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The Macmillan Cancer Pathways and Palliative Care Improvement Project

Introduction

The Big Cancer Conversation was the first phase of engagement of the 23 month Macmillan Cancer Pathways and Palliative Care Improvement Project (MIP). The period of engagement was 14 January 2019 to 30 April 2019, a total of 14 weeks.

Background

The Macmillan Cancer Pathways and Palliative Care Improvement Project commenced on the 1 August 2018 and will run until 30 June 2020. The project is a partnership between NHS Dumfries and Galloway, Dumfries and Galloway Health and Social Care Partnership and Macmillan Cancer Support. There are 2 workstreams within the project, 1 relates to cancer care and treatment and the other is focussing on palliative care. This report is in regard to the work associated with the cancer care and treatment workstream. This is a project to:

- Engage with people over the age of 18 years old affected by cancer, their spouses, partners, family members and Carers. Also to engage with the people who provide care and support to them across the NHS, the Council, third sector organisations and private care providers. This engagement is to understand their experiences, aspirations and concerns
- Map people's care and treatment across the 9 cancer pathways, to better understand peoples experiences
- Support the NHS Board to consider options in regard to future pathways of care and treatment for people with cancer

Project Aims

The aims of the cancer care and treatment workstream are:

- To improve the experience of people affected by cancer from Dumfries and Galloway, together with those of their spouses, partners, families and Carers
- To inform and support the NHS Board to make decisions about the future delivery of cancer care and treatment

Cancer Care and Treatment Pathways

There are 9 cancer pathways of care and treatment included within this project. They are:

- Breast cancers which affect the tissues and structures of the breast
- Colorectal cancers such as bowel and rectal cancers
- Gynaecology cancers such as cervical and womb cancers
- Haematology cancers of the blood and tissues, such as bone marrow
- Head and neck cancers such as tongue and throat cancers
- Lung cancers which affect the tissues and structures of the lungs
- Neurology cancers of the brain and nervous system
- Upper gastric intestinal and hepatic, pancreatic and biliary (HPB) cancers such as the stomach and liver cancers
- Urology cancers such as bladder and prostate cancers

Project Team and Governance

The 3 members of the project team are based at Mountainhall Treatment Centre, Dumfries. They are members of the Strategic Planning and Commissioning Department of the Dumfries and Galloway Health and Social Care Partnership.

The governance of the project is through the Macmillan Cancer Pathways and Palliative Care Improvement Project Board. People affected by cancer have representation on the project's Public Engagement Group. The Lead Cancer Team, the strategic leadership team for Dumfries and Galloway cancer services provided in Dumfries and Galloway, specialist input and leadership to the project.

Macmillan is represented on the project board and provides professional support to the project team members in their capacity as Macmillan professionals. They are also invited to attend the Lead Cancer Team meetings.

The Big Cancer Conversation

Scope of Engagement

The purpose of The Big Cancer Conversation was to engage with people living in Dumfries and Galloway over the age of 18 years old and affected by cancer, their spouses, partners, family members and Carers. Together with the people who provide services to them across the NHS, the Council, third sector organisations and private providers of care and support. The purpose being to understand their experiences, aspirations and concerns.

Period of Engagement

The engagement period opened on 14 January 2019 and was closed on 30 April 2019, which was a total of 14 weeks. Originally the engagement period was promoted as 14 January 2019 to 25 March 2019, a total of 10 weeks. Due to a local technical issue in being able to access completed survey data, the period was extended to maximise the opportunities for engagement.

Methods of Engagement

The Statement of Engagement can be found at [Appendix A](#).

- The survey for people affected by cancer their spouses, partners , families and Carers
 - This was a survey of 26 questions available on line and in paper format. It aimed to capture quantitative and qualitative data with regard to people's experiences of cancer care and treatment. This was about care and treatment delivered both in and out with Dumfries and Galloway.
 - The survey questions were broken into 4 sections:
 - Tell us about you
 - Start of cancer journey to diagnosis
 - Treatment
 - Follow-up and aftercare
 - The survey was available online at www.dghscp.co.uk/cancer and in a paper format with a pre-paid return envelope provided. The project team offered support to complete the survey to anyone who requested assistance

