PC 26
Ymchwiliad i ofal sylfaenol
Inquiry into primary care
Ymateb gan: Cymorth Canser Macmillan
Response from: Macmillan Cancer Support

Inquiry into Primary Care

The Response of Macmillan Cancer Support to the Health, Social Care and Sport Committee's Consultation

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1. Introduction

1.1 Macmillan Cancer Support welcomes this opportunity to contribute to the inquiry into Primary Care. We are also signatories and endorse the paper produced by the Welsh NHS Confederation policy forum - "Our Community": Ten actions to support Primary Care in Wales"[1].

1.2 In Wales, 19,000 (WCISU Feb 2015) people are diagnosed with cancer every year and more than 130,000 people are currently living with or beyond cancer, almost 4.5 percent of the population. By 2030 it is expected that 250,000, almost eight percent of the Welsh population, will have been affected by a cancer diagnosis and one in two of us will be affected by cancer at some point in our lives.

1.3 The good news is that survival rates are steadily improving and many people recover. On average 70 percent[2] of Welsh residents diagnosed with cancer can expect to survive at least one year.

1.4 Higher cancer prevalence, improvement in survival rates and an increase in people living with and beyond cancer mean more people are increasingly dependent on Primary Care; whether that is at the point of diagnosis, or post-treatment for an increasing number of people, possibly living with the impact of the treatment they received.

1.5 The role of Primary Care is vital to ensure people affected by cancer be provided with timely high quality information about the disease, options, treatment and consequences so that they can make informed decisions about their treatment and care. The importance of ensuring people are enabled to self-manage their condition as best as possible sits well within the context of Prudent Healthcare, that public and professionals are equal partners through co-production.

1.6 Macmillan wants every person diagnosed with cancer in Wales to have an assessment discussion and be offered a personalised written care plan and treatment summary.

[1] Welsh NHS Confederation Policy Forum. (2016) "Our Community": Ten actions to support Primary Care in Wales" http://www.nhsconfed.org/resources/2017/02/our-community-ten-actions-to-support-primary-care-in-wales
[2] Welsh Cancer Intelligence and Surveillance Unit Official Statistics 2012 data. Published 10 April 2014

1.7 A written care plan should be shared with the person affected by cancer and their GP, so that healthcare professionals working in Primary Care understands the support required during and after treatment to help the patient come to terms with their diagnosis, the side effects of treatment, its financial impact and preparing for care and self-care after treatment.

1.8 This has led to the development of the Macmillan Framework for Cancer in Primary Care Programme – expanded upon in section 2. Macmillan's interaction with Primary Care occurs largely via this Programme, informing our comments in section 3.

2. The Macmillan Framework for Cancer in Primary Care Programme

2.1 The Macmillan Framework for Cancer in Primary Care programme[3] is a five-year project to support Primary Care professionals to diagnose, care and support people affected by cancer and improve their outcomes and experience.

2.2 There have been significant changes in the treatment and care of people affected by cancer over the last thirty years. Many more people are surviving some cancers; some are cured, but many continue to live with the impact of their cancer and treatment. In response to this changing face of cancer, Macmillan's Framework for Cancer in Primary Care Programme provides clinical leadership to bring about a large-scale shift in how primary and Secondary Care works together to implement wide spread and sustainable improvements for cancer services in Wales. The Macmillan Framework for Cancer in Primary Care Programme seeks to influence Health Boards, Primary Care and relevant Secondary Care and support transformational change to happen through clinical leadership, championed by and engaging with a passionate "community of practice" of GPs and nurses.

2.3 The Programme's key priorities are:

- **Early diagnosis** – early diagnosis of cancer is critical, in most cases and for most cancers, the earlier cancer is diagnosed the greater a person has of survival.
- **Support through treatment** – NHS Wales can support people better if it improves the communication and information flow and better integrates treatment between Primary and Secondary Care.
- **Living with and Beyond Cancer (after acute treatment)** – More people are surviving cancer. For many people cancer is now a "chronic condition" that requires a new approach to longer term care to deal with the consequences of cancer and its treatment.

2.4 **The Programme aims to help health boards in Wales to deliver their commitment as set out in the Welsh Government's Cancer Delivery Plan[4].**

2.5 Colleagues from the Macmillan Framework for Cancer in Primary Care have been actively involved in the development of the early diagnosis pilot programme focussing on the three-legged Danish model for early diagnosis. In April 2016, a multidisciplinary team of cancer professionals from NHS Wales and the Macmillan Framework for Cancer Programme, visited Aarhus in Denmark to learn about the model and to consider translation into the Welsh system.

