



Macmillan Insight Project

Final Report

March 2017

Working in partnership:



Contents

Introduction	p3
Project Brief	p3
Local Statistics	p5
Method	p6
Findings	p7
Appendices	p16

Introduction

This is a report to accompany the Insight Project spreadsheet (**Appendix 1**). It begins with an outline of the project brief with information about Macmillan Cancer Support and Self Help UK, the project partners, and continues with some local cancer statistics as background information. There is a description of the method next, with reference to the Project Planning Group, and the meetings and visits undertaken as part of the research. The findings of which are presented in the main section of the report, and features guidance on best practice, gaps in provision, recommendations and the information needs which have been identified.

Project Brief

The brief was to develop insight into the cancer self help and support activities that currently exist in Nottingham and Nottinghamshire and analyse the data to inform the baseline assessment and development of the next Macmillan Engagement and Action Plan for Nottinghamshire. The brief also included:

- Analysis of key stakeholders and activities
- Identification of good practice
- Identification of gaps in provision and make recommendations
- Analysis of local information needs of people affected by cancer

This Macmillan project was run in partnership with Self Help UK; other partnership projects include the Beyond Diagnosis and Early Diagnosis Projects.

Time on project: 18.5 hours a week from 1st September 2015 to 31st August 2016.

Macmillan in Nottinghamshire

Macmillan has outlined the need for community engagement across Nottinghamshire to support the delivery of Macmillan's nine outcomes for people affected by cancer (**Appendix 2**). Macmillan aims to encourage key stakeholders and partners to work together to engage with communities to improve the lives of people affected by cancer. A new vehicle for this is the new local Macmillan Cancer Partnership.

Macmillan Cancer Partnership in Nottinghamshire

The Macmillan Cancer Partnership Nottinghamshire

Shaping and improving
your cancer care **together**

The Macmillan Cancer Partnership in Nottinghamshire was formed in June 2015 to improve and develop new ways to support people living with, and beyond, a cancer diagnosis. The partnership comprises professionals from health and social care and the voluntary sector. The Macmillan Cancer Partnership in Nottinghamshire has sought the views and ideas of people affected by cancer at various events and an action

plan is being developed. Four key themes have been identified for the most important issues for patients and carers:

- Information and support
- Managing my condition
- Professionals working with me
- Work

The findings of the Insight Project are summarised under these four themes.

Self Help UK

Self Help UK (SHUK) is a unique organisation which helps create, support and promote self help groups. The organisation is well-established with more than 34 years of experience in Nottingham and Nottinghamshire. It has an enviable reputation for helping people to start and grow self help groups to improve their health and wellbeing. The organisation also bridges the gap between self help groups and health and social care professionals. It has recently extended its delivery to include services that support people to self-care.

The Department of Health has recognised SHUK as a beacon for best practice and so SHUK also works in other areas of the country.

Information and Insight Officer Role at Self Help UK

Whilst working 18.5 hours a week on the Macmillan Insight Project, the Information and Insight Officer also worked 11.5 hours a week at SHUK managing the Information Team. Tasks relevant to this project included managing:

- The production of the annual Self Help Groups Directory
- The Information Line (which provides information about self help groups and signposts the public and professionals to services)
- Information about self help groups on the Nottinghamshire Help Yourself website www.nottshelpyourself.org.uk

- Self-care and self help group information on the Nottingham City CCG Bulwell pilot project website: www.nottinghamselfcare.org.uk

Much of this work also informed the Macmillan Insight Project.

Local Statistics

Local cancer statistics by Clinical Commissioning Group area are included in this report, as background information to the project.

Numbers of people diagnosed with cancer are continuing to increase. Macmillan predicts that there will be 1,000 people diagnosed with cancer per day in the UK by the end of 2016. Breast, prostate, lung and colorectal cancer accounted for over half the cancers diagnosed in the UK in 2013 (ONS). Figures for those cancers are included here by area.

Overview of Cancer stats 2013	Headline indicators			Cancer incidence				New cases
	Under 75s mortality	% diagnosed at early stage	One year survival	Breast	Bowel	Lung	Prostate	any cancer
Per 100,000 population								
Bassetlaw	295.7	54.2%	67.9%	186.1	76.7	83.1	174.8	571
Mansfield & Ashfield	153	55.4%	66.5%	140	71	92	212	546
Newark & Sherwood	128.5	56.3%	71.4%	174.7	76.1	75.9	208.2	601
Nottingham City	133	55.4%	66.6%	137	67	111	177.7	374
Nottingham North and East	124	58.7%	69.4%	186	67	79	208.1	630
Nottingham West	119	60.1%	68.2%	152	69	63	176.2	575
Rushcliffe	111	65.6%	72.0%	235	83	53	198	581
England average	122	54.5%	69.3%	165.9	74.1	79.3	177.7	612

Age standardised cancer incidence rates show that there were 683.1 male and 542.2 female cancer cases per 100,000 in England in 2013. The incidence rate is 26% higher for males and increasing.

Nottingham City is amongst the top 20 local authorities list of the highest rates of premature death from cancer in the UK (House of Commons Briefing Paper 2015). Lung cancer incidence is higher than the national average in Bassetlaw, Mansfield and Ashfield, Newark and Sherwood and Nottingham City areas. Bowel cancer incidence is higher than the England average in Bassetlaw, Newark and Sherwood and Rushcliffe. Breast cancer incidence is higher than the national average in Bassetlaw, Newark and Sherwood, Nottingham North and East and Rushcliffe. Prostate cancer incidence is the same or higher than the England average in Nottinghamshire except in Bassetlaw and Nottingham West.

Whilst this summary is based on crude incidence rate figures, it demonstrates there is certainly a need for more awareness raising work in this area.

Method

Starting Point

Initially the Information and Insight Officer looked at recent work that had already been undertaken, such as the document collated by Lisa Janiec (Cancer Pathways Redesign Programme Project Manager) following a meeting in June 2015 which listed services and information sources across Nottinghamshire. This showed that whilst many sources existed, many were only accessed by NHS staff or GPs and not available to the public. Many healthcare professionals were consulted and the overwhelming need identified was to have publicly accessible information about cancer support services in one place.

Planning Group

After initial research, a planning group was established in October 2015 to help steer the project. Membership included professionals from Macmillan, Self Help UK, Nottingham University Hospitals NHS Trust, Sherwood Forest Hospitals NUH Trust and CityCare. Terms of Reference were agreed (**Appendix 3**) and the group supported the project throughout with useful feedback and direction.

Meetings and Visits

The views of people at different stages of the cancer journey, and their carers, were sought at a range of events and meetings during the year of the project. Similarly, by talking to professionals and volunteers that signpost people affected by cancer to services, information was compiled about the cancer self help groups and support activities in Nottinghamshire.

