Listening to dying people in Wales

The case for improved patient experience data in Wales

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1. Introduction

The planning and delivery of excellent healthcare greatly depends on the availability of a wide range of information. This includes general information such as size, age and distribution of populations. It also includes very specific information on the availability of skills to do specific things and the effectiveness of certain treatments for certain conditions and, increasingly, for certain people.

The information needed to plan and deliver excellent care however, must also include patient and carer experience.

All this information has to be collected in a way that enables meaningful analysis and allows the less good to learn from the best. It must also have a direct relevance to how healthcare and other support services are planned and delivered.

This evidence based and person centred approach is in line with the Welsh Government’s Minister for Health and Social Services’ vision of prudent healthcare for the future of health services in Wales. Central to this is ensuring that the patient is an active participant in planning and delivering their care.

- Those responsible for creating health policy need to know that their policies are having the desired impact and that the resources they provide are being used effectively.
- Those responsible for planning and delivering services need to know that they are doing so on the basis of sound information and that their services benchmark well with peers. They also need to be able to see what others are doing that is better.
- Those receiving care need to know that the people delivering that care are doing a good job. If care isn’t good they must be able to effectively feed their experience into the system.

We all need to know about the experiences of people at the end of their lives and about the care and support they received so that we can be reassured or able challenge organisations and people to change and improve.

Planning and delivering healthcare services for terminally ill people is very complex. They will be dying from a range of different illnesses requiring a wide range of different care. They will have personal wishes about where they wish to be cared for and where they wish to die. They will have many non-healthcare needs which impact on their wellbeing just as much as their healthcare does. This could be as seemingly mundane as who looks after the family pet or as overwhelming as who will provide for a family.

The Welsh Government published their End of Life Care Delivery Plan in 2013¹, and each Health Board has since been required to develop their own plans. The indicators in the government’s plan are currently being revised as many of those originally identified are not routinely collected. We hope that the new indicators will generate information that will be needed to inform services planning and delivery.

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It is also vital to gather the views and experiences of those who use end of life care services if we are to develop and deliver high quality, evidence based and person centred services for the dying in the future. The delivery plan identifies existing patient satisfaction surveys such as iWantGreatCare and patient concerns data regarding end of life care as key NHS performance measures in this respect.

Yet these measures alone and in their current format cannot give a detailed enough view of patient experience. The Welsh Government’s Framework for Assuring Service User Experience (2013) explicitly recognises this point. It recommends a four quadrant framework of patient feedback methods, using real time, retrospective and proactive/reactive surveys as well as balancing methods such as patient stories to provide assurance that patients are receiving great care.

At present, this framework is not being fully implemented for palliative and end of life care services. Equally the ability of the iWantGreatCare survey to capture the patient voice has been overstated.

Gathering retrospective feedback from those who experience end of life care is clearly a very sensitive issue. We therefore need to think of ways in which in-depth information which covers the whole of end of life care can be collected.

This can be done through a variety of methods. Some would be new to Wales such as a survey similar to the VOICES National Survey of the Bereaved undertaken in England. Others would be adaptations of current approaches followed in Wales.

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2 Framework for Assuring Service User Experience (April 2013), NHS Wales and Welsh Government
2. The iWantGreatCare survey

Following the recommendations of The Sugar Report (2008), the All Wales Palliative Care Implementation Board (now known as the End of Life Care Implementation Board) worked with an independent web based organisation, iWantGreatCare (iWGC), to establish a Wales-wide system for collecting patients’ views on the care they received from specialist palliative and hospice care services. The introduction of iWGC surveys in 2009 was the first real attempt to listen to terminally ill patients’ voices. It is considered a key part of the on-going assessment and evaluation to ensure service provision remains fit for purpose, and alongside the Dying Well Matters initiative has received funding from the Welsh Government³.

A copy of a iWGC survey form

The aim is to offer simple survey forms to all patients referred to specialist palliative care services. Patients are able to provide both quantitative and qualitative feedback. The forms are available in both Welsh and English. Returned forms are anonymised and independently analysed by iWGC⁴. All comments and patient stories collected are then distributed to the relevant provider on a monthly basis, along with a report which shows performance compared to peers and the national average. Feedback is monitored by the Welsh Government’s End of Life Care Implementation Board.

⁴ iWantGreatCare case study of All Wales Palliative Care Board available at http://iwgc.org/case-studies/
The iWantGreatCare approach to gathering patient experience does have the potential to deliver useful information and needs to be retained in some form. It does not, however, deliver all that is needed in terms of people’s experiences and certainly does not, of itself, provide the information that is needed to challenge services and in turn improve them.

**Benefits**

**Real time review**
The survey system allows patients and families to rate and review their care as they receive it, anonymously if they choose. iWGC then distribute monthly reports which give basic analysis and comparison of a provider’s performance in terms of quantitative scores and the feedback section as written by the patient, their carer or family member. This allows reported problems to be addressed quickly.

