Macmillan Mental Health Cancer Care Research Project

Exploring the experiences of people living with a mental health condition and affected by cancer
A BIG THANK YOU
Reasons for research project

• Research reveals that people living with a mental health condition and are diagnosed with cancer have poorer outcomes than people who don’t have a mental health condition

• Locally we did not know how many people were living with a mental health condition and were affected by cancer or what their experiences were like
Aims:
1. To identify and increase awareness of the needs and challenges for people with mental health conditions to enhance their experience and improve outcomes in relation to cancer.

2. To identify ways to improve the experiences of people with mental health conditions who have a cancer diagnosis

Objectives:
Work with people living with a mental health condition and affected by cancer, their carers and professionals who volunteer to participate in the project

Identify the number of mental health service users affected by a cancer diagnosis

Research and evidence improvements that will best meet the needs of this target group

Produce a final report on findings and recommendations

Outcomes:
Produce recommendations on:

What is needed to improve outcomes for people living with mental health conditions and affected by cancer

Quality improvements to services

Improved support for mental health service users affected by cancer

Improved identification of mental health service users affected by cancer

Improved access to support within health & care pathways
## Scope of project

### Mental health
- Common mental health problems e.g. low mood, stress, anxiety
- Mood disorders e.g. Depression, SAD
- Anxiety disorders e.g. GAD, Health Anxiety etc
- Severe and enduring mental illness e.g. Schizophrenia, Bi-polar disorder

### Cancer pathway
- Pre-cancer and cancer prevention programmes
- Referral and diagnosis
- Treatment pathways
- Living with and beyond cancer
- Palliative care and end of life

### Geographical area
- Hartlepool and Stockton on Tees CCG and North Tees & Hartlepool NHS Foundation Trust
- South Tees CCG and South Tees Hospitals NHS Foundation Trust
- Tees, Esk and Wear Valley Mental Health NHS Foundation Trust
Steering Group

Met quarterly
Chaired by M&S Mind and Macmillan

Responsible for:
• The development, direction and delivery
• Providing leadership and strategic direction

Members:
• CCG’s
• Oncology Services
• Mental Health services
• Public Health
• Primary Care
• Macmillan
• M&S Mind
• VCS organisations
• People with experience
Project Phases:

1. Desktop Research
2. Information Gathering
3. Developing Recommendations
**Academic Research** : 57 Research papers reviewed

- Cancer screening – the barriers and challenges
- The prevalence, survival rates and mortality
- The challenges of managing mental and physical co-morbidities
- Impact on caregivers of caring for someone with cancer

**Demographics**
- Cancer Incidence and mortality
- Mental health prevalence
- Levels of Deprivation
- No of people living with mental health conditions and cancer

**Service Mapping**
- Cancer services, mental health services, public health and other support services / organisations

**Strategies, Policies and Action Plans**
- Five year forward
- No health without mental health
- Achieving world class cancer outcomes
- Integrated care services
- Treat as one
- Recovery package
- Closing the gap
- Sustainable Transformational Plans
- And others……
Information Gathering

Stories collected through semi-structured interviews

Other methods used:
- 3 Focus groups
- 3 Workshops
- 4 Public consultations
- 5 Surveys
- Team meetings
- 1:1 meetings with various organisations
Developing Recommendations

Thematic Analysis revealed themes for further investigation and led to the creation of the final recommendations.
Co-production Group

Members are volunteers with personal experiences of living with mental health conditions and cancer or caring for someone who has been affected.

The group meets fortnightly and have co-produced the recommendations.

The members have also attended other meetings, prepared and presented their stories, designed and co-facilitated workshops.
What the members say

“I wanted to give something back to the community. I wanted to help improve the cancer pathway for people living with a mental health condition.”

“Being involved in this project has helped me to speak out – find my voice. My confidence has improved.”

“I feel supported by people who have had a similar experience. It is good that we can share views from different communities, ages and experiences.”
Research Findings

• Barriers to accessing cancer screening, diagnosis and treatment mean that people have poorer outcomes if they live with a mental health condition and are affected by cancer

• Locally there are higher than national averages of mental health and cancer prevalence

• Local cancer services perform well against national targets

• Mental health services implemented strategies to address people’s physical health

• Examples of good practice and where the gaps are were identified

• Themes emerged from the stories, focus groups and workshops
Where services work well

• Professionals working together to support people with complex mental health conditions to access diagnosis and treatment
• Development of proactive cancer screening programmes in forensic services
• Implementation of annual physical health checks in mental health services
• Rapid referral for cancer diagnosis and treatment
• People are pushed / pulled through the cancer pathway
Themes identified through research

• Gaps in systems and processes to share information between mental health and cancer services and through the cancer pathway

• Gaps in knowledge about cancer and mental health in mental health and cancer professionals

• Inconsistent offer of information at diagnosis and no information on managing a mental health condition and a cancer diagnosis

• Carers feel unacknowledged and unsupported

“We don’t know that the person has a mental health condition until we meet them in clinic”

“We don’t know enough about mental health conditions and how best to support someone”

“I wasn’t given any information about my cancer, just the diagnosis”

“No-one asked me how I was doing”
Outcomes and Recommendations
1. People are supported to manage and share their own information about their specific mental health needs whilst undergoing cancer treatment.