Examples of events, meetings and professional contacts

- Macmillan Cancer Partnership in Nottinghamshire
- SHUK events and links with self help groups
- Stints on the Macmillan bus in Nottinghamshire
- Visiting the Macmillan Information and Support Centres at the City Hospital and King's Mill and talking regularly to their staff and volunteers (Alison Hall, Jo Gregg)
- Range of cancer meetings e.g. Greater Nottingham Patient and Cancer Carer Forum, Better Together Cancer Group, Nottingham City Cancer meeting

- Meetings with Macmillan and other healthcare professionals (e.g. Lisa Janiec, Laura Cutler, Danielle Mellows, Lynda Burton, Abi Powell, Helen Kirkham, Ellie Robinson, Clinical Nurse Specialists)
- Meetings with local organisations e.g. Healthwatch Nottingham, Healthwatch Nottinghamshire, Maggie's, Boots Supporting people affected by cancer Volunteering service
- Links with colleagues working on cancer projects.

This research has identified the perceived gaps in services. Some gaps noted are real gaps, however, some are only perceived gaps as in some cases support is available but there is no awareness of services.

Findings

Visit to New Horizons, near Doncaster, Yorkshire

The Information and Insight Officer visited New Horizons, a project set up in a similar way to this one, with Macmillan and Doncaster CVS working together. The project manages a database of local services for people affected by cancer that are 'cancer friendly' kite marked. During the visit, New Horizons staff talked about the systems that they use and how their services were displayed online using the E-Spatial mapping tool.

Staff undertake home visits to assess the needs of new clients and continue to support the clients for as long as they need. Reviews are built into the process, including reviews of the services they signpost to. If a service fails to deliver, they are removed from the database.

RECOMMENDATION: this system worked well and could be replicated in other areas with suitable infrastructure and funding.

All of the project findings are compiled in the Insight Project spreadsheet (**Appendix 1**). This is where the majority of the project data is presented.

Self Help Groups and Services Spreadsheet – (Appendix 1)

Appendix 1 lists self help groups, projects and services specifically for people affected by cancer providing contact details, what they offer and the area covered. The list of what is offered is aligned by subject to the order of questions that are asked during the electronic Holistic Needs Assessment (eHNA) (see page 12), so that this can be used alongside the eHNA in future. Hospital-based groups are highlighted in yellow. A few selected services that are not just for people affected by cancer, but which may be useful, have been included and are highlighted in green. There are services and groups for people with long term conditions that would also provide support for people with cancer, but given the timescale and brief for this project, they are not included here.

Good Practice

Nottinghamshire County FC **Football in the Community (FITC)** delivers the Cancer Rehabilitation and Exercise (CARE) Programme in partnership with Macmillan Cancer Support. The project uses physical activity to help patients during their recovery from cancer and is currently based at the Portland Centre in the Meadows, Nottingham. Feedback from participants is that, not only has it helped with their physical wellbeing, but also it has provided a social network of people in a similar situation whom they can talk to. FITC is hoping to set up a similar project in Mansfield and Newark areas, subject to funding.

RECOMMENDATION: that this project is extended to other areas of Nottinghamshire. There are many people who would participate, but who live too far away.

GP Exercise Referral Programmes

In mid-Nottinghamshire (Newark and Sherwood, Mansfield and Ashfield), exercise programmes are offered to people with long term conditions (but not to people with cancer unless they also have another long term condition!) at Leisure Centres by GP referral. These sessions are currently led by instructors with a Level 3 qualification in Rehabilitation Exercise. This physical activity provision is limited due to a lack of qualified instructors in the existing exercise referral schemes. Exercise referral qualifications enable individual and safe exercise programmes for a variety of long term health conditions, but do not include cancer. Yet it is known that physical activity is beneficial at any point during the cancer patient journey. The Wright Foundation offer Level 4 qualifications to upskill existing instructors, however providers in Mid-Nottinghamshire do not currently offer this. (This is available across Lincolnshire and in Nottingham City).

www.wrightfoundation.com

RECOMMENDATION: that Level 4 Cancer Rehabilitation qualifications are funded to upskill existing instructors, so that a safe exercise programme can be devised for cancer patients in the mid-Nottinghamshire area.

Macmillan Information and Support Centres

Following research into information services for cancer patients, Macmillan identified four key issues:

- Some people with cancer receive limited or no information about their diagnosis or living with cancer
- Some people feel overloaded with information
- Many people with cancer do not understand the information they have been given
- Information was not provided at the right time in the cancer journey.

Macmillan developed Information and Support Centres across the UK to address these issues by providing:

- Information when people need it from a reliable source in a comfortable environment
- Staff and volunteers that can explain the information and provide support
- A personalised service including practical and emotional support e.g. getting financial help

Macmillan's recent Impact Brief reports that these centres are working well. The Macmillan Information and Support Centres at the Nottingham City Hospital (Nottingham), Maggie's and King's Mill Hospital (Sutton-in-Ashfield) are a much used and needed resource, offering free information and support when people need it.

RECOMMENDATION: consider setting up similar Information Centres in other areas of Nottinghamshire.

There are many other examples of good practice. Details of current projects in this area on the Macmillan Cancer Partnership in Nottinghamshire web page:

<http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/macmillansprogrammesandservices/macmillancancerpartnershipinnottingham.aspx>

Gaps in Provision and Recommendations

The gaps identified are listed in the table below.

Gaps identified

Information and support	Managing my condition	Professionals working with me	Work
No information about returning to normal activities e.g. swimming	Need to increase awareness of long term effects	Holistic Needs Assessment - how communicate results	Returning to work support
No brain cancer support networks	More self care support	Primary care nurses to link with secondary specialist nurses	Lack of understanding by employers
No peer support	Fear/anxiety of recurrence- support	Lack of communication between hospital and community	Lack of information about returning to work
Educate the public	Raise awareness of long term treatment effects	GP Education re late effects	
Support for people living with and beyond cancer outside hospital needed		Multi-disciplinary teams for joined up working	
Buddying/mentoring/support after diagnosis			
Gynae cancer awareness			
Testicular cancer - no support groups	testicular cancer - no support groups		
bladder cancer - no support groups	bladder cancer - no support groups		
Need more community locations/comfortable venues for groups as hospitals are a clinical location			
No information about returning to normal activities			
	No brain cancer support networks		
Support needed for people living with and beyond cancer outside of hospital needed			
Need for Health and Wellbeing events		Communication needed across the pathway between professionals, services and patients	
Information - there can be a lack of or overload		Breakdowns in pathway e.g. discharge problems	
Need right balance of information at right time		Need personal and tailored support to patients and support for families caring	
		Provide training and support to professionals to ensure they are aware of and working to pathways	

Information and Support

Gaps identified included self help groups for brain cancer, testicular cancer and bladder cancer. There were also requests for non- hospital based groups and comfortable venues as people affected by cancer already spend too much time in hospital without having to attend groups there too.

