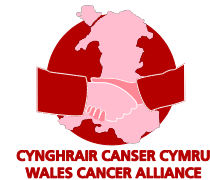


Meeting people's needs

A Wales Cancer Alliance Policy Paper
Summer 2017



Meeting people's needs: overview

More work needs to be done to meet the needs of patients, both as they undergo treatment for cancer and beyond. In 2014 we welcomed the work carried out by the Welsh Government in developing and publishing new guidance¹ around the allocation of Key Workers to those who have received a cancer diagnosis and are undergoing treatment. This guidance is captured in the Welsh Health Circular² sent to Health Boards and Velindre NHS Trust in September 2014 with the aim of ensuring greater consistency in the support to individuals provided by Key Workers. To date, implementation of this guidance has been patchy and people are not able to access the support they need as they are treated for their cancer.

The Cancer Implementation Group has recognised the need to act on this policy area and the Alliance welcomes the prioritisation of person centred care as an area of focus. The Wales Cancer Alliance is pleased to be playing an active part in taking this work forward through the Meeting People's Needs sub-group established in March 2017.

Background

The Cancer Delivery Plan³ acknowledges that "cancer services in Wales have a great opportunity to improve patient outcomes by working more closely together". Yet to achieve better outcomes for patients it is important that health professionals deliver services adhering to clear guidance on how best to meet people's needs.

Cancer Delivery Plan for Wales 2016 - 2020⁴

The Cancer Delivery Plan acknowledges the importance of meeting people's needs, and sets out directives for health boards in support of achieving these outcomes. Local Health Boards are required to:

- Ensure all patients are routinely informed where to access welfare benefits advice.
- Offer timely, high quality and accessible information about specific cancers and treatments; this will include pre-diagnosis supporting information on complexities and complications of treatment and information on how to access care and support wherever they are in the cancer pathway.
- Establish routine liaison mechanisms between primary and specialist care to meet people's ongoing and post-treatment care needs and ensure seamless handover between primary and secondary care.
- Where possible, provide care locally and support patients who need assistance to travel or stay away from home.

Meanwhile, the Cancer Implementation Group will:

- Deliver further patient experience surveys and develop a longer-term approach to embedding patient reported experience outcome measure tools into service design, delivery and improvement.

And, the Wales Cancer Network will:

- Lead on the consistent application across Wales of elements of the 'recovery package' as

¹ Welsh Government. (2014) "[Principles & Guidance – Key Workers for Cancer Patients](#)",

² *Ibid*

³ Welsh Government. (2016) "[Cancer Delivery Plan for Wales 2016 – 2020: The highest standard of care for everyone with cancer](#)" pg4

⁴ Welsh Government. (2016) "[Cancer Delivery Plan for Wales 2016 – 2020: The highest standard of care for everyone with cancer](#)"

appropriate to identified needs (e.g. key worker, electronic holistic needs assessment, care planning, education and structured support programme)

- Evaluate MDT person-centred skills, specifically communication and palliative care, and develop and implement an action plan.

There is a consensus on the benefits of person-centred services that focus' on the requirements of an individual by taking an holistic approach. An approach that takes into account the patient's physical, emotional, spiritual, financial and practical needs, as well as their clinical treatment. By planning and delivering care in this way, patients and their carers feel more in control of their cancer treatment and experience⁵. In addition, these changes help people to self-manage their condition, both during and after treatment. Stratifying the levels of need for clinical and holistic care could free up resources and capacity for clinical teams to focus on more complex cases.

The Wales Cancer Patient Experience Survey (WCPES) is one of a number of tools that the NHS and its partners should use to improve patient experience and outcomes and to drive service improvement. WCPES captures and presents a robust analysis of patient experiences of their treatment and care. Its findings allows us to better understand how key actions within the Cancer Delivery Plan are being implemented. Understanding these experiences is crucial to improving and enhancing the design, delivery and quality of cancer services in Wales.