- The survey for people providing services to people affected by cancer their spouses, partners, families and Carers
 - This was a survey of 17 questions available on line and in paper format, to capture quantitative and qualitative data with regard to the delivery of services to people affected by cancer their spouses, partners, families and Carers delivered in Dumfries and Galloway
 - The survey was available online at www.dghscp.co.uk/cancer and in a paper format, a pre-paid return envelope was also provided
- A series of meetings were held with people providing services to people affected by cancer, their spouses, partners, families and Carers from across the health and social care partnership, primary and secondary care and private sector
- A number of focus groups were held with open invitations to members of established support groups
- The project team offered the opportunity for people to share their cancer journey experience in a one-to-one meeting
- The project team had a stand in the atrium of Dumfries and Galloway Royal Infirmary (DGRI) over 2 separate days, giving an opportunity to engage with both people in receipt of care, visitors and staff
- A partner in the Dumfries and Galloway Health and Social Care Partnership, Third Sector Dumfries and Galloway enabled the project team to attend four Third Sector Dumfries and Galloway regional roadshows held in communities across Dumfries and Galloway. This gave an opportunity to meet different communities of people and service providers

Equality and Diversity

An Equalities Impact Assessment was completed ahead of the commencement of the engagement period. There were found to be no negative impacts and 24 positive impacts. A summary can be viewed at [Appendix B](#).

The project team linked with key agencies and groups to maximise the reach of information and invitation to participate was a key action in working to enable inclusivity and opportunities with people who use services from across our diverse communities.

These included:

- LGBTplus Dumfries and Galloway
- Dumfries and Galloway Multicultural Agency
- DG Voice
- Visibility Scotland
- Alzheimer Scotland

What People Told Us

Overarching Themes

These themes can relate to any stage of a person's cancer experience. People told us that:

- It is preferable to have as many appointments and as much treatment as possible close to where you live
- Having appointments that take into account the time and length of travel to get there is helpful
- It is important for information to be given to the person affected by cancer at the right time, in the right way for them
- The way people who deliver care and treatment communicate and engage with people affected by cancer, their spouses, partners, families and Carers matters
- It is important that support and information is available to people when their treatment ends
- Support and how it works for people affected by cancer needs to be different for different people. Peer support was highlighted as one way that people found helpful
- People's overall experience of care and treatment was positive
- People are not clear how their GP fitted into their experience
- People have concerns about help, information and support for families and children

Prevention

People told us about screening and prevention in relation to their experience of cancer

- People who have been affected by cancer told us that it is important that national screening programmes are promoted and that people participate
- People who have been affected by cancer told us that it is important for all of us to have personal responsibility for self-checking and for our participation in national screening programmes

Investigation

People told us about the stage of their cancer experience when they were undergoing investigatory procedures such as CT-scan, biopsy, physical examinations.

- The speed and timing of investigatory tests and procedures has been highlighted as one of the most important issues. The time taken between the initial referral, or suspicion of cancer, and the diagnosis of cancer is highlighted as one of the most difficult times in a person's cancer journey, due to the worry and uncertainty
- Investigatory processes, such as imaging and biopsies, may not always take place in Dumfries and Galloway. The time of the appointment may not take into account the time and distance travelled, even for those scheduled within Dumfries and Galloway
- Key information systems do not always link up. For example, people have told us that they have contacted their GP at this time and the GP may not have had all the information on a person's appointments and investigations

Diagnosis

People told us about the stage in their cancer experience when it was determined, following investigation, that they had cancer.

- Treating people with courtesy and respect when giving a diagnosis is crucial and does not always happen
- Some consultants/oncologists record appointments as they are aware the person may not take in all of the information they are being given at the time of diagnosis. For example, the person is given a recording of their appointment or some people have recorded their conversation with a consultant on their phone. They can listen to all the information again. People told us this helps with understanding what is happening for them and to identify any questions they have
- People told us that they preferred to know a diagnosis at the earliest opportunity even if this meant being prepared to receive a phone with the news rather than attending an appointment.
- As we move to using more technology to facilitate appointments, people told us they want this to be used well and ensure every appointment is necessary. Should technology be used that it meets the needs and preferences of the person affected by cancer.
- People told us that the support of someone who has had a similar experience to them, peer support and buddying can help some people at this time. The support of family and friends is highlighted as a key source of support throughout someone's cancer experience

Treatment

People told us about the stage in their cancer experience when they received treatment for their cancer such as surgery, chemotherapy or radiotherapy. These comments relate to treatment within and also outwith Dumfries and Galloway.

