

Macmillan Summary

Wales Cancer Patient Experience Survey - Analysis of the free-text comments report, Southampton University, November 2014.

1. Introduction

The Wales Cancer Patient Experience Survey free- text Comments Analysis Report produced by Southampton University is being published today. The detailed Report can be accessed here on Macmillan's [website](#)

Following the launch of the Wales Cancer Patient Experience survey (WCPES) results in January 2014, Macmillan Cancer Support commissioned an academic research team at Southampton University to undertake an analysis of the comments provided by 4672 patients who had received cancer treatment in Wales. The aim of commissioning this piece of work was to better understand the overall patient experience of cancer care in Wales; identify key themes arising out of the free text comments; gain further insight into the extent and quality of person-centred care in Wales; ensure that the patient voice remains prominent and is used to help improve cancer services in Wales.

2. Why is good patient experience so important?

Making sure people with cancer have a good experience has the following benefits:

- A good experience makes people with cancer feel supported and respected;
- Evidence has shown that patient experience is linked to other outcomes including a patient's health, use of resources and patients following their treatment plans;
- A study has shown that providing patient centred care can reduce the time a patient stays in hospital and staff turnover, which can save hospitals money;ⁱ
- Poor patient experience can be a warning sign for more widespread failings;
- There is a close link between staff and patient experience. When staff feel valued and respected, they are more likely to treat patients in the same way and be happier in their role.ⁱⁱ

3. Background

The *Wales Cancer Patient Experience Survey 2014* (WCPES) results provides a robust and comprehensive analysis of people's experiences of cancer care in Wales, with the survey capturing the views of 7,352 patients and achieving a completion response rate of 69%. The WCPES provides an important benchmark in relation to the patient experience and the extent to which Health Boards /Trust are meeting people's needs as set out in the Welsh Government (WG) Cancer Delivery Plan.

It is important to acknowledge that the Wales CPES results in January 2014 revealed high levels of satisfaction with NHS cancer care in Wales, with 89% of patients rating their overall care as excellent or very good. This is a very clear indication that overall experience is a good one and provides a high baseline for further improvement.

4. Highlights and key themes

The Comments Report provides a thorough analysis of the comments provided by 4672 participants, dividing these into key themes with positive and negative areas identified.

Key themes :

- Positive comments generally outweigh the negative comments but positive comments appear briefer and negative comments more detailed (n=3,818 positive and n=2,313 negative).
- It is notable that a patient's experience at the beginning impacts on the whole of their cancer journey and if there is an early negative experience this can translate into uncertainty, anxiety and loss of confidence throughout the care pathway.

Within the diagnostic phase:

- There were some positive comments around GPs' speed of referral and indicates that patients felt confident in their individual GP and in the service being provided, however, negative comments outweighed the positive in this section of the report.
- The comments which reveal areas of concern were around initial identification of symptoms, delayed referrals and waiting for diagnostic appointments. There are varying perceptions of individual GPs' responses to patient symptoms, ranging from some patients praising the speed and accelerated reaction to their symptoms to others feeling that their symptoms were not taken seriously enough, dismissed and sometimes misdiagnosed.
- There appears significant variation in communicating a cancer diagnosis to patients, with some exemplary discussions noted, whilst some patients perceive the disclosure as too brief and insensitive. Several patients noted that they should have been advised to bring someone along with them for additional support.

Within the treatment phase:

- There is praise from patients regarding the speed of diagnosis and clear and accurate communication about treatment.
- Specialist nurses were highly praised and appreciated and their positive impact on integrating care commended but it was noted that there was often no cover available if the specialist nurse was on leave and they were sometimes unavailable due to other commitments.
- General nursing care received a mixed range of comments, with the negative comments outweighing the positive. Comments often attributed incidences of poor care to inadequate staffing levels or financial constraints and there were some comments where patients highlighted that they were treated with a lack of dignity and respect.
- Comments relating to specific treatment such surgery, chemotherapy and radiotherapy were mainly highly positive.

Within the aftercare phase:

- Comments reveal some patients struggling with the emotional, social, psychological and financial affects of their cancer with support services appearing either unavailable or unknown to patients.
- There appears inconsistent continuity of care and transitions from primary care to secondary care and vice versa. This is a particularly anxious times for patients.
- A lack of clear, tailored and appropriate information for individual patients is reported particularly during the aftercare phase where patients appear unprepared and uncertain of how to manage living with and beyond their cancer treatment.

5. Detailed Comments

5a. Early Diagnosis / Delays. The Wales CPES results show that whilst 78% of patients felt they were seen as soon as necessary, 1,524 patients felt that they should have been seen sooner.