Macmillan has already identified someone interested in setting up a new group for people affected by bladder cancer in Nottinghamshire. Work is already under way to encourage groups to choose comfortable, accessible, non-hospital-based venues. Self Help UK would be happy to support any new group development.

RECOMMENDATION: that Macmillan Cancer Partnership in Nottinghamshire and Self Help UK put together a pack for new groups listing support offered by both organisations. A meeting has already taken place between Self Help UK and Macmillan to take this forward.

Buddying/mentoring after a cancer diagnosis is another gap that has been identified. The Beyond Diagnosis project has recently been extended to cover Newark and Sherwood and Nottingham City areas, so this will support some of the need. One to one support is also offered by the Boots Volunteering Service and the Children's, Teenagers and Young Adults Late Effects Service.

RECOMMENDATION: to promote and extend existing projects so that people affected by cancer across Nottinghamshire can access support.

'Educating the public' about cancer was another gap identified and part of this will be addressed by the Macmillan Cancer Partnership in Nottinghamshire's plan to set up 'Cancer Champions' in GP surgeries.

'Information about returning to normal activities' was named as a current gap. This was discussed by the Project Planning Group and it was recognised that people affected by cancer want information at different times during their cancer journey – there isn't a 'one size fits all'. An information pack is currently given to every cancer patient at Nottingham University Hospitals NHS Trust and Sherwood Forest Hospitals NHS Trust at diagnosis, but many people do not remember that they have received this.

As part of one of the Macmillan Cancer Partnership in Nottinghamshire events, Self Help UK ran a workshop that focused on the how/who/when/what/where of the information that people needed during their cancer journey. Feedback showed that the level of information required at each stage depends entirely on the individual. Some want all the information at diagnosis, "I want it all, and I want it now!" said one respondent. Others find the amount of information available overwhelming and need it in stages. A variety of sources were accessed to obtain information including printed resources, websites and verbal information given.

A Care Plan produced by the LIVESTRONG Foundation has been useful for some people as it provides a treatment summary that includes possible late effects and it can be printed: www.livestrongcareplan.org

RECOMMENDATION: the Planning group proposed devising a ‘Information Menu’ that could be given to cancer patients at the start of their journey, to use for reference, so they can request information when they need it. ‘Returning to normal activities’ could be included.

Managing My Condition

‘Awareness of long term treatment effects’. This was raised as an issue at many events and will be fed back to clinical staff by the Macmillan Cancer Partnership in Nottinghamshire. To a certain extent this will be addressed by the cancer pathways work at Nottingham University Hospitals NHS Trust and in mid-Nottinghamshire along with the use of electronic Holistic Needs Assessments and care planning with patients.

RECOMMENDATION: that long term treatment effects information is included in the ‘Menu of Information’ for patients, tailored for different cancers where appropriate.

‘Managing anxiety of recurrence’ is partly addressed by regular contact with cancer specialist nurses and through undertaking electronic Holistic Needs Assessments with cancer patients (see eHNAs on page 12). The Macmillan Cancer Support Service, which works in partnership with City Care, is currently being piloted in Nottingham City (Abi Powell/Helen Kirkham). The service works alongside Macmillan specialist cancer and palliative care services to look after the health and wellbeing needs of people who are affected by cancer out in the community. This project, launched in April 2016, has already received 150 referrals, including 115 from people with a cancer diagnosis. The project signposts to other services, where appropriate. Local Macmillan GPs have shown interest in working more closely with this project as whilst they undertake patient reviews, they often do not have time to find services for patients. Through projects like this, emotional support can be offered to manage the anxiety of recurrence.

RECOMMENDATION: that electronic Holistic Needs Assessments become integral to cancer patient care planning and support across Nottinghamshire. That projects like the Macmillan and CityCare Cancer Service are rolled out across Nottinghamshire.

The need for more self-care support was raised as a gap at various events. There are a wide range of self-care options including exercise, advice about diet, walking groups, befriending, and self help groups. Maggie’s Nottingham offer short courses and drop-ins as well as emotional support. Not all groups are cancer specific and what is available varies by geographical location. Awareness of self care options may be the issue. Self Help UK currently manages the self-care information on the Nottingham City Self Care website: www.nottinghamselfcare.org.uk and the Nottinghamshire Help Yourself website: www.nottshelpyourself.org.uk. The annual Self Help Groups Directory produced by Self Help UK includes a self-care contacts section.

RECOMMENDATION: promote self-care options through partnership working.

‘Request for Health and Wellbeing events as part of the Recovery package’ Macmillan and Self Help UK are currently taking this forward in Nottinghamshire.

Professionals Working with Me

'Better communication between hospital/GPs/community' was raised as a concern and frustration. Hopefully with Cancer Pathway Redesign programmes and the electronic Holistic Needs Assessments pilot projects in progress, communication will improve.

RECOMMENDATION: review how well this is working by obtaining patient feedback in 2017/18.

'Transport from hospital' was identified as a key issue, which affects the whole patient experience. Often patients wait a long time for hospital transport and if carers live out of the county, they should arrange their own transport separately. This is far from ideal. Car parking at hospitals is also an issue, although there may be no easy solutions.

RECOMMENDATION: that transport is considered from the cancer patient perspective.

Work

'Returning to work support' and 'lack of understanding by employers' were raised as big gaps by people affected by cancer. The Macmillan Cancer Partnership in Nottinghamshire intends, as part of the current Action Plan, to promote Macmillan's offer to unions and to communicate support available, and how to access it to non-Macmillan professionals.

It was noted that small and medium-sized enterprises are more likely to find it a challenge to support people affected by cancer back into work. Macmillan plans to work with some small and medium-sized enterprises to look at support needed.

'Lack of information about returning to work' was raised as a gap. 'Fit for work' – gaps in benefits have been identified. The Macmillan Welfare Benefits Service trialled in the West Midlands will be rolled out by Macmillan at the end of 2016 and will include the Nottinghamshire area.

RECOMMENDATION: promote existing sources of information e.g. Macmillan. Include returning to work information in 'Information menu' given to people after cancer diagnosis.

Electronic Holistic Needs Assessments (eHNAs) Project

This project's aim is to implement eHNAs across Nottingham University Hospitals so they are undertaken routinely for every patient at key points such as diagnosis, completion of treatment and end of life. The aim is to better support patient needs by identifying the concerns of cancer patients, signposting them to local services and support and delivering tailored care.

