Seldom Heard Groups Project

Service

Macmillan Information and Support Service - Nottingham

Project Lead

Alison Hall - Macmillan Cancer Information Specialist

National Information

Seldom heard groups experience many barriers to accessing services and are often under-represented in healthcare decision making. The Cancer Patient Experience Survey (CPES) 2016 reported statistically significant differences between cancer patients identifying as Lesbian, Gay, Bisexual and Transgender (LGBT) to their heterosexual counterparts in respect of 24 dimensions of experience. These included communication and access to adequate practical and emotional support. The Public Health Outcomes Framework LGBT Companion Document highlights health inequalities experienced by LGBT people across their life course, including cancer risk factors such as smoking, alcohol use and obesity, suggesting important inequalities in cancer care.

The Macmillan Report 'The Emerging Picture: LGBT People with Cancer' highlighted that:

- LGBT people with cancer are less likely than heterosexual people with cancer to be given written information about the type of cancer they have.
- LGBT people with cancer are less likely than heterosexual people with cancer to receive information from the hospital ward about self-help and support groups for people with cancer.

The CPES also reported that Black And Minority Ethnic (BAME) cancer patients have statistically significant differences in 20 specific aspects of care, including the provision of information and access to help and support.

The Macmillan Report 'The Rich Picture: People with Cancer from BAME Groups' highlighted:

- Cancer awareness and help-seeking behaviours among people from BAME groups are low across all ethnic groups.
- The sample of BAME participants living with cancer generally wanted less technical, more personalised information, presented pro-actively.

There is little recorded evidence regarding information provision and support for people with communication impairments who are living with or who are affected by cancer, both nationally and locally. This project will aim to rectify this at a local level by collecting data and producing a report to highlight interactions with people from this seldom heard group.
Local Information

The Macmillan Information and Support Service supports anyone affected by cancer regardless of their gender, race, religion, or disability and does not discriminate. The service provides information and support in a wide range of formats that is available for all. In 2016 the Service received only 14% of its enquiries within its Centres' from individuals identifying as being from a Black And Minority Ethnic (BAME) group. This increased in the outreach service where 48% of people who accessed the service identified as being from the BAME community. This data was taken from the Service's data collection tool which is configured by Macmillan Cancer Support. The LGBT community and those with communication impairments are not currently recorded in the Service's general statistics. Data used to inform this project was taken from the Service's 2016 Annual Report; no report was produced for 2017 and outreach work was suspended when the current Macmillan Cancer Information Specialist was on maternity leave.

Project Outline

The Macmillan Information and Support Service is well placed to undertake work locally with an aim to improve the quality and accessibility of information and support available to people affected by cancer from a seldom heard group.

This project’s overall objective is to engage with BAME and LGBT communities and those with communication impairments in Nottinghamshire to understand information and support needs and to tailor involvement accordingly. The project’s aims are:

- To understand the needs and priorities of seldom heard groups affected by cancer;
- To find out how individuals from seldom heard groups prefer to receive information and support;
- To understand the communication needs of people affected by cancer who are from a seldom heard group;
- To improve accessibility of the Service for those affected by cancer from a seldom heard group;
- To work with a range of partners, including people affected by cancer, community partners and service providers to understand needs and design solutions; and
- To collect more in-depth data in order to evaluate the impact of the project.

The project supports NUH objectives and Macmillan’s 9 outcomes for cancer patients. The Macmillan Information and Support Service’s 2018/19 Service Objectives and 2016 Annual Report has informed this project and the positive impact of the project will be documented and made public.

This 18 month project commenced in June 2018 and once this initial project has been completed, a second piece of work will be undertaken to include people affected by cancer who; are from rural areas; have mental health difficulties and older people. The project was designed and is led by the Service’s Macmillan Cancer Information Specialist - Alison Hall with support from the Macmillan Information and Support Service Team.
Outcomes and Anticipated Benefits

- More opportunities provided for people from a seldom heard group to access the Service;
- Increased information provision to individuals from seldom heard groups;
- The type of information provided is appropriate to the individual;
- Increased support provided to individuals from seldom heard groups;
- Individuals from seldom heard groups have increased knowledge of the service available to them;
- Individuals from seldom heard groups have increased knowledge of cancer awareness and prevention;
- Improved collection of data for future service analysis;
- Increased footfall; and
- More equitable service in line with service philosophy, Macmillan Standards, NUH core values and National Guidelines.

Clinical Governance / Quantity Standards

The project will aim to bridge the gap in equity of provision of information and support to seldom heard groups and communities. The aim of the project supports NUH objectives and Macmillan’s 9 outcomes for cancer patients. The Macmillan Information and Support Service’s 2018/19 Service Objectives and 2016 Annual Report has informed this project and the positive impact of the project will be documented and made public.

In addition, the findings of the CPES has been used to directly influence the scope of the project and the project has been designed with advice from the Macmillan Information and Support Service’s steering group.

Planned start date, and any milestones that must be achieved before that date

Start Date: June 2018
Review: December 2018 – see 2018 Annual Report
Project End Date: December 2019