'I went to my GP on the Thursday and I was seen by the following week. The consultant in the hospital which I had biopsies taken and told that same day I had cancer, and it was dealt with very quickly and I was very happy with the care I was given and how quickly it was treated '

'I was diagnosed with suspected cancer in May 2012. It was confirmed by biopsy in July 2012. It was several months later in January 2013 before I received the operation to remove tumour. This was much too long a wait - and caused me severe anxiety'

Macmillan response:- Cancer patients must receive access to the right diagnostic tests and treatment promptly to give them the best chance of surviving or living longer with cancer. Unnecessary delays in diagnosis and starting treatment can cause severe distress and anxiety for patients, and their families, as well as adversely affecting their clinical outcomes.

The NAW Health and Social Care Committee Inquiry into the implementation of the Cancer Delivery Plan (October, 2014) recommends that GPs receive appropriate training regarding cancer symptoms; supported with tools and resources; have clarity about referral routes available to them; and that the strategy to support diagnostic services across Wales is monitored. **Recommendation 5, 6 and 7.**

5b. Key worker/Clinical Nurse Specialists. Throughout the Wales CPES results, patients assigned a Clinical Nurse Specialist as a Key Worker consistently reported more positively on areas covering verbal and written information, involvement in their care, information on finances, discharge information, post discharge care and emotional support.

'Key Worker system with specialist nurse very good; reduces the amount of chasing around. Excellent way of getting information, as often don't want to take up too much of doctor's time'

'It has been difficult, if not impossible to contact the nurse specialists. This has delayed getting advice and treatment at least twice and caused stress and anxiety.'

Macmillan's view is that, a Clinical Nurse Specialist (CNS) enhances the delivery of cohesive care and should, during active treatment, be appointed the Key Worker, responsible for co-ordinating treatment and care on behalf of a team of professionals caring for the patient, ensuring smooth transition and communication with the team, the patient and their families. Adequate cover for leave should be provided. When active treatment has finished, the Key Worker role, in most cases, should be transferred to primary care e.g. the GP, practice or community nurse as the main point of contact. The transition between secondary and primary care is often a difficult phase for patients and integrated care is essential to reduce patients feeling abandoned. A Key Worker is crucial in providing support or promotion of self care during this transition period.

The NAW Health and Social Care Committee Inquiry (October, 2014) recommends that the WG Key Worker Guidance is monitored and re-emphasises that all patients should be assigned a key worker and provided with a written care plan by 2016. The Committee requests that the Minister of Health & Social Care provides an update on progress in 2015. **Recommendation 9.**

5c. Nurse Staffing levels. The Wales CPES results show that 60% (n=2580) of patients felt that there were enough nurses on duty to care for them in hospital, 1229 patients indicated 'sometimes' and 478 patient 'rarely or never' enough nurses on duty.

'Wonderful staff, always helpful and friendly even when they were understaffed.'

'I was in hospital in September and the staff were stretched to the limit. The care in hospitals is very poor, because of the shortage of staff'

5d. Treated with respect and dignity. The Wales CPES results show that 85% (n=3660) of patients felt that they were treated with respect and dignity by doctors and nurses and other hospital staff.

'I was treated with respect, courteousness, understanding. From the receptionist receiving me at entry to the outpatient team as a whole was an excellent experience under a stressful time of treatment'

'Care of the ward and more compassion by nurses. I felt some of the nurses left me feeling humiliated when I was in a mess'.

'Sometimes I felt I was treated like a piece of meat or idiot as medics discussed me with colleagues, without ever talking to me directly.'

Macmillan response:- everyone with cancer should have a positive experience of care and be treated with the highest level of dignity and respect. NHS staff should be supported to do this.

5e. Assessment and Care planning. There is evidence within the Wales CPES results that shared decision making and care planning needs to significantly improve, with only 58% of patients highlighting that a discussion about their needs had taken place and only 22% of patients said they had been offered a written care plan.

'I have not been offered a care plan or ever asked about my emotional needs or asked if I need help with

anything.'

Macmillan response:- Many cancer patients in Wales are not being offered vital support in the months during, and after, their treatment to help them come to terms with their diagnosis, the side effects of treatment, its financial impact and preparing for care and self care after treatment. Appropriate assessment and care planning routinely implemented would help to ensure that this vital support is provided consistently across Wales.

The NAW Health and Social Care Committee Inquiry (October, 2014) recommends that alongside the key worker all patients should be offered a written care plan by 2016. **Recommendation 9.**

5f. Information and Support. The Wales CPES highlighted that 32% of patients were not given written information about their type of cancer which was easy to understand, and a quarter of patients indicated a lack of written information about their operation and side effects of treatment.

'very informative and explained everything about my operation before and after'

'Better information given to the patient. If you know what's coming, you're better prepared for it, not knowing creates anxiety.'

Macmillan response:- Patient comments reveal a need for more tailored information relating to their cancer and treatment. Timely access to high quality information and support is closely linked to a positive patient experience and can help reduce anxiety and uncertainty.