**Establishing the emotional experience of patients and carers**
The Marie Curie Palliative Care Research Centre (MCPCRC) in Cardiff carried out an analysis of the views collected via iWGC surveys in a report published in 2011, with a focus particularly on the ‘free text data’ written by patients and carers (i.e., the ‘Your Feedback’ section, image above). Detailed qualitative analysis of these responses highlighted the importance of the emotional experience of care, which in turn allows for a better understanding of what constitutes good care in the eyes of the patient.

**High scores validate investment in services**
Quantitative analysis shows that the patients who respond are generally very happy with the services provided which validates (however, see below) the continued investment in palliative and end of life care. The then Palliative Care Implementation Board’s report, Dying Well Matters⁵, states that ‘feedback has proved beneficial in validating the investment in services…’

**Popularity with staff**
The consistently high scores and positive feedback from the iWGC surveys are reported to boost the morale of the staff delivering services.

The iWantGreatCare survey does deliver some patient experience feedback. However, the information they provide is neither extensive nor representative enough to support meaningful service planning on the scale that is needed in Wales. The limitations of the survey must be fully recognised when seeking assurance that the views of individuals and families are heard.

**Limitations**

**Not representative of all dying people**
iWGC only provides feedback from people who receive palliative care services. By definition, they will have been identified as being at the end of life in order to be referred to palliative care services. There is no feedback from people who have not been identified as dying, or from those who have been identified but not referred to palliative care services.

**Who gets the survey?**
Though everyone who receives palliative care is supposed to receive a survey from each of the care environments there is no way of establishing what proportion actually receive a survey. As the survey is given out by individual care environments (e.g. hospital, community service or hospice) it is

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⁵ *Dying Well Matters*, Wales Palliative Care Implementation Board report (2008-2011)
impossible to establish whether someone has had the opportunity to give feedback on all aspects of their care.

**Scope of questions asked**
The survey asks ten questions which the patient or family member then rates on a scale of 0-10. Though the questions are designed to look at different aspects of care such as efficiency, timeliness, respect and involvement, the small number of questions means that it is not possible to cover all aspects of care. Key aspects of care are also missed out, e.g. nothing is asked about how effectively pain was relieved or medicines prescribed.

**Identifying patient characteristics**
Other than enabling someone to indicate whether they are a patient or family member completing the survey no information is sought to enable analysis by, for example, diagnosis, gender, ethnicity or age. There is significant evidence to suggest that these factors and others can impact on a patient’s experience of palliative and end of life care. The absence of this information means that we are unable to establish whether these factors are associated with the experience of care in Wales, which in turn hinders our ability to identify and address inequality, and adapt services to meet the needs of all dying people.

Without data on demographic characteristics, we are also unable to establish whether those responding to the survey are representative of the whole population of dying people in Wales in terms of age, gender, diagnosis, ethnicity and so on.

**Very low response rates**
Response rates for iWGC surveys are very low. The National Assembly for Wales’ Public Accounts Committee heard evidence in 2013 that some services had only had a few forms returned, whilst the highest return rate had been just under 10% of the patients.

Clinical staff caring for people at the end of their lives are very often working in highly emotionally charged environments. Explaining what the survey is about and how it can help support service improvement may, in many circumstances, get lost in this complex and sensitive care environment. Without further measures to gain higher volumes of feedback on palliative and end of life care services we are at risk of developing significant blind spots in relation to how these services are operating for different groups across the nation.

**Reporting the results**
No aggregate data appears to be publicly available. However, the Dying Well Matters report found that the average score across services was 9.6/10 in 2011. The MCPCRC 2011 report found that ‘this highly skewed data meant that finding areas that need improvement was difficult’ and two Local Health Boards have emphasised this point in their End of Life Care Delivery Plans.

“The low level of detail usually does not allow team to act on information to improve service”

Abertawe Bro Morgannwg UHB delivery plan

“Difficult to improve upon as scores are generally very high”

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6 Transcript from meeting of the Public Accounts Committee, Tuesday 10 December 2013
http://www.senedd.assemblywales.org/documents/s500001698/10%20December%202013.html?CT=2
Cwm Taf HB delivery plan

Although it is encouraging that small numbers of respondents are being very positive about the care they receive, it is impossible to use the results of the iWGC survey to plan service improvements based on the data when we do not know whether the respondents are representative of dying people across Wales.
3. Patient concern information

There is a further performance measure identified in the Welsh Governments End of life Care Delivery Plan; the number of concerns received about end of life care. Concerns (and complaints) data can provide Health Boards with valuable opportunities to review their services and learn lessons from what didn’t work in the past. However, further clarification as to what is meant by a concern or complaint regarding end of life care in particular and how this is to be monitored is required for this measure to be effective. Two Health Boards, Betsi Cadwaladr UHB and Cwm Taf HB, have raised this point in their local delivery plans.

"Risk to delivery: Not being informed of concerns regarding palliative care due to pathways of process"

Betsi Cadwaladr UHB delivery plan

"Further clarification is required from Welsh Government on the definition and data sources for some of the indicators, eg: … the definition of a concern or complaint regarding “end of life care”.