- The treatment plans should be person centred and information about options including locations should be clearly communicated in a way that the person prefers. The recording of appointments may help people to have time to revisit what they have been told and to inform questions they may have about their care and treatment.
- People from across Dumfries and Galloway told us, that travelling to and from treatment, and in particularly radiotherapy, is difficult when you are unwell
- People told us that not everyone is not aware that they may request alternative locations for treatment and that there is a formal process to consider each request
- The role of the Clinical Nurse Specialist as a single point of contact through a person's journey was highlighted as working well, though people are concerned for the pressure and capacity of the Clinical Nurse Specialists, which has been highlighted in comments about the capacity to return calls and respond to requests for assistance
- When travelling for treatment being prepared and knowing what will happen can help people organise refreshments and be prepared for a wait
- Transport provision for those who need it, generally works well
- People welcomed the services which support them with changes that can occur as an result of treatment, for example complimentary therapies, Move More, wig service

Follow-up

People told us about the stage in their cancer experience when they had completed treatment such as surgery, chemotherapy or radiotherapy and still require medical monitoring.

- People often do not want to “trouble” the Clinical Nurse Specialist with a question or concern in follow up. Their concern is about the Clinical Nurse Specialist capacity and taking them away from people who are currently in treatment
- Clinical Nurse Specialist led telephone follow-up appointments are received positively

After-care

People told us about the stage in their cancer experience of care and support when they have completed treatment.

- People report a sense of abandonment when the intensity of their diagnosis and treatment comes to an end
- The “What Now?” course at the Dumfries Cancer Information Centre is well attended but has limited capacity. Not all people completing their treatment seem to be aware of it
- People have concerns that not all communities across Dumfries and Galloway have sufficient levels of after care. Community led groups are developing to meet a need
- People are not effectively linked with existing support and activities in their own community. This is a particular issue for women who receive diagnosis and treatment through the Breast Cancer National Screening Service and are seen in Ayrshire and Arran and at The Beatson in Glasgow

What Happens Next?

What people have told us and what we have learnt from the Big Cancer Conversation will inform the future of cancer care, treatment and support for people from Dumfries and Galloway through:

- being reported to the NHS Board in October 2019 and informing the strategic work of the Lead Cancer Team
- being shared with members of the Health and Social Care Partnership to inform cancer care and treatment improvements and innovations
- continuing to work to understand the experience of people affected by cancer from across Dumfries and Galloway and build on the success of the Big Cancer Conversation
- informing the development of a cancer strategic plan for Dumfries and Galloway
- influencing and informing future Macmillan investment and partnership working in Dumfries and Galloway

Appendix A - Statement of Engagement

Engagement Events

Date	Event
14 Jan 19	Breast Cancer Support Group, Dumfries
16 Jan 19	Third Sector Dumfries and Galloway Road Show, Annan
21 Jan 19	MCA Focus Group, Dumfries
23 Jan 19	Third Sector Dumfries and Galloway Road Show, Stranraer
24 Jan 19	Third Sector Dumfries and Galloway Road Show, Moniaive
24 Jan 19	Women Affected by Cancer Group, Stranraer
29 Jan 19	Third Sector Dumfries and Galloway Road Show, New Galloway
30 Jan 19	Travellers Site, Collin
30 Jan 19	New Horizons – Long Term Conditions Group, Annan
01 Feb 19	Flow Coordinators Team meeting, Dumfries
04 Feb 19	Locality Managers Meeting, Dumfries
04 Feb 19	Meeting with respiratory nurse at Lockerbie Medical Practice
04 Feb 19	Meeting with the manager of Dryfemount Care Home, Lockerbie

Date	Event
06 Feb 19	Meeting with nursing lecturer from University of West Scotland, Dumfries
12 Feb 19	Meeting with members of the community at Galloway Community Hospital, Stranraer
14 Feb 19	Lockerbie Carers Group arranged by Alzheimer Scotland
18 Feb 19	Meeting with MSP
18 Feb 19	Wigtownshire Locality Team, Stranraer
19 Feb 19	Third Sector Dumfries and Galloway Roadshow in Gatehouse
19 Feb 19	Food Train Friends, Annan
19 Feb 19	Kate's Kitchen, Annan
19 Feb 19	Annan Dental practice
19 Feb 19	Visibility Service Users Group, Annan
20 Feb 19	Consultant - Palliative Care and team
21 Feb 19	Atrium, DGRI
21 Feb 19	Annan Social Work Team meeting
25 Feb 19	Meeting with the manager of Cumloden Manor Nursing Home, Newton Stewart
25 Feb 19	Visibility Group, Newton Stewart
27 Feb 19	Annan One Team meeting