Partners: Macmillan, Nottingham University Hospitals NHS Trust, and Sherwood Forest Hospitals NHS Foundation Trust, East Midlands Academic Health Science Network.

Initially the eHNA has been rolled out in Nottinghamshire by Nottingham University Hospitals NHS Trust working with Macmillan Cancer Support in conjunction with local Clinical Commissioning Groups (CCGs) and other care providers. The project features as a key part of the Macmillan Cancer Pathways Redesign Programme (Lisa Janiec) across the Nottinghamshire Health Community.

There is now a year's worth of data (June 2015 – June 2016) which is displayed in several lists (see **Appendix 5**). The concerns which were most frequently raised are shown in the 'total score' column (page 31). The concerns which were most worrying patients, on a scale of 1-10, are shown in the 'average score' column, with the highest concerns highlighted in red, lowest in green. These results are quite different to 'the most common concerns' results and presents a different perspective. For example, 64 out of 4003 patients mentioned caring responsibilities as a concern, but the level of concern has the highest score of all concerns, which is 7.11 out of 10. It would be useful to continue to look at both measures.

RECOMMENDATION: that the level of cancer patients' concern continues to be included in reviews of the electronic Holistic Needs Assessments. That closer working with GPs on patient reviews is piloted.

Information Needs of People Affected by Cancer

Given the time constraints of the project, rather than starting a new survey of information needs, the best approach was to look at the information questions that were asked as part of the National Cancer Patient Experience Surveys (NCPES) carried out by Quality Health (The data can be found in **Appendix 1b - pages 18-19** Patient Survey Results tabs.)

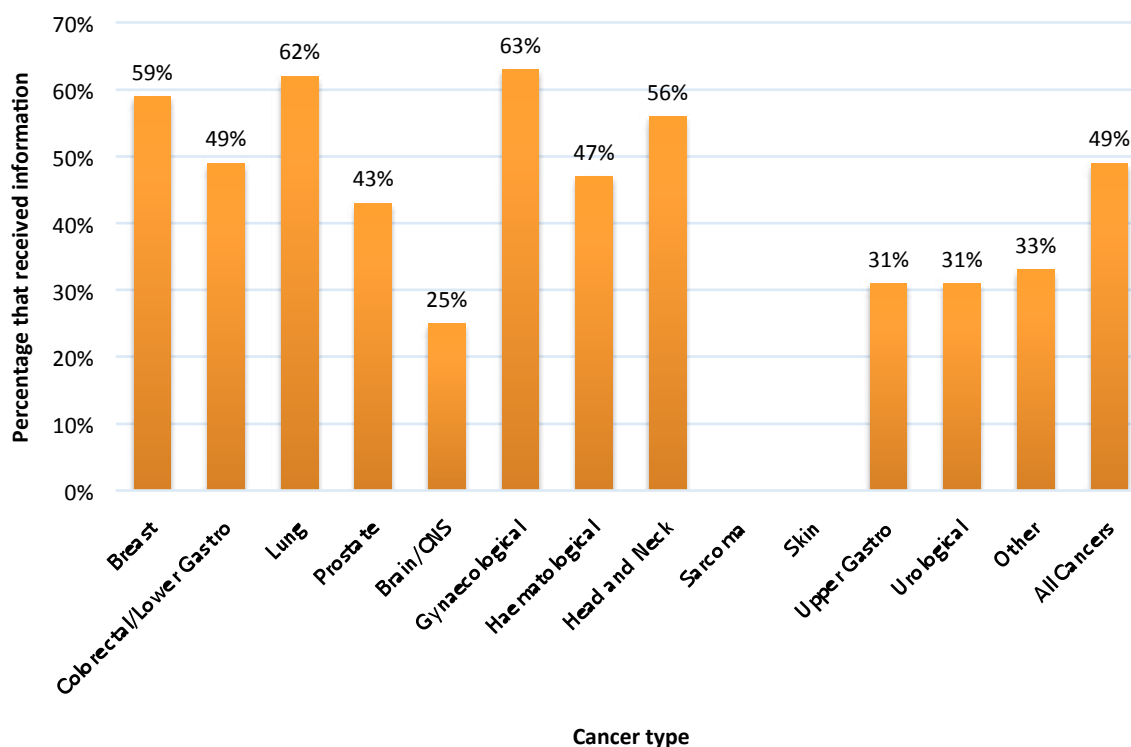
The questions were the same for 2010, 2012, 2013 and 2014 surveys and so it was possible to make comparisons over that period.

The local results were compared with the national average results. Any scores lower than the national average are identified in red, similar scores in amber and better than national average in green. The key focus was the 2014 survey; given that this was the most recent of the four. The breakdown of results by question showed a dramatic difference across different cancers locally and nationally (see Appendices 1c and 1d).

It is encouraging that both NHS Nottingham University Hospital Trust and Sherwood Forest Hospital NHS Trust results improved significantly between 2010 and 2014. The Macmillan Cancer Patient Experience Survey Report 2014 notes that Nottingham University Hospitals NHS Trust was in the top ten most improved trusts.

The results for Q27, 'information about financial help', were very low both nationally and locally in the 2014 survey. Again, responses varied hugely between cancers (see figure 1 – results for Q27 for Nottingham University Hospitals NHS Trust).

Figure 1
Q27 Information about Financial Help Cancer Patient
Experience Survey 2014- NUH NHS Trust



2015 Survey

The NCPES 2015 questions were asked slightly differently from previous surveys and so direct comparisons could not be made. Previous questions have been mapped to 2015 questions on page 19. This survey was released near the end of the project in July 2016. The results for the local Clinical Commissioning Group areas were compared with the national average.

Q11 'Patient given written information about the type of cancer they had.' Locally figures ranged from 69% to 78%. Nationally 10% of respondents said that written information was difficult to understand. 19% stated that they had not been given any written information.

RECOMMENDATION: to ensure that written information is presented so that it can easily be understood; test draft written information by use of focus groups or patient participation groups locally; use plain English when writing information (The Patient Information Forum provides some very useful factsheets about writing accessible information for patients: www.pifonline.org.uk).

The lowest scores both locally and nationally, as in 2014, were for Q22 'Information about getting financial help'.

RECOMMENDATION: promote existing information e.g. Macmillan. Ensure that information about getting financial support is included in the proposed 'Information Menu' given to newly diagnosed patients.

Q55 'Patient given a Care Plan'. This question also showed similar low results in the 2015 survey from 30%-38% locally and nationally. Work is taking place on this in Nottinghamshire, with the introduction of the electronic Holistic Needs Assessment tool as part of care planning.