Wales Cancer Patient Experience Survey 2016⁶

Although just under half of patients (48%) reported having had the opportunity to discuss their needs and to develop a care plan, this means that the majority did not. An even smaller proportion of patients were offered a written care plan - only 18% reported this.

The absence of involvement in developing care plans for most patients is worrying not just because of the importance of good involvement for person-centred care, but also because of the differences in the wider experiences of people who were and were not given this opportunity. Patients who were given the opportunity to discuss their needs and concerns in order to put together a care plan reported more positive experiences of their treatment and care across every phase of the patient journey compared to those without. A care plan, therefore, not only promotes the opportunity for better involvement and shared decision making in the delivery of treatment and care, but is associated with improved patient experience of it.

The patient experience is enhanced by having a named Key Worker, usually the Clinical Nurse Specialist (CNS) who provide support and ensure that patient's needs are met. The guidance for Key Workers of patients with cancer states, "all cancer patients must have an allocated Key Worker... and must be contactable and responsive"⁷. Their role, among many other things, includes providing information to patients and signposting to local support groups. The majority of patients (81%) said that they had access to a CNS as part of their care – including 69% who said that this person was their Key Worker.

While this is positive, it is short of the 100% aspired to within the Key Worker guidance. Patients also reported experiencing difficulties in contacting their Key Workers and CNSs. Of those who had tried, this was reported to be "sometimes" or generally difficult for 26% of patients in relation to Key Workers and 36% in relation to CNSs. When they were able to get in contact and had questions the vast majority of patients always, or mostly, received understandable answers to any important questions from their CNS (91%) and found that their Key Worker helped them to get answers (87%). Four in five (80%) said that

⁵ Macmillan, Welsh Government. (2017) "Wales Cancer Patient Experience Survey 2016"

⁶ Ibid

⁷ Welsh Government. (2014) "[Principles & Guidance – Key Workers for Cancer Patients](#)"

their CNS gave them the information they needed to make informed decisions about treatment and care. The positive impact of a Key Worker/CNS is clear. When compared to those without this support, patients with access to a Key Worker and/or CNS reported significantly more favourable experiences to all relevant questions regarding information, treatment and care, arranging home support and their overall NHS care.

Calls for Action

The Wales Cancer Alliance calls for:

1) Assessment and written care planning to be implemented for all people living with cancer

The National Assembly Health & Social Care committee's inquiry⁸ into the delivery of the Cancer Delivery Plan recommended that all patients should be offered an assessment, the outcomes of which should be recorded in a written care plan. The Welsh Government accepted the committee's recommendation in its response to the inquiry in December 2014.

The 2016 Wales Cancer Patient Experience Survey⁹ showed that only 48% of patients were "offered the opportunity to discuss their needs" and only 18% of patients had been offered a written care plan, a fall compared to the 2013 Patient Experience Survey¹⁰. The Wales Cancer Alliance continues to monitor progress in this area, and finds the lack of improvement between 2013 and 2016 disappointing.

2) Improved information and support to help shared decision making and provide information about treatment and care and encourage self- management

Clear and accessible information to patients is fundamental to delivering a high quality service and patient experience. The 2016 WCPES¹¹ highlighted that while 90% of patients said they had received complete explanations concerning test results a worrying minority of patients, received no explanation. It also found that only 75% of patients were informed of the possible side effects of treatment they may experience, and only 53% of those surveyed were "definitely" informed of potential future side effects. This reveals a need for more tailored information relating to their cancer and treatment, as timely access to high-quality information and support is closely linked to a positive patient experience¹² and can reduce anxiety and uncertainty.

3) Adherence to Key Worker principles and guidance issued by Welsh Government to achieve consistent interpretation and implementation of the Key Worker role across Wales. This approach should span the entire care pathway – from the acute setting, through to primary care.

4) An increased understanding by patients of the Key Worker role.