Recommendations:
Create a working party to design, develop and pilot a hospital passport type document to be used through the cancer pathway
Members: people with lived experience of mental health conditions and/or cancer, mental health and cancer professionals

What was said during consultations:
“This would really have helped us.”
“We would definitely use this.”

“He was getting distressed by the noise and people in the waiting room and he started to respond to his voices. It would have helped if he could have worn his headphones.”
2. People living with mental health conditions are offered support to take up cancer screening invitations and increase their knowledge of cancer and the risks

3. Staff in mental health services have basic cancer awareness knowledge and can signpost people to relevant services and organisations when needed

**Recommendations:**
The annual physical health check should include questions about cancer screening and support for the person to take up the screening invitations if needed
People, their carers and staff should have access to cancer awareness and campaign information and know how to access services for early diagnosis and treatment through the Recovery Colleges

**What was said during consultations:**
“"I would be happy to ask questions about cancer screening if I could provide the right support and signposting to people."
"If you have access to the right information, you can make a more informed decision."
4. The gap between mental health and physical health services is reduced with improved communication between services.

**Recommendations:**

Invite staff from cancer and mental health services to attend a solution focussed workshop to formulate an action plan to reduce the barriers between services and improve communication.

Consider the development of a brief mental health assessment and toolkit for use in cancer services.

Pilot a specialist mental health worker in cancer services.

**What was said during consultations:**

“We would be interested in a joint event with our colleagues from another service if it will improve outcomes for our patients.”
5. Physical health staff have a basic knowledge of mental health conditions and are able to offer support when required and signpost people to relevant services when required.

Recommendations:
A mental health training programme is offered to cancer staff by mental health training providers and Macmillan
A directory of services and contacts in mental health organisations should be available to staff in cancer services and kept up to date
The hospital passport type document should include details of mental health key worker where appropriate

What was said during consultations:
“It would be great if we could have access to the right information so a two minute job doesn’t end up being a twenty minute task.”

“We see lots of people with mental health problems but we don’t know who to ring for advice or help.”
6. People are offered information about managing their mental health condition when affected by cancer in a form that is accessible to them.

Recommendations:
All people should be given the opportunity to receive information in a format that is accessible to them
Staff should be aware of the different formats that information can be given in such as DVD and easy read
People living with mental health conditions should be offered information on how to manage their mental health conditions whilst affected by cancer – NEW booklet to be developed

What was said during consultations:
“There are no booklets about how to manage my mental health condition when I have been affected by cancer.”

“The only information I got was from the specialist nurse. It was ‘old’ information for her but ‘new’ information for me and I couldn’t take it all in. It felt like she was just going through the routine like an air stewardess.”
7. Carers needs are considered and they are signposted to relevant carer support organisations

Recommendations:
Information about local carers organisations for carers should be included in the hospital passport type document
Staff should be able to signpost carers to relevant organisations for information and support
Investigate need to create a peer support group for carers of people living with mental health conditions and affected by cancer

What was said during consultations:
“At the time I didn’t know where to turn. Nothing was offered.”
“It would have helped to be informed about what was available.”

“Nobody ever asked how I was doing and caring for my mother was having a huge impact on my own mental health condition.”
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<td>Develop, pilot and evaluate hospital passport type document</td>
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<td>Investigate the feasibility of including cancer screening questions on</td>
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<td>Develop a module on cancer awareness for Recovery Colleges</td>
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<td>Organise a joint workshop for cancer and mental health staff</td>
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<td>Provide mental health training &amp; information on services to cancer</td>
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<td>Develop content for a booklet on managing mental health conditions</td>
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<td>Explore the potential for a specialist mental health post in cancer</td>
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Final points

• The final report will be available from mid February 2019
• Review of Steering Group - Membership, Terms of Reference and purpose in January 2019
• Review of Co-production group in January 2019
• Action planning group meeting in January 2019 to link strands of work to strategic direction and potential future funding requirements
Future research ideas

• Further investigation of need for peer support groups for people living with mental health conditions and their carers

• Additional research into needs of carers of people living with mental health conditions and cancer

• Additional research to understand admission data of people living with mental health conditions and a cancer diagnosis
Your involvement in 2019

Sign up to a workstream that you would like to support in 2019

Investigate the feasibility of including cancer screening questions on the annual physical health check and additional staff knowledge required

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THANK YOU

And
Enjoy the refreshments.