Health and Wellbeing Board

25 September 2017

Macmillan Joining the Dots County Durham

Report of Amanda Healy, Director of Public Health, Durham County Council, Durham County Council

Purpose of the Report

1 To update the Health and Wellbeing Board on the Macmillan Joining the Dots County Durham project and to notify the Board of the intent to consult on the proposed model.

Background

2 Cancer is the highest cause of death in England in under 75s. Cancer contributes significantly to the gap in life expectancy between County Durham and England. Higher rates of cancer mortality account for around one-third of this gap. Within County Durham, life expectancy is lower in the most deprived communities and cancer is the biggest contributor to this gap. Improvements in diagnosis and treatment mean that more people are likely to survive cancer than die from it. More than half of people diagnosed with cancer today are living for more than 10 years. For many types of cancer, it can be seen as more of a long term condition than a death sentence.

3 Two in five cancers are preventable. The main impact on the increasing numbers of people being diagnosed with cancer are behavioural, lifestyle and environmental factors.

4 Despite considerable reductions, smoking tobacco remains the single biggest risk factor for developing cancer. Diet, being overweight or obese, alcohol consumption and UV exposure are also factors which can increase our risk of getting cancer. Workplace exposure to cancer-causing materials and substances also increases risk.

5 Macmillan Joining the Dots County Durham is a partnership project between Durham County Council and Macmillan Cancer Support, which has been in place since November 2015.

6 Durham County Council's public health team lead on the development of the project with two full time members of staff and part-time intelligence support; funded by Macmillan Cancer Support, who have been in post since March 2016. Macmillan Cancer Support have recently committed funding for the project manager and support officer until March 2020. The programme is governed by the Macmillan Joining the Dots Programme Board and has a

Coproduction Group which includes partners from primary and secondary care, clinical commissioning groups, as well as volunteers.

7 The project was established to develop a new “social model” of support which will make sure that all people affected by cancer in County Durham have the opportunity to receive early support for their individual needs; such as income, housing, practical support such as housework or dog walking, lifestyle and emotional support; from the point of diagnosis and throughout their journey.

Current Position

Challenges in the current system

8 The cancer pathways in County Durham are complex. Many people diagnosed with cancer, depending on the type of cancer or the course of treatment required, do not receive any or all of their treatment within County Durham and Darlington Foundation Trust. While many people are allocated a clinical nurse specialist (CNS) who can assist in signposting people to support around non-clinical needs, some are not. People report being in crisis before contacting their CNS around their non-clinical needs as they don’t want to be seen as “bothering” them. For those people who receive their treatment at a hospital outside of County Durham the nurses are unaware of local services which are available to meet the individual needs of people living in County Durham.

Coproduction volunteers

9 The project team, with assistance from Durham Community Action (DCA), has successfully recruited ten coproduction volunteers to the project. The volunteers range between 25 and 70 years old, are men as well as women and include those with their own cancer experience as well as those who have cared for others. The volunteers are managed on a day to day basis by Wellbeing for Life.

10 The coproduction group have met regularly since February 2017 and have analysed patient and carer engagement work and the Joining the Dots events, defined the issues as they see them and begun to develop solutions to the issues they have identified.

Patient and carer engagement

11 Macmillan Cancer Support kindly funded an evaluation of support needs and service provision for people affected by cancer in County Durham. An independent consultant carried out fifteen one-to-one semi-structured interviews with people. These people self-selected having previously completed a project questionnaire. The interviews were conducted in an individual’s own home or a Macmillan Information and Support Centre of their choice. All interviews were audio recorded, transcribed verbatim and thematically analysed.

12 The results of the work reinforced much of the national research which has already been compiled, and supports what Joining the Dots is aiming to achieve:

Diagnosis: feelings are overwhelming; people are unable to hear, process and respond to information they are given; assigning of a Clinical Nurse Specialist (CNS) is variable depending on site of tumour but, where people were assigned a CNS they welcomed the opportunity to discuss their disease in more detail and were often signposted to valuable places for support.