2.6 Reports have shown that cancer survival in the UK and Denmark is lower than in comparable countries. Studies in Denmark suggest that one of the causes of poor outcomes is potentially avoidable delays in presentation, diagnosis and treatment, which may lead to higher mortality

[3] http://www.walescanet.wales.nhs.uk/macmillan-framework-for-cancer
[4] Welsh Government (2016) "Cancer Delivery Plan for Wales 2016-2020: The highest standard of care for everyone with cancer" http://gov.wales/docs/dhss/publications/161114cancerplanen.pdf

and stage progression. Having identified late diagnosis as a potential cause, Denmark embarked on several initiatives to improve cancer diagnosis. This included the development of a three-legged referral model to support early cancer diagnosis.

2.7 NHS Wales and the Wales Cancer Network, in close collaboration with Macmillan's Framework for Cancer in Primary Care colleagues, are exploring a number of pilot schemes to test whether a similar model might work in Wales[5].

2.8 Macmillan believes that effective communication between Primary and Secondary Care can reduce harm, result in better outcomes and improve patient experience. An example of this in practice is the development of the Macmillan Acute Oncology Services across Wales:

A case study in communication: Macmillan Acute Oncology Services

Welsh Government policy outlines ambitions for seamless integration between Primary and Secondary Care. Clear and regular communication between healthcare professionals who deliver services in these care settings is vital if patients are to receive well-coordinated person centred care.

The 2012-16 Cancer Delivery Plan identified that "all Local Health Boards will need to consider how acute oncology services can be developed to support the diagnostic process in patients admitted as emergencies".

Acute oncology services provide people with timely access to specialist advice, reassurance and urgent treatment when presenting at health care settings (both Primary and Secondary) with problems relating to newly presenting cancers; complications of cancer and the toxicities to the treatment of cancer. The role of the GP in identifying health needs in relation to acute oncology interventions is vital.

Key to the success of acute oncology services is the use of the written care plan and treatment summary. By ensuring that the treatment summary is completed and understood by both the GP and the patient means that all parties are fully informed and prepared for any acute presentation that may occur.

For example, GPs who are fully aware of newly issued standards relating to neutropenic sepsis, will know the importance of urgent referral and should refer directly into the nearest Acute Oncology service, bypassing A&E and avoiding a life-threatening delay in treatment.

This is only one example of how GPs can enhance patient experience and outcomes, which can only be achieved through collaboration and an understanding on the part of Primary Care of:

- The Standards required regarding a specific area of care
- The process to follow should a patient present with symptoms
- The local context – where to refer within their patch
- Communication – for ongoing service improvement and good quality patient outcomes.

Through continued investment and the Macmillan Framework for Cancer in Primary Care we will continue to work collaboratively with GPs and Secondary Care to facilitate robust joint working in this and other areas with a view to delivering better patient outcomes and experience.

[5] Ibid, p. 8 - 9

3. Specific issues concerning Primary Care

3.1 The Committee has invited views on a range of specific points. These are set out below (in ***bold italics***) and are followed by our contributions. These comments are informed by the experience of our Macmillan GP leads who are practising GPs and interact with Primary Care on a day to day basis

a. How GP cluster networks in Wales can assist in reducing demand on GPs and the extent to which clusters can provide a more accessible route to care (including mental health support in Primary Care).

a.i Patients (in this instance anyone with concerns about the symptoms they are experiencing, or someone who has been through treatment for cancer) need to feel they are not "bothering" their GPs with persistent symptoms that are new and may be serious. GPs need to be available to see these patients and make the necessary assessment and investigation/referral decisions.

a.ii Reducing demand on GPs requires a mix of approaches:

- GPs need to be empowered and encouraged to not see themselves as the only person who can do GP work (assessing undifferentiated illness). GPs may be concerned, understandably so, that another clinician assessing the patient may miss a serious condition. Cluster Groups can support change by illustrating how other professionals, such as advanced nurse practitioners, work in practices and share the appropriate safety mechanisms and protocols.
- Ensuring cluster employed support, such as pharmacists; specialist nurses; physiotherapists etc work to collaboratively generated work plans.
- Clusters have the potential to facilitate new ways of working across more than one practice to share the burden, the benefit and the risk. Individual practices need capacity and resources to trial new models of working.

b. The emerging multi-disciplinary team (how health and care professionals fit into the new cluster model and how their contribution can be measured).

b.i The Cancer Delivery Plan stresses the important value of MDTs as the cornerstone of patient management in Secondary Care before noting that there is the potential to enhance their role as vehicles for governance and improvement. They also need to demonstrate real engagement with Primary Care to ensure GPs supported by specialist services[6]. Key actions 19 and 20[7] focus' on integration, and places the onus on health boards (supported by the Macmillan Framework for Cancer in Primary Care Programme) to create the links between clusters and specialist teams.

b.ii We believe that cluster groups are ideal vehicles for encouraging and co-ordinating the release of Primary Care resources to engage in MDT work.

b.iii Current barriers to MDT/GP integration (if there are any) can be boiled down to factors concerning meeting administration and clinical relevance. First, to ensure GP attendance at MDT meetings they need to occur on dates and at times and in locations that are mutually convenient. Once professional relationships are established the use of videoconferencing (where the facilities exist) would allow virtual attendance.