The NAW Health and Social Care Committee Inquiry (October, 2014) supports the provision of tailored patient information and a national single hub of cancer information in **Recommendation 3 and 9.**

5g. Non clinical needs. The Wales CPES identified that 68% of patients said that they had discussed or been given information about the impact of cancer on their work or education and 44% said they had been given information about how to get financial help or benefits by hospital staff.

'Dedicated, integrated team that looked after my health, well-being, and emotional needs.'

'Maybe more emotional support. Cancer is one of the hardest diseases to live with'

'Isolation. Especially living alone, trying to deal with side effects, often effects from the treatment. No follow up nursing care at all being house bound. Depression, unable to move on in a positive way.'

Macmillan's vision is that everyone diagnosed with cancer in Wales should have the opportunity to access benefits advice and support at the point of diagnosis, and at key stages of their cancer journey, timely and appropriate advice can significantly reduce financial hardship, alleviate anxiety and stress, improve quality of life and help people make informed choices throughout their cancer journey.

The NAW Health and Social Care Committee Inquiry (October, 2014) recommends that non clinical needs should be taken into account routinely in **Recommendation 10** and that these are captured in written care plans in **Recommendation 9**.

5h. Communicating the diagnosis of cancer. The Wales CPES results show that 84% (n=6073) of patients felt that they were told that they had cancer sensitively.

‘Consultant very considerate and explained in a no nonsense way.’

‘The original time I was told I had terminal cancer and nothing could be done for me was handled very badly. There was no support at all and the doctor was in and out of the room in about 6 minutes. It was as if my life counted for nothing, as if I was being thrown away, sad to treat someone like that’.

Macmillan response:- Patients must feel confident they can approach staff, ask them questions and receive answers in ways they can easily understand. They want staff to support them to make informed choices about their treatment and care and to be encouraged to give feedback, which will be acted upon. Effective communication is essential and there is a clear need to improve the knowledge of health professionals and support them to communicate the diagnosis of cancer sensitively and compassionately.

5i. Follow up and transition points of care. The Wales CPES identified that only 59% of patients felt that they were ‘definitely’ given enough care and help from health and social services after leaving hospital. Whilst, nearly 1300 patients indicated that they were not certain what was happening to their cancer when asked whether their cancer had responded to treatment.

‘Follow-up care after surgery has been excellent, both nurses and consultant.

‘After care needs to improve in my opinion as far as I’m concerned with more information and given written care plans laid out for people and as for key worker every time I rang it was always an answer machine so I gave up.’

‘Follow up care has been mediocre.’

Macmillan response:- Patients want to experience a clear and seamless journey between the different places where they receive their care such as their GP practices, hospitals and cancer centres. They want to know who is taking over their care and who they should contact if they have questions or concerns. This will help reduce anxiety and uncertainty, enable appropriate support to be provided and support self management.

The NAW Health and Social Care Committee Inquiry (October, 2014) recommends that aftercare needs should be taken into account routinely in **Recommendation 10**.

6. Conclusion

Macmillan believes that across the NHS in Wales, patient experience should have the same importance as clinical care and patient safety in improving outcomes for people with cancer.

The Wales CPES and the National free text comments Report demonstrate that person-centred care is not routinely implemented and has yet to be embedded into cancer care in Wales. Person-centred care needs to be part of normal practice, it is not an optional extra, it is core to delivering safe and effective and high quality care. Putting patients at the heart of cancer care is the solution to the increasing numbers of people needing care and the financial challenges facing the NHS in Wales. The NAW Health and Social Care Committee Inquiry into the implementation of the Cancer Delivery Plan (October, 2014) strongly supports person-centred care in **Recommendation 9 and 10**.

These results are a noteworthy resource and provide compelling evidence to support the case for change in the area of cancer care in Wales and in particular:-

- supports the need for all patients with a cancer diagnosis to be allocated a key worker, receive a holistic needs assessment and written care plan and for GPs' to receive an end of treatment summary to support transition from secondary to primary care.
- highlights that non clinical needs should be routinely assessed, identified and supported throughout the clinical pathway and should cover work, finances, emotional support and information provision for family and friends.
- flags up the need to ensure that all patients receive / or are offered written information about their cancer which is easy to understand and should receive tailored information and support throughout their cancer journey.
- identifies the need to support GP education and an opportunity to integrate and develop new tools and processes within primary care across Wales.

The Wales CPES quantitative and qualitative data provides a rich and important source of evidence of patient experience during September 2012-March 2013. A repeat survey in 2015 is crucial in order to continue to highlight good practice, address areas of concern and measure improvements in cancer services in Wales.

We are extremely grateful to the 7,352 patients who took the time to complete this survey and for providing this valuable insight of their experience.

ⁱ Charmel P, Frampton S. Building the business case for patient-centered care. *Healthcare Financial Management*. 2008. 62(3): 80-5.

ⁱⁱ The King's Fund. *Leadership and engagement for improvement in the NHS*. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/leadership-for-engagement-improvement-nhs-final-review2012.pdf (accessed July 2013).