The enquiry is dealt with on the day and further contact is unlikely

## LEVEL 2

1. Interaction that involves discussion (face-to-face or telephone) to assess person's information needs
2. Worker/volunteer provides verbal support as part of interaction to clarify the information or to enable user to understand the information fully
3. User requires information involving more than one topic
4. The worker/volunteer generally needs to take some action after the visit such as referral or contact with another service
5. The user may need further information or support at a later stage

## LEVEL 3

1. Interaction that involves discussion (face-to-face, telephone) to assess person's information needs
2. Worker/volunteer provides verbal support as part of interaction to clarify the information or to enable user to understand the information fully
3. User has complex or multiple issues that cross at least two information areas (e.g. cancer information and finance) and needs emotional support
4. The worker/volunteer needs to take at least one action on behalf of the user such as contacting another service or health professional
5. It is likely that the user will need further information or support at a later stage

## LEVEL 4

1. Interaction that involves discussion (face-to-face, telephone) to assess person's information needs
2. Worker/volunteer provides verbal support as part of interaction to clarify the information or to enable user to understand the information fully
3. User has complex or multiple issues that cross at least two information areas and needs emotional support
4. Follow-up action by worker/volunteer with another service or health professional is essential soon after the interaction
5. The user will need further contact with the service or support in order to resolve the matter

# CORE DATA FORM

## CORE DATA COLLECTION FORM

**WE ARE  
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Form ID \_\_\_\_\_ Date   /   /

- Gender**
  - Male  Female
  - Other (please specify) \_\_\_\_\_
- 2. How was contact made?**
  - Face to face
  - By email
  - By phone
  - By letter
  - Other (please specify) \_\_\_\_\_
- 3. Who is the service user?**
  - Person who has cancer
  - Person who had cancer
  - Carer
  - Healthcare professional
  - Social care professional
  - Family
  - Friend
  - General public
  - Other (please specify) \_\_\_\_\_
- 4. Primary cancer site**
  - Breast
  - Prostate
  - Colorectal (bowel cancer)
  - Melanoma (skin cancer)
  - Bladder
  - Non-Hodgkin lymphoma
  - Womb
  - Head and neck
  - Lung, trachea and bronchus
  - Cervical
  - Other cancer type (please specify) \_\_\_\_\_

User didn't want to say  
 Unknown  
 Not relevant
- 5. Stage of cancer pathway**
  - Undergoing tests
  - Recently diagnosed
  - Undergoing treatment
  - Recently completed treatment
  - Living with cancer
  - Receiving palliative care
  - Bereaved
  - Secondary diagnosis / relapse
  - Other non-cancer condition
  - Unknown
  - Not applicable
- 6. How did the service user hear about the service?**
  - Used it before
  - Just passing
  - Family / friend / colleague
  - Local media
  - Healthcare professional
  - Social care professional
  - GP
  - Self help / support group
  - Macmillan publicity
  - Macmillan Support Line (MSL)
  - Macmillan website
  - Outreach event / mobile centre
  - Referral from health / social care professional
  - Referral from elsewhere
  - Other (please specify) \_\_\_\_\_
- 7. Reason for visit**
  - 7a. Emotional support**
    - Counselling / psychological support
    - Wants to talk
    - Relationship issues

- 7b. Practical support**
  - Benefits / welfare advice
  - Carer issues
  - Dietary advice
  - End of life issues
  - Financial support (grants, etc.)
  - Complementary therapies
  - Fundraising / donations
  - Living with cancer
  - Local information / support
  - Prevention / awareness
  - Respite / hospices
  - Travel
  - Work related issues
- 7c. Clinical support**
  - Genetic concerns
  - Screening
  - Symptoms
  - Treatment / side effects
  - Palliative care
  - End of life
- 7d. Other**
  - Other (please specify) \_\_\_\_\_

- 8. Actions or outputs**
  - Listening ear
  - Written / audio / visual information
  - Verbal information
  - Help with forms
  - Macmillan grants
  - Help / support with information
- 9a. Signposted user to:**
  - Healthcare professional
  - Social care professional
  - Self help / support group
  - Benefits advice / financial guidance
  - Local agency or partner
  - Other Macmillan services, e.g. MSL
  - Complementary therapies
  - Other (please specify) \_\_\_\_\_
- 9b. Referred user to:**
  - Healthcare professional
  - Social care professional
  - Self help / support group
  - Benefits advice / financial guidance
  - Local agencies & partners
  - Other Macmillan services, e.g. MSL
  - Complementary therapies
  - Other (please specify) \_\_\_\_\_
- 10. Postcode**

What is the first part of the user's postcode (or which area do they live in)

\_\_\_\_\_
- 11. Level of complexity (please circle)**

1    2    3    4
- 12. Time spent with user**
  - Less than 5 minutes
  - 6–15 minutes
  - 16–30 minutes
  - 31–60 minutes
  - Over one hour
- 13. Location type**
  - Information and support centre
  - Anywhere in hospital
  - Library
  - Outreach event
  - Community location
  - Other (please specify) \_\_\_\_\_
- 14. Total number of people present**

\_\_\_\_\_

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