Welsh Government guidance¹³ states that all cancer patients should have access to a Key Worker and notes that the Key Worker role is likely to be member of the MDT and could be a Clinical Nurse Specialist or a rehabilitation specialist. It also states that when the patient is not under active management by the cancer MDT, the Key Worker would be a member of the primary care team. The standards expected are that:

- All cancer patients must have an allocated Key Worker;
- The name of the Key Worker must be recorded in the patient's notes;

⁸ National Assembly for Wales Health & Social Care Committee (2014) "[Inquiry Into Progress Made To-Date on Implementing the Welsh Government's Cancer Delivery Plan](#)"

⁹ Macmillan Cancer Support, Welsh Government, Picker (2017) "[Wales Cancer Patient Experience Survey 2016](#)"

¹⁰ Macmillan Cancer Support, Welsh Government, Quality Health (2014) "[Wales Cancer Patient Experience Survey 2013](#)"

¹¹ Macmillan Cancer Support, Welsh Government, Picker (2017) "[Wales Cancer Patient Experience Survey 2016](#)"

¹² *Ibid*

¹³ Welsh Government (2014) "[Principles & Guidance – Key Workers for Cancer Patients](#)"

- The name of the Key Worker must be recorded on CANISC;
- The name of the Key Worker must be passed to the patients GP;
- Patients must be given a completed Key Worker card with the contact details for the Key Worker, as well as a patient information leaflet description.

The 2016 WCPES¹⁴ found that the 100% aspiration contained within the guidance is not being met, with 81% of patients reporting that they have received the name and contact details of a Key Worker. The positive impact of the Key Worker is clear, of those patients allocated a Key Worker 87% reported that person helping to get answers concerning treatment and care.

5) An end of treatment summary sent to patients' GPs

It is critical to patients' ongoing care that they receive an end of treatment summary, so they know the patient has received the ongoing care needed and the potential consequences of these treatment. This is why an end of treatment summary is so important in supporting a seamless transition between stages along the cancer treatment and recovery pathway.

6) A review of care after treatment to ensure it is person centred, providing for ongoing, clinical surveillance and ongoing care after acute treatment has finished which better supports cancer survivors

Despite the learning gained from the 2013 WCPES, issues around patient support post-treatment were still identified, there remains room for improvement. For instance, only 59% of patients¹⁵ felt they were definitely given enough care and help from health and social services, the same score as the 2013 survey.

The 2014 National Assembly Health & Social Care committee inquiry¹⁶ made recommendations that aftercare needs should routinely be taken into account as it is vital that patients have a clear, consistent and seamless journey between the different places where they receive their care whether that is their GP practice, hospitals and/or cancer centre. Patients want to know who is taking over their care and who they should contact if they have questions or concerns.

7) The adoption of a two-year rolling programme to carry out the Wales Cancer Patient Experience Survey.

The Wales Cancer Patient Experience Survey¹⁷ provides a robust and comprehensive analysis of people's experiences of cancer care in Wales, capturing the views of thousands of patients.

While the surveys reveal findings worth celebrating, for instance – the very high levels of patient satisfaction with their care, the survey also highlights areas of significant variation between health boards, and where improvements are needed against Cancer Delivery Plan priority areas and actions.

Ensuring that the Survey is repeated to monitor progress against these important benchmarks is clearly integral to improving the experience of cancer patients in Wales.

8) Supporting the needs of carers

Crucial to good treatment and recovery is the support offered to the carers looking after family or friends affected by cancer. It is imperative that the legal duties placed on the relevant health and social

¹⁴ Macmillan Cancer Support, Welsh Government, Picker (2017) "Wales Cancer Patient Experience Survey 2016"

¹⁵ Ibid

¹⁶ National Assembly for Wales Health & Social Care Committee (2014) [Inquiry Into Progress Made To-Date on Implementing the Welsh Government's Cancer Delivery Plan](#),

¹⁷ Macmillan Cancer Support, Welsh Government, Quality Health (2014) ["Wales Cancer Patient Experience Survey 2013"](#)

care providers¹⁸ are implemented and effectively monitored.

¹⁸ Social Services and Well-being (Wales) Act 2014