RECOMMENDATION: that in Nottinghamshire the aim is to provide every cancer patient with a Care Plan.

Results from Care Plans undertaken between March 2015 and February 2016 with people with cancer in the Nottingham City area show that self help groups are still high on the list for supporting information needs. For example, of those who completed Care Plans, information about support groups was requested by 40% of those with cervical cancer; 34% of those with endometrial cancer and 25% of those with uterine cancer.

General Recommendations

- Use Nottinghamshire Help Yourself website for information about cancer self help groups and activities: www.nottshelpyourself.org.uk
- Consider linking Nottinghamshire information with Macmillan pinpoint map
- Find results of other relevant surveys e.g. Stonewall Nottingham lesbian, gay, bisexual, trans cancer survey – NUH (Jan 2015)
- Some actions to be added to the Macmillan Cancer Partnership in Nottinghamshire Action Plan.

Appendices

- Appendix 1** **Main Insight Project spreadsheet including:**
- 1a Link to self help groups and services list
 - 1b National Cancer Patient Experience Survey results 2010-2014
 Mapping questions of 2014 survey to 2015 survey
 National Cancer Patient Experience Survey results 2015
 - 1c NUH Patient Survey results
 - 1d SFH Patient Survey results
-
- Appendix 2** **Macmillan Nine Outcomes Document**
-
- Appendix 3** **Planning Group Terms of Reference**
-
- Appendix 4** **References**
-
- Appendix 5** **Care Plan Concerns July 2015- June 2016 – Lisa Janiec/
Stephanie Day**

Appendix 1 Main Insight Project spreadsheet

1a Self help & support - Nottinghamshire

www.selfhelp.org.uk/CancerInsight

1b National Cancer Patient Experience Survey results 2010-2014

Cancer Patient Experience Survey National Reports 2010-2014		2010			2012			2013			2014			Findings by Tumour group 2010-2014	Mapping Questions of 2014 survey to 2015 survey		
Question	Written information related Qs	Sherwood Forest Hospitals NHS Foundation Trust	Nottingham University Hospitals NHS Trust	National	Sherwood Forest Hospitals NHS Foundation Trust	Nottingham University Hospitals NHS Trust	National	Sherwood Forest Hospitals NHS Foundation Trust	Nottingham University Hospitals NHS Trust	National	Sherwood Forest Hospitals NHS Foundation Trust	Nottingham University Hospitals NHS Trust	National		Questions 2010-14		Questions 2015
Q8	Given easy to understand written information about the test	78%	81%	85%	88%	86%	86%	81%	88%	88%	89%	90%	87%		Q8	Given easy to understand written information about the test	
Q14	Patient given written information about the type of cancer they had	60%	65%	66%	74%	68%	69%	71%	70%	71%	76%	74%	72%	Significant variation for different types of cancer. 58% - 81%	Q14	Patient given written information about the type of cancer they had	
Q18	Patient given written information about side effects	69%	80%	80%	78%	82%	81%	73%	84%	82%	80%	84%	82%	Significant variation. 69% skin cancer- 90% breast cancer	Q18	Patient given written information about side effects	Q13
Q25	Hospital staff gave information about support groups	74%	75%	79%	75%	80%	82%	68%	84%	82%	82%	87%	83%	Significant variation. 69% urological cancer to 89% breast cancer	Q25	Hospital staff gave information about support groups	Q20
Q26	Hospital staff gave information about impact cancer could have on work/education	no data	no data	no data	no data	no data	no data	61%	71%	74%	73%	78%	75%	Significant variation. 63% urological cancer to 78% breast and prostate cancers.	Q26	Hospital staff gave information about impact cancer could have on work/education	Q21
Q27	Hospital staff gave information on getting financial help	48%	37%	50%	45%	38%	52%	34%	48%	54%	40%	49%	54%		Q27	Hospital staff gave information on getting financial help	Q22
Q34	Patient given written information about the operation	61%	69%	68%	77%	78%	73%	74%	77%	74%	79%	82%	76%	Significant variation in proportion of patients saying they were given easy to understand information. 56% sarcoma to 84% breast and prostate cancers	Q34	Patient given written information about the operation	Q26
Q53	Given clear written information about what should/should not do post discharge	80%	80%	82%	86%	79%	84%	84%	85%	84%	87%	86%	85%	Significant variation. 79% gastro/sarcoma to 91%	Q53	Given clear written information about what should/should not do post discharge	Q38
Q55	family definitiely given all information needed to help care at home	62%	52%	58%	61%	57%	60%	58%	60%	61%	63%	62%	60%	Significant variation. 55% urological and other cancers - 64% skin cancer	Q55	family definitiely given all information needed to help care at home	Q49
Q67	Given the right amount of information about condition and treatment	86%	85%	88%	92%	87%	89%	86%	87%	88%	88%	88%	88%	No significant overall differences	Q67	Given the right amount of information about condition and treatment	Q44, Q45, Q47, Q48

Cancer Patient Experience Survey 2015									
Questions	Written information related Qs	NHS Mansfield and Ashfield CCG	NHS Newark and Sherwood CCG	NHS Nottingham City CCG	NHS Nottingham North & East	NHS Nottingham West CCG	NHS Rushcliffe CCG	National average	Comments
Q5	Given easy to understand written information about the test	no data	no data	85%	no data	no data	no data	89%	3% would have liked more written information
Q11	Patient given written information about the type of cancer they had	71%	75%	78%	78%	75%	69%	72%	10% said written information was difficult to understand. 19% were given no written information
Q13	Side effects explained	71%	77%	84%	72%	71%	77%	83%	Effects of treatment explained to 73%. (No question re written information)
Q20	Hospital staff gave information about support groups	80%	79%	93%	88%	91%	87%	83%	
Q21	Hospital staff gave information about impact cancer could have on day to day activities	78%	72%	87%	85%	81%	85%	81%	(Question asked slightly differently - impact of cancer on day to day activities including work.)
Q22	Hospital staff gave information on getting financial help	52%	38%	52%	48%	54%	46%	55%	
Q26	Staff explained how the operation had gone in an understandable way	68%	72%	83%	76%	81%	79%	78%	3% said they would have liked more written information; 2% wanted more verbal information; 1% more verbal and written information.
Q38	Given clear written information about what should/should not do post discharge	84%	85%	90%	87%	84%	89%	84%	
Q44	Beforehand patient had all the information needed about radiotherapy treatment	85%	82%	89%	93%	88%	85%	86%	
Q45	Patient given understandable information about whether radiotherapy was working	63%	45%	66%	69%	59%	50%	60%	
Q47	Beforehand patient had all the information needed about chemotherapy treatment	82%	83%	88%	81%	84%	85%	84%	
Q48	Patient given understandable information about whether chemotherapy was working	61%	63%	75%	59%	59%	60%	68%	
Q49	Hospital staff gave family or someone close all information needed to help with care at home	53%	57%	63%	62%	57%	53%	58%	
Q55	Patient given a Care Plan	30%	34%	33%	38%	34%	36%	33%	Low scores!!

