



May 2014

Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

1 Follow up evidence from Marie Curie Cancer Care

1.1 Marie Curie Cancer Care welcomes the opportunity to provide further evidence to the Health and Social Care Committee regarding their inquiry into the progress made so far on implementing the Welsh Government's Cancer Delivery Plan.

1.2 Marie Curie provides hospice and community-based care and support to terminally ill people, their families and their carers in Wales and the rest of the UK. In the last year, just under three-quarters of the people our nursing service supported in the communities of Wales (about 1,300) and just under 90% (over 400) in our hospice had a cancer diagnosis.

1.3 Our initial response to the committee's inquiry focused on its first point of reference, 'Whether Wales is on course to achieve the outcomes and performance measures, as set out in the Cancer Delivery Plan, by 2016'. We raised concerns regarding progress towards delivery on two specific outcomes in the Cancer Delivery Plan. These are:

Outcome 4 - People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer

Outcome 5 - People approaching the end of life feel well cared for and pain and symptom free

1.4 Here we will expand on the points made previously and also discuss the inquiry's second point of reference, 'Progress made in reducing the inequalities gap in cancer incidence and mortality rates', based upon NHS statistics recently made available to us regarding cancer mortalities in the year 2012.

2 Putting people with terminal cancer at the heart of care (Outcome 4)

2.1 Under Outcome 4 in its summary of outcomes, the Cancer Delivery Plan stipulates that people have 'their individual needs identified and met' and 'patients and carers are involved in the design of services and people's views on services are sought regularly and

acted on to ensure continuous improvement'. Section 6.5 of the Delivery Plan sets out that LHBs are to 'Support participation in cancer patient experience surveys, in particular the iWantGreatCare survey of palliative care patients and their families'.

2.2 Marie Curie believes that the current measures in place including the iWantGreatCare (iWGC) survey and use of patient concerns data is not sufficient to guarantee that the broad range of individual needs and views of people with cancer at the end of life across Wales can be identified and thus met. We have recently published a report, 'Listening to Dying People in Wales'¹, which explains why these measures alone and without refinement cannot go far enough (in line with the Welsh Government's 'Framework for Assuring Service User Experience'²) to ensure that service planning puts the needs and wishes of all people with terminal cancer at the heart of care.

2.3 Key messages from this report to note here include:

- 2.3.1 There are crucial points for analysis that are missed in iWGC data. For example, no information on the characteristics of the patient – such as their age, ethnic background, post code (by which the impact of socio-economic factors may be analysed using the Welsh Index of Multiple Deprivation) or type of cancer – is collected, and we know that all of these factors can influence the experience of care someone has at the end of life.
- 2.3.2 No information is collected on how well pain and symptoms were controlled in the final days of life.
- 2.3.3 The iWGC survey response rate is very low. Further to this, feedback is only collected from patients who are in receipt of care from a Specialist Palliative Care Team. Statistics show that less than half of those who died with cancer as the underlying cause in 2012 received any specialist palliative care. This means that over half of the people who died with cancer may not have had the opportunity to provide feedback on the care they received towards the end of life. For men who died from malignant neoplasms of the male genital organs (e.g. testicular cancer and prostate cancer) this figure is as low as 40%. Evidence also shows that the oldest patients are least likely to have received palliative care, therefore are least likely to have been asked for their thoughts on the care they did receive (see Appendix A for full information).
- 2.3.4 The feedback measures currently in place do not tell us about the coordination of end of life care services, such as how well the patient or patient's family felt the GP, District Nurse and Specialist Palliative Care Team worked together.

¹ 'Listening to Dying People in Wales' (April 2014), Marie Curie
<http://www.mariecurie.org.uk/Global/Policy/Listening-to-dying-people-in-Wales.pdf>

² 'Framework for Assuring Service User Experience' (April 2013), Welsh Government and NHS Wales
<http://www.wales.nhs.uk/sitesplus/documents/1064/Framework%20for%20Assuring%20Service%20User%20Experience%20-%20April%202013.pdf>

2.4 The ability to understand needs and plan services so that they meet the outcomes set out in the Cancer Delivery Plan for those with terminal cancer requires that we know as much as possible about the patient, family and carer experience at the end of life. In 'Listening to Dying People in Wales', Marie Curie makes a series of recommendations. These include clearer guidance on the use of concerns data by Health Boards, and the introduction of an annual bereavement survey similar to the VOICES (Views of Informal Carers – Experience Survey) survey that is carried out in England. Without expanding sources of data to include such measures, it is difficult to see how individual needs will be identified and therefore met for a significant proportion of the people who die from cancer each year.