[6] Welsh Government (2016) "Cancer Delivery Plan for Wales 2016-2020". p10

[7] Ibid. p11

b.iv Secondly, meeting agendas should be clinically relevant to appeal to GPs and secure their attendance. All the focus should be on the needs of the patient and how Primary/Secondary Care can achieve/enhance this. Attendance at meetings that are focused on Secondary Care managerial issues are difficult to justify.

b.v In specific terms of cancer MDTs, GPs will rarely have need to attend but in specific cases, for example those with other specific illnesses, frailty or disabilities, GPs may have a considerable insight. The flexibility and ability to videoconference in at an appointed time to contribute could be invaluable and would recognise the contribution from the GP and promote the delivery of holistic care.

c. The current and future workforce challenges.

c.i Traditionally, the independent contractor model has been attractive as it has allowed GPs to manage their own practices and workload. Given the increased work pressures, it now appears that this aspect of general practice is often seen as a burden by newer GPs.

c.ii One of the strengths of general practice is that it gives the GP a wide range of opportunities to take on specific clinical interests and additional roles (GP trainer, accredited GP with a Special Interest, Clinical lead, educational work, medical leadership work). This is attractive to newer GPs with portfolio working in mind, however capacity needs to be built into the system to be able to allow this to happen whilst maintaining safe service provision.

c.iii Some anecdotal evidence we have received from medical students is concerning. We need to guard against dampening student enthusiasm about careers in Primary Care. We should take care to ensure that cultural factors are not turning away talented medical students from Primary Care at an early stage in their career.

c.iv Fluctuation in GP income restricts the ability of the practice to invest in innovation, more nurses and more allied health professionals.

c.v Peer Review of cancer services in Primary Care has been welcomed by the sector and has demonstrated improvement in patient outcomes. Macmillan would press upon the NHS to enhance this programme of quality assurance within Primary Care.

c.vi Macmillan Cancer Support carried out a major project to pilot new ways of providing one-to-one support for people with cancer across the UK[8]. One to one support for people living with a diagnosis of cancer might best be understood as a service that support the patient journey across the whole cancer pathway. Much of this journey will take place through interaction with the Primary Care team.

c.vii Ten of the most prevalent concerns raised with pilot colleagues during the evaluation phase were a blend of health, social and psychological care issues which demonstrates the need for the care of cancer patients to take a holistic view of the individual.

c.viii In future proofing the wider workforce in Primary Care, consideration should be given to the development of roles with the skills to take on complex interventions and find solutions within health, social care and community settings.

[8] Macmillan Cancer Support. "Evaluation of Phase 1 of the One-to-One Support Implementation Project" http://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/onetoonesupportpilotreportfinal.pdf

c.ix Too often efforts are focused on shifting pressure from Secondary Care, without providing additional resource to Primary Care. Also, decisions often appear to be based on what will relieve pressure on Secondary Care rather than what is best for patient care

d. The funding allocated directly to clusters to enable GP practices to try out new ways of working; how monies are being used to reduce the pressure on GP practices, improve services and access available to patients.

d.i We wish to draw your attention to what we consider a significant issue. Clusters (and practices) are not given enough time and notice to generate sufficiently innovative bids to explore new ways of working, thereby the value from the additional funding is not fully maximised. Additionally, funds may arrive late in the financial year and roll over into the following financial year is not being allowed by the responsible Health Boards, which further constrains the opportunity for innovation.

d.ii Feedback suggests that allocating and directing some funding to specifically allow practices to collaborate with specialist support to develop ideas into feasible working models would maximise and add value. For example - facilitated workshops and dedicated service development support to develop ideas. Greater flexibility, longer project cycles and reduced aversion to risk would have a similar impact, promoting and supporting a culture of innovation.

d.iii We would like to better understand how successful innovations are to be funded after the initial funding comes to an end. If financial sustainability is not built into the system of funding, if funding is not picked up by the health board, new ways of working face a short lifespan.

f. The maturity of clusters and the progress of cluster working in different Local Health Boards, identifying examples of best practice.

f.i We believe that cluster group leadership needs regular robust review (whether via peer review or via time-limited appointment/re-appointment) in order to empower cluster groups to develop into dynamic innovative structures.

f.ii Where training is provided for cluster group leads it should be rolled out uniformly with consistency across Wales. We believe that to fully discharge their role and responsibilities cluster group leads should have demonstrable leadership and facilitation skills (and/or be prepared to undertake the necessary training to reach that level). This will allow them to identify, draw out and develop sound ideas and innovations from colleagues and take an active, leadership role in implementing them.

f.iii Health Boards have an interest in investing resources and training in the cluster group staff, but it needs to be planned in collaboration with the cluster and be subject to adequate oversight.

For any further information regarding this response, please contact Greg Pycroft, Policy Officer, Wales – [redacted] or [redacted]