Date	Event
27 Feb 19	Nithsdale Locality Team meeting, Dumfries
28 Feb 19	Podiatry Team meeting, Stewartry and Wigtownshire, Gatehouse of Fleet
28 Feb 19	1:1 interview re Cancer, Dumfries
04 Mar 19	Lockerbie Social Work Team meeting
04 Mar 19	Visibility Group, Lockerbie
04 Mar 19	Development Day, Physical Disability Team, Dumfries
05 Mar 19	Visibility Group, Stranraer
06 Mar 19	Upper Annandale District Nurses meetings, Lockerbie
06 Mar 19	The Men's Shed, Lockerbie
07 Mar 19	Atrium, DGRI
07 Mar 19	Senior Charge Nurse meeting, Dumfries
08 Mar 19	District Nurses, Stranraer
12 Mar 19	Allied Health Professionals meeting, Dumfries
13 Mar 19	Langholm Surgery
13 Mar 19	Specialist Children's Nurses, Dumfries
14 Mar 19	Alzheimer's Carers Support Group, Lockerbie

Date	Event
18 Mar 19	East Care and Support Services (CASS), Dumfries
20 Mar 19	Esk Valley District Nurses, Gretna
21 Mar 19	Macmillan Nurse, Newton Stewart and Stranraer
27 Mar 19	Moffat Hospital staff
27 Mar 19	Met with the manager of Dryfemount Care Home, Lockerbie
28 Mar 19	Alzheimers Carers Support Group, Kirkcudbright
28 Mar 19	1-2-1 interview in Palnure
28 Mar 19	Community Link Project Workers, Newton Stewart
02 Apr 19	Flow Coordinators Team meeting, Dumfries
02 Apr 19	Can Survive group, Stranraer
03 Apr 19	Acute Elderly / Respiratory Ward Clinical Nurse Specialist, Dumfries
03 Apr 19	Specialist Palliative Care Nurses, Dumfries
04 Apr 19	Cancer attended Carers Centre, Dumfries
09 Apr 19	Consultant - Palliative Care
09 Apr 19	Podiatry Team East, Annan
10 Apr 19	Staff at Thornhill Hospital

Date	Event
11 Apr 19	Occupational Therapist meeting, Castle Douglas
11 Apr 19	Nurse Manager Oncology, Dumfries
15 Apr 19	Heart Failure Specialist Nurse, Dumfries
17 Apr 19	Head and Neck Support Group, Dumfries
18 Apr 19	Renal Team, Dumfries
22 Apr 19	LGBT Plus, phone meeting
23 Apr 19	Community Occupational Therapist Assistants, Castle Douglas
23 Apr 19	Acute and Community Dieticians, Dumfries
01 May 19	Thornhill Medical Practice
09 May 19	1-2-1 interview in Castle Douglas

Communication, Media and Marketing

Date	Action
21 Dec 18	Press release regarding Public Engagement Group and opportunities for engagement
7 Jan 19	Information sent out in Capability Scotland newsletter
16 Jan 19	E-mail sent out to organisations with information on engagement opportunities and period of engagement 14 January to 25 March 2019. See list of organisations below

Date	Action
16 Jan 19	Hard copies of leaflets and materials sent to Libraries, GP Surgeries, Pharmacies and Dentists
17 Jan 19	Hard copies of leaflets and materials sent to University of Glasgow
25 Jan 19	Hard copies leaflets and materials sent to Kirkconnel and Kelloholm Community Council following a request by e-mail
30 Jan 19	Information communicated via internal communication methods to NHS Dumfries and Galloway - NHS Core Briefing and NHS Beacon intranet page
11 Feb 19	Following up e-mail sent to organisations emailed on 16 January 2019 to encourage participation
12 Feb 19	E-mail from Langholm Health Centre confirming information on display
15 Feb 19	E-mail from Greencroft Medical Centre (South) Annan confirming displaying information
15 Feb 19	Information shared by Caroline Shannan Children, Young People and Lifelong Learning (CYPLL) – circulated around her team by e-mail
18 Feb 19	SHAP (Safe and Healthy Action Partnership), SONAS, Annan circulated project information mid January and posted on SHAP Facebook page
18 Feb 19	E-mail to Emma Murphy, Patient Experience Team Manager, NHS D and G to circulate information
18 Feb 19	E-mail to Scottish Health Council to circulate information
18 Feb 19	E-mail to Shelagh Kingtree, Head of Physiotherapy around engaging her teams
21 Feb 19	E-mail to Julie Davidson, Healthcare Improvement Scotland – sent information out to individuals on our Involving People database
22 Feb 19	E-mail to locality managers to share information in their localities