1c NUH Patient Survey results

National Cancer Patient Experience Survey 2014/ Information Questions – Local Results

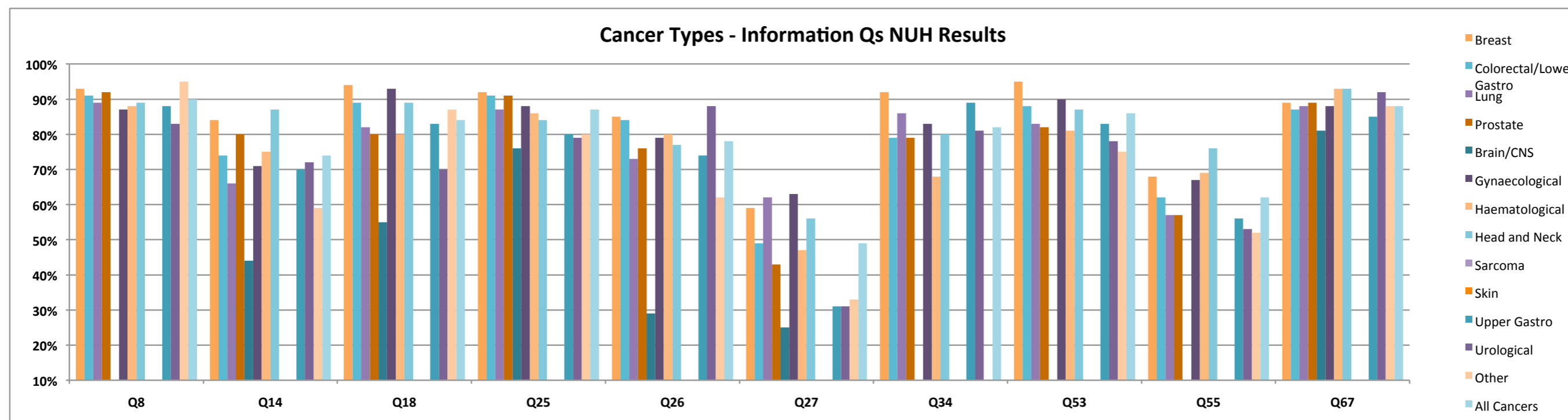
Information questions asked within survey

Q8	Q14	Q18	Q25	Q26	Q27	Q34	Q53	Q55	Q67
Given easy to understand written information about the test	Patient given written information about the type of cancer they had	Patient given written information about side effects	Hospital staff gave information about support groups	Hospital staff gave information about impact cancer could have on work/education	Hospital staff gave information on getting financial help	Patient given written information about the operation	Given clear written information about what should/should not do post discharge	Family definitely given all information needed to help care at home	Given the right amount of information about condition and treatment

Nottingham University Hospitals NHS Trust (NUH)

	2014	Q8	Q14	Q18	Q25	Q26	Q27	Q34	Q53	Q55	Q67
Breast		93%	84%	94%	92%	85%	59%	92%	95%	68%	89%
Colorectal/Lower Gastro		91%	74%	89%	91%	84%	49%	79%	88%	62%	87%
Lung		89%	66%	82%	87%	73%	62%	86%	83%	57%	88%
Prostate		92%	80%	80%	91%	76%	43%	79%	82%	57%	89%
Brain/CNS			44%	55%	76%	29%	25%				81%
Gynaecological		87%	71%	93%	88%	79%	63%	83%	90%	67%	88%
Haematological		88%	75%	80%	86%	80%	47%	68%	81%	69%	93%
Head and Neck		89%	87%	89%	84%	77%	56%	80%	87%	76%	93%
Sarcoma											
Skin											
Upper Gastro		88%	70%	83%	80%	74%	31%	89%	83%	56%	85%
Urological		83%	72%	70%	79%	88%	31%	81%	78%	53%	92%
Other		95%	59%	87%	80%	62%	33%		75%	52%	88%
All Cancers		90%	74%	84%	87%	78%	49%	82%	86%	62%	88%

Comparisons by tumour group for this Trust. The following tables show the Trust percentage scores for each question broken down by tumour group. Where a cell in the table is blank this indicates that the number of patients in that group was below 20 and too small to display.



Appendix 2 Macmillan Nine Outcomes Document

Macmillan Report: Cancer in the UK 2014, State of the Nation Report (published April 2014)

Macmillan examined the state of cancer in the UK in terms of the nine issues that people affected by cancer have told Macmillan matter most to them. These issues include not only clinical outcomes, but also the impact of cancer on the whole person's life. This report presented the results and recommendations, a key one of which is the need for community engagement in many locations, including Nottinghamshire, to support the delivery of Macmillan's nine outcomes for people affected by cancer.

The Macmillan Insight Project was initiated to assess levels of community engagement in cancer support groups and activities in Nottinghamshire.

You can read the full report here

<http://www.macmillan.org.uk/documents/aboutus/whatwedo/cancerintheuk2014.pdf>

Appendix 3 Planning Group Terms of Reference

About the Project

The Insight Project, in partnership with Self Help UK, began in September 2015 and runs for a year.

The aim is to gain community engagement intelligence about cancer self help and support activities across Nottinghamshire including an analysis of key stakeholders. Findings will be collated, analysed and presented in a final report, which will identify key priorities and make recommendations to inform the development of a comprehensive Macmillan Nottinghamshire Engagement Strategy and Implementation Plan.

Overall Aim

To support and steer the Insight Project

Objectives:

- To agree terms of reference for the project
- To provide input into project research and delivery methods
- To share information about community engagement in cancer support activities
- To identify the information needs locally of people affected by cancer
- To provide input into how the project findings can be presented/disseminated

Membership

Michele Banton	Self Help UK
Lynda Burton	Macmillan
Stephanie Day	Nottingham University Hospitals NHS Trust
Jo Gregg	Macmillan
Lisa Janiec	Nottingham University Hospitals NHS Trust
Danielle Mellows	Macmillan
Abi Powell	Macmillan/CityCare
Josh Wood/James Wheat	Self Help UK/Macmillan
Sue Sanderson	Macmillan

Measures of Success

Success will be measured through:

- The quality of the information
- Good practice identified
- Mapping of existing community engagement activities
- Gaps in provision identified
- Understanding of information needs locally
- Barriers to accessing provision identified

Meetings

Every two months until the end of the project.