3 Ensuring people approaching the end of life feel well cared for and pain and symptom free (Outcome 5)

3.1 The following outcomes are included under Outcome 5 of the Cancer Delivery Plan:

- 3.1.1 More people receive palliative and end of life care and support on a 24/7 basis
- 3.1.2 People whose symptoms have not improved after 48 hours are referred to specialist palliative care
- 3.1.3 Less people being admitted unnecessarily to hospital

3.2 As stated above, statistics show that over half of people in Wales who died from cancer in 2012 did not (according to their medical records) receive specialist palliative care (see Appendix A). 3.1.1 and 3.1.2 will therefore require continued significant efforts if they are to be achieved. The focus on ensuring people at the end of their lives are on a Palliative Care Register (a key outcome indicator measure included in the Welsh Government's End of life Care Delivery Plan) should significantly improve this outcome. However, we are starting from a low (but fast improving) baseline. In 2009/10 3,721 people were on the Palliative Care Register rising to 7,152 in 2012/13. On the basis of estimated need this could still be as low as 25% of all those with a need for specialist palliative care. Some caution is needed in respect of these figures as there does not at present appear to be a direct read across between being recorded as being on a palliative Care Register and receiving specialist palliative care.

3.3 Regarding 3.1.3, statistics show that, in their final year of life, the 8,673 people who died with cancer as the underlying cause in 2012 were admitted to hospital over 21,000 times (please see Appendix B, 1a and 1b). Almost two thirds of these admissions were emergency rather than elective. On average, a person who died of cancer in 2012 spent almost 23 emergency days in hospital in their final year of life. When elective bed days are taken into account, the average number of bed days in the final year exceeds a month.

3.4 An emergency admission to hospital can be incredibly stressful for a dying person, and may well be clinically unnecessary. It is also very costly, not just financially, but in terms of the impact on the terminally ill person and their family. When pain and symptoms can be controlled and it is in line with their wishes, terminally ill people should be supported in the community as much as possible. There must also be adequate services in place to make sure

that people who decide to remain at home are well cared for and pain and symptom free. Of the 46 Welsh GPs who responded to a recent survey commissioned by Marie Curie and Doctors.net.uk, only 40% felt that the majority of their patients being cared for at home in the final three months of life were completely free of pain all of the time. Less than a third felt that patients were able to get adequate access to care at night and weekends.

4 Progress made in reducing the inequalities gap in cancer incidence and mortality rates

4.1 The recent Public Health Wales Welsh Cancer Intelligence and Surveillance Unit's 'Cancer in Wales' report³ found variations in cancer mortality rates dependent upon age, type of cancer, area of deprivation and across Health Boards. Point 2.3.3 above shows that factors such as age and type of cancer also correspond to variations in the likelihood of being referred to or in receipt of specialist palliative care for terminal cancer patients (please see Appendix A).

4.2 According to the 'Cancer in Wales' report, cancer mortality is over 50% higher in the most deprived areas of Wales. Data from the NHS Wales Informatics Service suggests that the journey through care for people who are dying with cancer in their final year may look quite different depending on similar factors. For example:

4.2.1 Admissions - There are variations in the balance between emergency and elective admissions depending on levels of deprivation (see Appendix B, 2A), with patients from the most deprived groups tending to undergo a higher number of emergency admissions whilst those from the least deprived have more elective admissions. A similar trend exists for deaths caused by cancers of the digestive and respiratory organs, which continue to be two major causes of death in Wales (Appendix B, 2B and 2C).

4.2.2 Bed days - For all deaths with cancer as an underlying cause and for malignant neoplasms of digestive organs, the average number of emergency bed days in the final year also increases in the final year as levels of deprivation increase. For digestive cancers, the average number of bed days is over 20% more for those in the most deprived group than for the least deprived (Appendix B, 3A and 3B – note only a very small upwards trend is found for malignant neoplasms of respiratory and intrathoracic organs).

4.3 Finding the narrative which explains these trends is a very difficult process which must go further than quantitative analysis. However, one possible route to explore may be that people with terminal cancer from the least deprived groups are more likely to have plans and supports in place which better facilitate their care within the community. Further work needs to be carried out to determine why these inequalities exist to ensure that any unjustifiable variations which exist in cancer care at the end of life are remedied.

³ 'Cancer in Wales' (April 2014), Public Health Wales
<http://www.wcisuwales.nhs.uk/sitesplus/documents/1111/CANCERinWALESApril2014FINAL%28Eng%29.pdf>