Diagnosis to treatment: people feel anxious, alone and unsupported; they need someone to talk to outside of the family unit as they are often reluctant to discuss worries with family; people value having a medical professional to talk to; people reported having difficulties contacting CNS at this time; the drop-in nature of the Macmillan Information and Support Centres was seen as a good thing; people would also value peer support (someone who's been through this) at this time.

Financial concerns: caused by inability to work during treatment, feeling forced into "retirement", the person providing the sole household income being diagnosed, rising heating bills, difficulty in informing job centre due to there being no privacy, reduced household income makes managing regular expenses problematic and managing debt and unexpected costs much more difficult, termination of contract, cost of clothing for hospital, transport and parking, advice on life policies/pensions, people suggested that they need support to access what is available

Planning for the future: people wanted to get their paperwork in order such as wills and powers of attorney, funeral planning, there were also concerns from some that their condition could be hereditary and concern over whether their family would inherit the disease.

Change in appearance: People were concerned about their own hair loss during chemotherapy identifying feelings as insecure and unhappy. Changes in bodily appearance left people feeling unfeminine, losing their identity requiring psychological support and support with practical needs such as clothing. The Macmillan Information and Support Centres with their advice on wigs and headscarves were highlighted as important in helping people deal with changes in appearance.

Physical and practical issues: People felt unable to undertake routine tasks such as housework, basic gardening and care of pets. Some required adaptations and advice to ensure they could move safely in and around the home. The volume of medications people are required to take was seen as unclear and confusing.

Carers' needs: Some carers sought help from Macmillan Information and Support Centres where they were often made aware of Durham County Carers Association and the emotional and practical support that

they could offer. Healthy lifestyle advice and support for the whole family was seen as important at this stage. The caring responsibilities of the person diagnosed with cancer sometimes overlooked at the treatment stage leading to one man sharing that he discharged himself from hospital immediately after surgery to continue caring for his wife.

Post Treatment: People identified that they feel as though they are falling off a cliff, in limbo, isolated and out of control. Ideas included someone to "touch base" with after a couple of months, the desire to have more local support groups in place, further roll out of the Look Good Feel Better and Hope programmes and meditation classes. People valued the drop in nature of the Macmillan Information and Support Services. Financial worries continued beyond treatment with people citing complex and lengthy paperwork as an issue.

13 The project team has also undertaken survey work, outreach work through Macmillan Cancer Support bus as well as through four Joining the Dots stakeholder events.

Plans for the future

Evidence base

14 National Institute of Clinical and Health Excellence (NICE) Guidance on Supportive and Palliative Care (2004) recommends that:

- Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points throughout a person's cancer journey;
- There should be a unified approach to assessing and recording patients' needs;
- Assessments should be carried out in partnership with patients and carers;
- Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of 'key worker' for individual patients;
- Explicit partnership arrangements should be agreed between local health and social care services and the voluntary sector to ensure that the needs of patients with cancer and their carers are met in a timely fashion and that different components of social support are accessible from all locations.

15 Any new model within County Durham would be based on a case management approach to for assessing, planning, facilitating, coordinating and advocating options for people with long-term conditions. The evidence shows that case management is widely recognised as an effective approach to coordinating and integrating care (Ross et al, 2011). Effective case management can also help to empower people to manage their condition themselves reducing reliance on an already saturated health system (Ross et al, 2011).

16 According to The Kings Fund, there are five key elements of case management: case-finding, assessment, care planning, care coordination and case closure. An individual to coordinate care is a key element of case

management (Ross et al, 2011). Indeed, care coordination is at the heart of achieving integrated care with link workers/navigators being the enabler (HEE, 2016). Continuity of care provided by an individual case manager has been shown to be of value to the individual in terms of easy and quick response, time taken to assess needs and develop support plans and trust from relationship building (Ross et al, 2011).

17 Case management with a single point of access can ensure that each individual who is referred is offered a consistent assessment (Ross et al, 2011). A single point of access also ensures that there is a simple route to access support for both the individual and clinical referrers in otherwise complex systems (Ross et al, 2011; Wise, 2013).

18 Case management can be more preventative and proactive in approach through the identification of needs at an early stage, before they reach crisis. Case management can also enhance support for self-care through making referrals to services to support with things such as exercise and healthy eating; advocating for and negotiating on behalf of an individual and psychosocial support (Ross et al, 2011).