Appendix 4 References

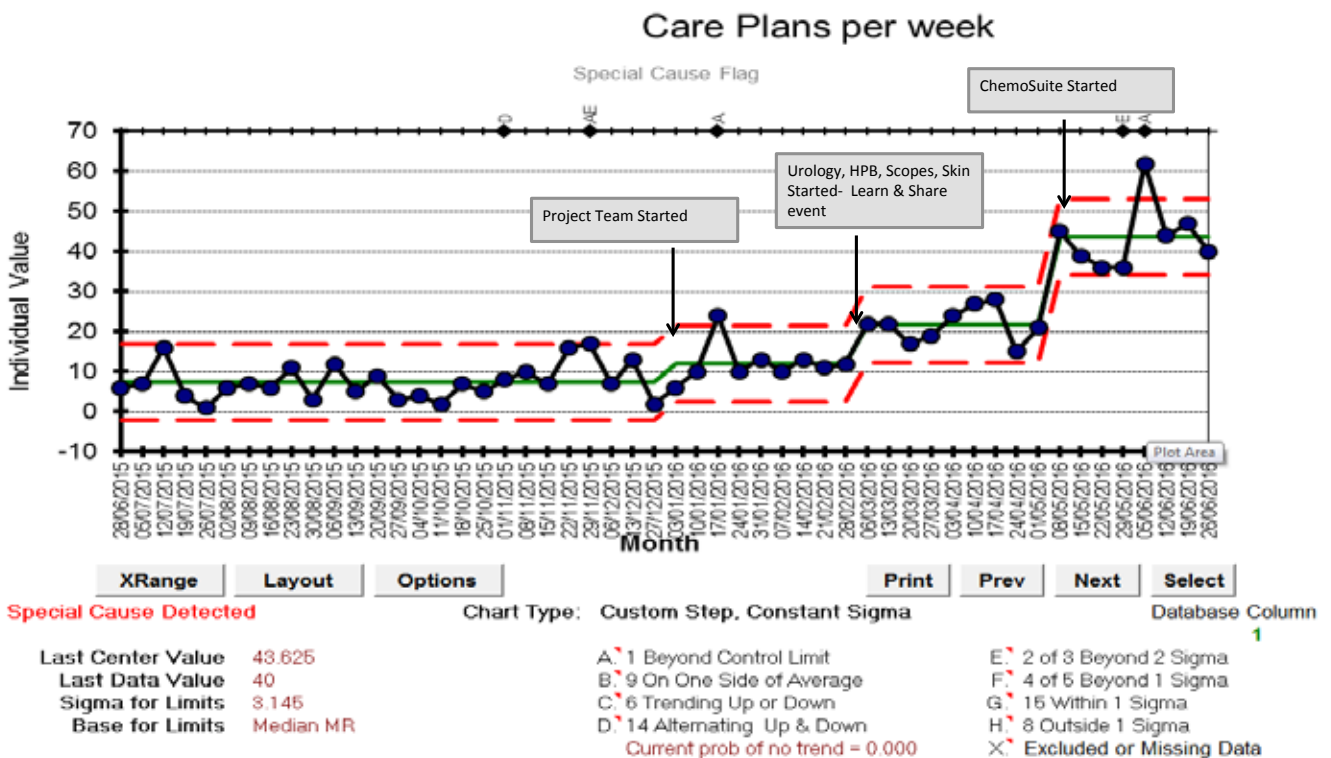
Title	Author	Date published
Achieving World Class Cancer Outcomes: A Strategy for England 2015-2020	Independent Cancer Taskforce (established by NHS England)	2015
Cancer Indicators Dashboard (presentation)	Nottingham City CCG	09/16
Cancer Patient Experience Survey: Insight Report and League Table 2014	Macmillan	10/14
Cancer Nottingham City JSNA	Public Health, Nottingham City Council	2015
Enhanced Supportive Care - Integrating Supportive Care in Oncology	NHS England	2015
Gynaecological eHNACare Plan Outcomes -March 2015-February 2016 (presentation)	Nottingham City CCG? (Sean McVeigh)	06/16
Healthwatch Nottinghamshire Annual Report 2014/15	Healthwatch	2015
Health Profile - 2014 Nottingham City	Public Health England	08/14
Hear Me Now - One Year On	Rose Thompson, BME Communities	2014
Implementing the Cancer Taskforce Recommendations: Commissioning Person Centred Care for People Affected by Cancer	NHS England	04/16
Mid Nottinghamshire Cancer Programme Scoping Exercise Summary Report	Julia King, Better Together/Macmillan Cancer Partnership Nottinghamshire	08/15
Mid Nottinghamshire CCGs Strategy for Delivering Adult Cancer Services	M&A CCG; N&S CCG	
National Cancer Intelligence Network. Cancer statistics:availability and location	Public Health England	02/16
National Cancer Patient Experience Programme 2010 Survey - NUH NHS Trust	Quality Health (on behalf of DoH)	2011
National Cancer Patient Experience Programme 2014 Survey	Quality Health (on behalf of DoH)	2015
National Cancer Patient Experience Programme 2015 Survey	Quality Health (on behalf of DoH)	07/16
National Cancer Patient Experience Programme 2014 Survey - NUH Sherwood Hospitals NHS Foundation Trust	Quality Health (on behalf of NHS England)	2015
Nottingham City Joint Health and Wellbeing Strategy 2013-2016	Nottingham City Council	2013
Patients Shaping Cancer Services in Nottinghamshire. Open Space event June 2015	Macmillan Cancer Partnership Nottinghamshire	10/15
Quality of Life of Cancer Survivors in England. One Year on from the 2011 Survivorship Survey Pilot.	Quality Health	09/13
Working Together for a Healthier Nottingham- Commissioning Strategy 2013-2016	Nottingham City CCG	2013
eHNA and Cancer Support Directory (presentation)	NHS Ayrshire & Arran/Macmillan	2016

Appendix 5 Care Plan Concerns July 2015- June 2016 – Lisa Janiec/Stephanie Day

Summary

eHNA & Care Plans from 01-07-2015 to 30-06-2016		Female	%	Male	%
eHNA's completed	983				
Care Plans completed	877	664	76%	213	24%
Conversion Rate	89%				
Concerns raised	4003	2692	67%	1311	33%
Actions	660	454	69%	206	31%
Information needs	139				

eHNA & Care Plans from 01-03-2015 to 01-03 2016		Female	%	Male	%
eHNA's completed	479				
Care Plans completed	368	323	88%	45	12%
Conversion Rate	77%				
Concerns raised	1419	1221	86%	198	14%
Actions	235	197	84%	38	16%
Information needs	139				