Date	Action
22 Feb 19	Stewartry locality Change Programme uploading information to local Facebook page
26 Feb 19	40 leaflets and surveys sent to Greyfriars Medical Practice, Dumfries
30 Apr 19	DG Voice requested further information which was sent and advised surveys have been extended

E-mail Distribution List for Engagement Information - 16 January 2019

Alzheimer Scotland	Breast Cancer Support Group, Dumfries
Food Train Befriending	British Legion branches
Capability Scotland	Care at Home Providers
Care Homes across Dumfries and Galloway	Community Councils
Community Hospitals	Council Elected Members
Community Children's Nurse	D and G Young Carers
Day Centres across Dumfries and Galloway	Dentists
DG Voice	Dumfries and Galloway Housing Partnership (DGHP)
Funeral Directors across Dumfries and Galloway	Gates
GP Surgeries	Health and Social Care Senior Management Team
Hard of Hearing Group	Ice Bowl
Learning Disability Service	LGBT plus
Libraries	Loreburn Housing
Macmillan Nurses	Macmillan Support Centre, DGRI
Cancer Drop-in Centre, Galloway Community Hospital	Marie Curie Nurses
MP's / MSP's	Dumfries and Galloway Multicultural Association
Oncology Centre	Pharmacies
Podiatry Teams	Police Scotland
Public Health Practitioners	Public Health Team

Queen of the South Football Club	Rotary Clubs
Scottish Ambulance Services	Scottish Fire Service
Social Work Teams	Spiritual Care Lead
Strategic Commissioning Team	Integration Joint Board (IJB) JB members
Third Sector Dumfries and Galloway	User and Carer Involvement (UCI)

Appendix B – Equality Impact Assessment – summary of impact

Impact Area	Positive Impact	No Impact	Negative Impact
Age	2	1	
Disability	3	1	
Sex	3	1	
Gender reassignment and Transgender	2	1	
Marriage and Civil Partnership		2	
Pregnancy and Maternity		3	
Race	3	1	
Religion or belief	2	1	
Sexual orientation	1	2	
Human Rights	1	1	
Health & Wellbeing & Health Inequalities	2	1	
Economic & Social Sustainability	3		
Environmental Sustainability, Climate Change and Energy Management	2	1	
	Total Positive Impacts = 24	Total No Impacts = 16	Total Negative Impacts = 0

Appendix C - Analysis of the Responses - the people affected by cancer, their spouses, partners, families and Carers survey

Overview

There were a total of 118 responses to the survey. 50% of people completing the survey have had a diagnosis of cancer. With 65% of those either currently receiving treatment or having completed treatment within the last 3 years, making their experiences highly relevant to current service and support provision.

95.4% of the 108 people, who chose to share their ethnicity, identified themselves as Scottish or English.

Cancer Type

107 people identified their cancer diagnosis or that of their partner, spouse, family member or person they are a Carer for. Of the responses from a person who has a cancer diagnosis, 39.8% have experienced breast cancer with almost half of these having started their cancer journey through a National Breast Screening Service mammogram. Women with a diagnosis of breast cancer are known to generally engage with services and share their experiences more readily than other groups. This may also reflect the higher incidents of breast cancer in the wider population and the survival rates.

10 people identified that their experience or that of their spouse, partner, family member or person they care for involved more than 1 type of cancer.

Table 1: All responses by cancer type

Cancer type	People affected by cancer survey responses	Patient Cancer Experience Survey (2018)	ISD incidence of cancer (national)
Breast	39.8%	26%	14.7%
Colorectal	6.7%	16%	11.7%
Gynaecological	4.2%	10%	NA
Haematological	7.6%	8%	NA
Head and Neck	5.1%	7%	3.9%
Lung	6.7%	5%	16.5%
Neurological	2.5%	NA	NA
Urological	10.2%	24%	13.5%

Cancer type	People affected by cancer survey responses	Patient Cancer Experience Survey (2018)	ISD incidence of cancer (national)
Upper GI	5.9%	3%	3.0%
Blank/Did not wish to say	12%	NA	NA

Partners, spouses, families and Carers

Just under 40% of responses came from people who are a spouse, partner, family member or a Carer of someone affected by cancer. The survey invited people to identify themselves in more than 1 way. It was surprising that only 3% of people, who identified themselves as a spouse, partner or family member, also identified themselves as a Carer.

Gender

People identifying themselves as female accounted for 83% of all responses. This reflects general trends that more women are likely to respond to surveys that are not specifically and targeted towards males. No one responding identified themselves as transgender.

Age

77.99% of responses were completed by people over the age of 45 years, with 24.77% being over 65 and 5 people, 4.24% of responses were completed by people over 75 years of age.