19 Care planning based on individual needs has been shown to improve people's health outcomes particularly in respect of physical and psychological health. It has also been shown to increase people's capacity to self-manage their condition in comparison to usual care (Coulter et al, 2015).

Proposed model of operation

20 The proposed model seeks to enhance and compliment work already been undertaken in relation to holistic needs assessment across the North East in tertiary, secondary and primary care.

21 The coproduction group has identified that there needs to be a "hub"; a single place for people to be referred, by their healthcare professional or self-refer to, which is accessible via a single telephone number, single email address, via a webpage and via text message. The group feel that a systematic/ automatic referral, as soon after the point of diagnosis, to the hub would be the only way to reduce the inequalities experienced currently but data sharing issues currently prevent this from being possible.

22 The concept of the "hub" would be:

- administrative,
- where referrals are received from all sources,
- where initial appointments are made with people affected by cancer at a time and place convenient to them,
- where holistic needs assessments could be undertaken via telephone if someone does not want a face to face meeting,
- where it is ensured that the necessary support has been delivered and accessed by the individual,
- a single place to record the results of holistic needs assessment and associated support plans,

- available after normal working hours and at weekends,
- a “home” base for the key worker.

23 A key worker would be allocated by where people live – not on the type of cancer they have or the hospital that they are receiving their treatment in. Key workers would be based in the local community in a mobile/outreach capacity. They will undertake holistic needs assessments to identify people’s individual needs and develop support plans with the individual affected by cancer to meet these needs. The key worker would broker and make referrals to existing support services based on the agreed support plan, coordinate delivery of support, use a case management approach and liaise with clinical teams in both primary and secondary care where required.

24 Making use of peer support is also a key component of the desired model. People who have experience of cancer to help guide people through their journey and provide emotional support and advice.

25 The coproduction group has recognised that different people have different levels of need and therefore there needs to be a tiered approach to support, ranging from self-directed individual needs assessment and identification of support, to a case management hand-holding support.

26 A graphical illustration of the proposed model of operation is available to view at appendix 2.

Next steps

27 The proposed model will be publicly consulted upon from Monday 25th September 2017 to Monday 6th November 2017. The consultation proposals were signed off by Durham County Council Consultation Officer Group on 1st September and include plans to cascade the model via press release, social media and appropriate access points.

28 Following consultation, amendments will be made to the model and a final proposal, together with an implementation plan for piloting the model will be placed before the Macmillan Joining the Dots programme board on 1st December 2017.

Recommendations and reasons

29 The Health and Wellbeing Board is recommended to:

a) Acknowledge the work undertaken through the Macmillan Joining the Dots County Durham project so far;

b) Facilitate the dissemination of the consultation to partners and to the general public; and

c) Agree the model for consultation and provide collective and/or individual feedback to the proposals within the deadline

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Appendix 1: Implications

Finance

Macmillan Cancer Support have allocated £1million pounds to the development of this project. There will be approximately £500k remaining in the budget for implementation. A full impact assessment on the development of the model will be undertaken prior to a final proposal being submitted to the Programme Board.

Staffing

Macmillan project manager and project support officer are in post to support the development and implementation of the project until March 2020.

Risk

Sustainable funding of any model post Macmillan Cancer Support.

Equality and Diversity / Public Sector Equality Duty

An Equality Impact Assessment of the project has been undertaken and is reviewed regularly to ensure any issues are assessed, identified and addressed through the development of the model. No adverse implications have been identified to date.

Accommodation

Implications if the “hub” model is adopted for housing of administrative staff.

Crime and Disorder

No adverse implications

Human Rights

No adverse implications

Consultation

Pre-engagement work is detailed within the report. DCC Consultation Officer G has signed off consultation proposals.

Procurement

Plans for procurement will be developed in due course.

Disability Issues

No adverse implications identified through the Equality Impact Assessment

Legal Implications

No adverse implications

OUR PLANS FOR A NEW SERVICE FOR PEOPLE AFFECTED BY CANCER