Concerns

Total Concerns Raised			
Concern	Total score	Count	Average score
Worry, fear or anxiety	1823	283	6.44
Tired/exhausted or fatigued	1577	269	5.86
Hot flushes/sweating	932	174	5.36
Sleep problems/nightmares	1042	173	6.02
Pain	1011	165	6.13
Sadness or depression	881	144	6.12
Sore or dry mouth	683	128	5.34
Getting around (walking)	732	127	5.76
Anger or frustration	698	119	5.87
Eating or appetite	643	113	5.69
Memory or concentration	618	111	5.57
Breathing difficulties	566	111	5.10
Dry, itchy or sore skin	541	107	5.06
Changes in weight	558	98	5.69
Constipation	468	94	4.98
Loss of interest/activities	523	92	5.68
Tingling in hands/feet	445	90	4.94
Difficulty making plans	552	89	6.20
Indigestion	351	85	4.13
Hopelessness	523	84	6.23
Swollen tummy or limb	444	76	5.84
Diarrhoea	300	66	4.55
Unable to express feelings	375	65	5.77
Passing urine	373	65	5.74
Caring responsibilities	455	64	7.11
Partners	451	64	7.05
Money or housing	408	61	6.69
Children	401	61	6.57
Nausea or vomiting	307	60	5.12
Taste/sight/hearing	322	59	5.46
Other relatives/friends	352	58	6.07
Loneliness or isolation	345	57	6.05
Guilt	351	56	6.27
Work and education	286	47	6.09
Sex/Intimacy/Fertility	269	46	5.85
Wound care after surgery	224	40	5.60
My appearance	213	40	5.33
Transport or parking	227	38	5.97
Not being at peace with or feeling regret about the past	189	37	5.11
Insurance and travel	181	33	5.48
Loss of meaning or purpose of life	166	33	5.03
Preparing meals/drinks	182	31	5.87
Contact/communication with NHS staff	162	31	5.23
Grocery shopping	180	29	6.21
Laundry/housework	172	29	5.93
Washing and dressing	126	28	4.50
Speech problems	109	26	4.19
Housework or shopping	121	21	5.76
High temperature or fever	85	18	4.72
Loss of faith or other spiritual concerns	24	8	3.00
		4003	

Actions

Action	Count	Female	Male
Discussed concern, general advice given	409	301	108
Information given	112	68	44
Other referral	20	13	7
Medication reviewed	14	8	6
Short term follow up by CNS	11	7	4
Psychologist referral	10	7	3
Dietitian referral	8	1	7
Fatigue referral	8	6	2
Information prescription given	8	6	2
Counselling referral	6	4	2
Medication changed	5	4	1
Ongoing complex follow up by CNS	5	2	3
Pain clinic referral	5	2	3
Physiotherapy referral	5	4	1
Discharged from active case load	4	4	0
Signposted to support group	4	1	3
Assessment for physical activity needed	3	1	2
Medication prescribed	3	3	0
Gastroenterologist referral	2	1	1
Information or service not available	2	1	1
Lymphoedema clinic referral	2	2	0
Sexual dysfunction therapist referral	2	0	2
Specialist nursing referral	2	1	1
Trust car parking letter/permit given	2	0	2
District nursing team referral	1	1	0
Occupational Therapist referral	1	1	0
Palliative care team referral	1	1	0
Physical activity advice/referral	1	0	1
Social worker referral	1	1	0
Stoma service referral	1	1	0
Urology referral	1	1	0
Welfare or benefits referral	1	1	0
	660	454	206

Diagnosis

Diagnosis	Count	Female	Male
Breast cancer	315	315	0
Endometrial (womb/uterine) cancer	107	107	0
Prostate cancer	65	1	64
Breast cancer, DCIS	36	36	0
Cervical cancer	31	31	0
Ovarian cancer	31	31	0
Myeloproliferative Neoplasm	26	15	11
Breast cancer, secondary	23	23	0
Rectal cancer	23	11	12
Colon cancer	20	7	13
Leukaemia (chronic lymphocytic)	18	7	11
Bladder cancer	15	4	11
Lung cancer	15	9	6
Oesophageal (gullet) cancer	15	4	11
Bowel cancer	9	4	5
Melanoma	7	2	5
Pancreatic cancer	7	3	4
Vulva cancer	7	7	0
Tongue cancer (base)	6	1	5
Tonsil cancer	6	2	4
Kidney and renal pelvis, secondary	5	0	5
Neuroendocrine tumours	5	0	5
Stomach cancer	5	2	3
Brain tumours	4	0	4
Lymphoma (Hodgkin)	4	4	0
Lymphoma (non-Hodgkin, other)	4	3	1
Skin cancer	4	1	3
CUP (respiratory and digestive)	3	3	0
Digestive organ cancer (other)	3	1	2
Liver cancer, secondary	3	1	2
Vagina cancer	3	3	0
Gastrointestinal stromal tumour	2	1	1
Kidney cancer (other)	2	1	1
Myeloma	2	0	2
Pharyngeal cancer (oropharynx)	2	0	2
Skin cancer, secondary	2	0	2
Uterine cancer (other)	2	2	0
Anal cancer	1	1	0
Bile duct cancer (cholangiocarcinoma)	1	1	0
Bladder/other urinary organs, secondary	1	1	0
CUP (other specified sites)	1	0	1
CUP (unspecified site)	1	1	0
Fallopian tube cancer	1	1	0
Gall bladder cancer	1	1	0
Kaposi's sarcoma	1	0	1
Kidney cancer (except renal pelvis)	1	1	0
Kidney cancer (renal pelvis)	1	0	1
Larynx cancer	1	0	1
Leukaemia (acute lymphoblastic)	1	0	1
Liver cancer	1	1	0
Lung cancer, secondary	1	0	1
Lymphoma	1	1	0
Mouth cancer (other)	1	0	1
Nasal cavity and inner ear cancer	1	1	0
Other brain/CNS, secondary	1	1	0
Other monocytic leukaemia	1	1	0
Other specified sites, secondary	1	1	0
Ovary, secondary	1	1	0
Rectosigmoid junction cancer	1	1	0
Testicular cancer	1	0	1
Thymus cancer	1	1	0
Unspecified site, secondary	1	1	0

The Macmillan
Cancer Partnership
Nottinghamshire

Shaping and improving
your cancer care **together**

This report was created by Clare Quigley as part of The Macmillan Cancer Insight and Intelligence Project which was delivered in partnership with Self Help UK.