Location

Responses were received from across Dumfries and Galloway with the exception of the postcode area DG16, which is the Gretna area. This may reflect that people in the area are more likely to be registered with a GP in NHS North Cumbria and may not consider the survey relevant to them. One person responding lived out with Dumfries and Galloway.

Most responses were from people living in the DG1 and DG2 postcode areas of Dumfries and surrounding areas (Nithsdale). Next highest response was postcode area DG9 (Stranraer and surrounding area) followed by those living in Castle Douglas and the Stewartry, DG7 postcode area.

Start of cancer journey to diagnosis

Starting Point

Of the 71 people who answered this question over half said the starting point for their cancer diagnosis started with a visit to their GP. 15 people started with a mammogram at the National Breast Screening service and 1 person identified the National Bowel Cancer Screening programme. 5 people said the starting point was undergoing tests for other conditions and 1 person chose not to say.

When asked to rate overall their experiences from the start of journey to the time of diagnosis, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.6

Satisfaction with information received during the period from the start to time of diagnosis

When asked to rate the information received during this period, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.7.

Satisfaction was also rated about where the source of the information during this period originated. Of the 290 ratings as either satisfied or very satisfied, most people rated the information provided by consultants highest at 17.58% with oncologist and Clinical Nurse Specialist both scoring 14.1%. The information provided by GPs was rated least satisfactory with 28.2% of the 39 responses rating information as dissatisfied or very dissatisfied.

Satisfaction with support received during the period from the start to time of diagnosis

When asked to rate the support received during this period, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.1.

Satisfaction was also rated about where the source of the support during this period originated. Of the 246 ratings as either satisfied or very satisfied, most people rated the information provided by consultants was rated highest at 18.6%, with oncologist at 14.6% and Clinical Nurse Specialist at 13.8%. The support received from GPs was the highest rated least satisfactory with 36.1% of the 36 responses rating support received as dissatisfied or very dissatisfied.

Tell us what went well about cancer service for people from Dumfries and Galloway from start of journey to diagnosis

Care and treatment

- Having services and appointments as close to home as possible
- The right information, at the right time in a way people wanted it. For example some consultants record their appointments and give people a CD so they can listen back to it
- The support of your own GP
- Taking time in appointments and not feeling rushed
- Speed of referral from GP to DGRI
- The time it takes to be diagnosed

Information and support

- Peer groups and support from the earliest stages of a cancer journey
- The support and quality of care from staff in Dumfries and Galloway

Tell us what you would like to improve or change about cancer service for people from Dumfries and Galloway from start of journey to diagnosis

Care and treatment

- The time and distance travelled to appointments and diagnostic tests and images. The streamlining and co-ordination of appointments
- For people from the western side of the Dumfries and Galloway there is a preference for services to be Ayrshire and Arran and Glasgow where possible, easing travel time and the need for unnecessary travel
- Time taken between the procedure, such as a CT scan, and the result being available
- Timing and speed of the whole process to diagnosis
- To be recognised as an individual and be treated with respect and courtesy

Information and support

- Information about the person linking up across services, DGRI with other hospitals and with GPs
- Having the right information, at the right time in a way that the person would like it.
- Peer support and having a buddy who has lived experience can be helpful
- Support for families and children

Treatment

When asked to rate overall their experiences during the period of treatment, with 0 being not satisfied at all to 10 being very satisfied, the average score was 6.1.

At what location is treatment taking place or did treatment take place and how satisfied are you with them?

When asked about the satisfaction of the location of where treatment was received of the 97 ratings given as either satisfied or very satisfied, DGRI and Western General Hospital, Edinburgh were most satisfactory with 25.2%. Only 9 ratings were given as dissatisfied or very dissatisfied and of these over half were for DGRI with the next highest being St John's Hospital in Livingston.

Satisfaction with information received during the period of treatment

When asked to rate the information received during this period, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.8.

Satisfaction was also rated about where the source of the information during this period originated. Of the 212 ratings as either satisfied or very satisfied, most people rated the information provided by oncologists was rated highest at 17% with consultant scoring 16.5% and Clinical Nurse Specialist scoring 14.6%. The information provided by Clinical Nurse Specialist and GPs was rated least satisfactory with 19% of the 42 responses rating information as dissatisfied or very dissatisfied.

Satisfaction with support received during the period of treatment

When asked to rate the support received during this period, with 0 being not satisfied at all to 10 being very satisfied, the average score was 6.1.

Satisfaction was also rated about where the source of the support during this period originated. Of the 210 ratings as either satisfied or very satisfied, most people rated the information provided by consultants highest at 17.6%, with oncologist at 15.7% and Clinical Nurse Specialist at 13.8%. The support received from Clinical Nurse Specialist was rated least satisfactory with 22.2% of the 36 responses rating support received as dissatisfied or very dissatisfied.

Tell us what went well about cancer service for people from Dumfries and Galloway during treatment

Care and treatment

- Person centred care and being kept informed at all stages is very important plus being able to ask questions at any time
- The chemotherapy suite at DGRI and Galloway Community Hospital the staff and care
- Having a link with a Clinical Nurse Specialist (CNS) throughout your journey
- Smooth swift referral to Edinburgh Cancer Centre when required
- Access to complimentary therapies

Information and support

- Information and support services in Dumfries
- Peer support and having a buddy who has lived experience can be helpful

Tell us what you would like to improve or change about cancer service for people from Dumfries and Galloway during treatment

Care and treatment

- Travel for treatment and making sure that all travel is necessary. Use digital appointments more
- Making sure GPs have all the relevant information about someone's treatment helps them to provide support and treatment when needed
- Help people stay in contact with family and friends when they are away from home for treatment
- Having a link with a Clinical Nurse Specialist (CNS) throughout your journey and helping them have capacity to respond to calls
- To use Carlisle for radiotherapy treatment
- To know what choices I have with regard to the location of treatment and how any decision is made

Information and support

- Support for families and children affected by the cancer journey of a family member
- Linking people with existing support and information services in Dumfries and Galloway, particularly when they are receiving treatment outside Dumfries and Galloway
- Links to financial support and information
- Travel support for those who need it
- Understanding the personal impacts of treatment and support with living with those changes, for example hair loss

End of treatment care and follow-up

When asked to rate overall their experiences at the time of end of treatment care and follow-up, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.6.

At what location is end of treatment care and follow up taking place or where did after care and follow up take place and how satisfied are you with them?

When asked about the satisfaction of the location of where follow-up and aftercare was received of the 49 ratings given as either satisfied or very satisfied, DGRI was most satisfactory with 53%. With University Hospital, Crosshouse, Ayr and Western General Hospital, Edinburgh being equally satisfactory with 14.3% each.

11 ratings were given as dissatisfied or very dissatisfied and of these 36.4% were for DGRI.

Satisfaction with information received during the period of end of treatment care and follow up

When asked to rate the information received during this period, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.8.

Satisfaction was also rated about where the source of the information during this period originated. 145 ratings were either satisfied or very satisfied. The information provided by consultants was rated highest at 18.6% with Clinical Nurse Specialist scoring 16.6% and oncologist scoring 14.5%. The information provided by Clinical Nurse Specialist was rated least satisfactory with 24.2% of the 33 responses rating information as dissatisfied or very dissatisfied.

Satisfaction with support received during the period of end of treatment care and follow-up

When asked to rate the support received during this period, with 0 being not satisfied at all to 10 being very satisfied, the average score was 5.7.

Satisfaction was also rated about where the source of the support during this period originated. Of the 132 ratings as either satisfied or very satisfied, most people rated the information provided by consultants and Clinical Nurse Specialists were rated highest at 16.6%, with GPs at 15.2%. The support received from consultants was rated least satisfactory with 22.6% of the 31 responses rating support received as dissatisfied or very dissatisfied.

Tell us what went well about cancer service for people from Dumfries and Galloway during end of treatment care and follow-up

Care and treatment

- Having a link with a Clinical Nurse specialist throughout your journey and then have them there through follow-up
- Being able to have follow-up appointments in Dumfries and Galloway

Information and support

- Macmillan information centre and Cancer drop in centre
- The What Now? course for people having completed their treatment

Tell us what you would like to improve or change about cancer service for people from Dumfries and Galloway during end of treatment care and follow-up

Care and treatment

- Better communication between services so people can be linked better
- Having a named person you can go to for support or information in Dumfries and Galloway

Information and support

- Peer support is very important but not available for everyone across Dumfries and Galloway
- Promote on-line support and forums

Helping to shape future cancer services

49 people chose to share their contact details with the project and expressed an interest in being informed about the project and to help shape future cancer services for people from Dumfries and Galloway.

Appendix D – Analysis of the Responses - people providing services to people affected by cancer, their spouses, partners, families and Carers survey

Overview

There were a total of 49 responses to the survey. 18 people identified themselves as being employed by an organisation providing services and 11 identified themselves as being a volunteer for an organisation providing services to people affected by cancer their spouses, partners, families and Carers. Other people chose not to respond to the question.

32.26% of respondents worked or volunteered for NHS Dumfries and Galloway in an acute hospital location. 25.81% worked or volunteered in NHS Dumfries and Galloway in a community or locality setting. 12.9% work or volunteer for a not-for-profit or charitable organisation. 2 responses were from people who work at the Cumberland Infirmary, Carlisle.

The organisations represented provide services to people affected by cancer across all 9 pathways included in this project. Geographically the organisations are located in most postcode areas of Dumfries and Galloway with the exception of DG2 and DG3. However people receiving services were located in all postcode areas with all age ranges from 18 years to 75 years plus.

The organisations represented are providing services to people affected by cancer across the different stages of their experience, from start of journey to time of diagnosis, through treatment and after treatment care and follow up.

How well do you believe your service(s) meet the needs of people affected by cancer their spouses, partners, families and Carers?

When asked to rate 'how well do you believe your service(s) meet the needs of people affected by the support received during this period?', with 0 being not satisfied at all to 10 being very satisfied, the average score was 7.0.

How well do you believe all service(s) meet the needs of people affected by cancer, their spouses, partners, families and Carers?

When asked to rate 'how well do you believe your service(s) meet the needs of people affected by the support received during this period?', with 0 being not satisfied at all to 10 being very satisfied, the average score was 6.4.

What do you believe works well in cancer services for people from Dumfries and Galloway, their spouses, partners, families and Carers?

Care and treatment

- The Alexandra Unit service works well though there are concerns about the capacity and number of beds
- Communication and linking between acute hospital care and GPs and community care works well and provides continuity of care
- Care and treatment is person centred and people delivering services and care are able to build a relationship with the person affected by cancer and their family and Carers

- The role of the Clinical Nurse Specialists in linking people to services and providing a central contact point aiding continuity of care when people are receiving treatment out with Dumfries and Galloway
- Most people, who require it, benefit from receiving chemotherapy in the Oncology Centre in Dumfries

Information and support

- The Macmillan Support Centre at DGRI works well
- Links that exist between oncology services, the Macmillan Information Centre and other services such as psychology and Carers support

What would you like to change or improve about cancer services for people from Dumfries and Galloway, their spouses, partners, families and Carers?

Care and treatment

- Easier pathways to other boards with improved access to all multi-disciplinary team meetings
- Better use of digital appointments to lessen the burden of travel for people affected by cancer from Dumfries and Galloway. People can travel for hours for a 10 minute appointment
- Clearer guidance and information on the choices people have for treatments closer to home and the processes associated with requests being met

Information and Support

- Increased and improved linking of people with existing services
- More support for the families of people affected by cancer
- More after treatment services across Dumfries and Galloway

Helping to shape future cancer services

20 people chose to share their contact details with the project and said they would be happy to be contacted by a member of the project team. 17 people said they would like to have the opportunity to participate in future engagement activities and events.

Appendix E – Response themes from other engagement events

People were asked in your opinion what works well in cancer care and treatment for people from Dumfries and Galloway

Care and Treatment

- Promotion and importance of screening programmes
- Surgeons are very good at explaining what will happen during the operation
- One stop clinics for diagnosis work well

Information and support

- Cancer Information at DGRI and Cancer Drop-in Centre in Stranraer
- Other support groups Head and Neck Support Group, Breast Cancer Support Group, both in Dumfries
- Initial information pack

People were asked in your opinion what could be improved in cancer care and treatment for people from Dumfries and Galloway

Care and Treatment

- Health and wellbeing activities and complementary therapies can help wellbeing during the cancer journey for example Move More
- Phone and digital appointments to limit travel for short appointments works well with the Clinical Nurse Specialist
- Improve call back response from Clinical Nurse Specialist
- Use Carlisle more for radiotherapy
- Radiotherapy at DGRI
- Respecting people's faith and culture should be reflected in care and treatment including the environment and menu choices
- Links between and oncology and palliative care

Information and support

- More buddies and support groups in our communities
- Promote on-line support communities
- Mental health and psychological support
- Support with lymphoedema
- Linking people with existing services, financial, psychological, complimentary, support groups

Contact details

This report was prepared by the Macmillan Cancer Pathways and Palliative Care Improvement Project Team. If you would like to contact the team you can do so by telephone on 01387 272725 or by e-mail on dg.mip@nhs.net

Other formats and languages

If you would like some help understanding this or need it in another format or language please contact 030 33 33 3000