"Risks to delivery: Difficulty monitoring concerns unless they are specifically relating to the SPCT [Specialist Palliative Care Team]"

Cwm Taf HB delivery plan

It is important that patient concerns are collected in a structured way, that people know how they can raise concerns and to whom. Individual concerns must be addressed through the appropriate channels but they must also be used as an indicator of service issues. The Francis report into the problems at the Mid Staffordshire NHS Trust reinforces in no uncertain terms how important patient concerns are in scrutiny and service improvement.

Methods will need to be developed to enable Health Boards to theme concerns that are raised about end of life care and these methods should be included in the contracts and service level agreements that the NHS in Wales has with third sector providers of palliative and end of life care.

The information gathered from patient concerns should be included in reports to Health Boards and collated on an all Wales basis.
4. What a bereavement survey can deliver

There have now been two national bereavement surveys in England. They are known as the VOICES (Views of Informal Carers – Evaluation of Services) surveys. The first was in 2011 and the second in 2012. The surveys were undertaken by the Office of National Statistics and commissioned by NHS England.

The surveys were sent to a sample of people recording a death between 1\textsuperscript{st} November 2010 and 30\textsuperscript{th} June 2011 and between 1\textsuperscript{st} January 2012 and 30\textsuperscript{th} April 2012. Deaths were excluded where the causes of death were accidents, suicides and homicides as well as those where the place of death was recorded as ‘Elsewhere’. This includes places such as roads and parks, public places and work places.

In the first survey the sample size was 48,766 and in the second it was 49,207. The surveys achieved a consistently high response rate of 45.7\% (22,292 surveys returned) in the first survey and 46.0\% (22,635 surveys returned) in the second.

The survey was sent between 4 and 11 months after the death with a carefully and sensitively written letter which recognised that it might be a difficult time for the recipient and apologised for any distress caused by receiving the survey. A Freephone number was provided for the ONS Survey Enquiry Line which is open outside normal office time and staffed with people experienced in handling calls of a sensitive nature.

The recipient was invited to complete the survey or give it to someone who they feel is in a better position to complete the survey.

Above all this type of service can be sent to a representative sample of people who register a death, not just those who receive palliative care. The information returned therefore, gives us a full view of the experience of dying people, through the eyes of people close to them. It can tell us a lot about how many people are being reached by palliative care services, and what the experience of dying is like for those who do not access palliative care services.

The surveys asked questions in the following groups:

- Care at home
- Urgent care provided out of hours
- Who was contacted
- How good the care received was
- District and community nurses
- Care from a GP
- Care homes
- Last hospital admission
- Last hospice admission
- Experiences in last two days of life
- Circumstances surrounding the death

The surveys also asked for some information about the person completing the survey such as their relationship to the deceased, age group and ethnicity as well as asking similar questions about the deceased.

Space was provided in the surveys for respondents to write anything they wished about the care received by the deceased and whether they were happy for these comments to be shared with local care organisations.

The responses enable analysis which includes looking at:
• Coordination of care
• Dignity and respect
• Pain and symptom management
• Involvement in decisions about care
• Expressing a preference about place of death
• Preferred priorities: Respondent considered deceased died in their preferred place of death
• Support for carers in the last three months of life for those at home

It also allows analysis by certain characteristics of the deceased person and by their usual place of residence which can be linked to the Wales Index of Multiple Deprivation, based on the postcode of the usual place of residence of the deceased.

Examples of the analysis of the VOICES data by deprivation can be found in the following blog written by Marie Curie’s head of Analytics - http://blog.mariecurie.org.uk/2013/06/21/end-of-life-care-across-the-socio-economic-spectrum/

The VOICES surveys represent a significant leap forward in the understanding of patients and their families and carers’ experiences of end of life care in England. The results provide an opportunity for localities to measure their own performance individually and in comparison with others and to take action to address areas of weakness and to put in place measures to improve services.

The second survey conducted in 2012 cost £219,195. Working on the basis that costs would in general be pro rata to the numbers of people surveyed and responding this would suggest that the costs for a similar survey in Wales using a similar sized sample of deaths over a similar period would be in the region of £13,000. However, this cost could rise once the following were taken into account:

• Work to adapt the VOICES survey for use in Wales
• Increased number of people surveyed to generate statistically valid results on a Health Board by Health Board basis
• Production of the survey in Welsh and English

As more VOICES surveys are undertaken it will also enable analysis of trends.

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7 DH departmental spending over £25,000: data for January 2013, Department of Health
5. Why we need a bereavement survey in Wales

Person-centred healthcare must be informed by the voices of patients and their families. With the balance of benefits and limitations of the current measures laid out above in mind, there is a clear case for implementing new ways of securing robust information on experiences of palliative and end of life care in Wales.

Local Health Board End of Life Care Delivery Plans indicate that some progress is being made. For example, Cwm Taf Health Board's plan to design and undertake a carers' survey in 2014 represents a positive step forward and should enable the Health Board to collect valuable information about the care and support it provides.

The commitment to patient and families reference groups expressed in plans for almost all of the Health Boards should again be welcomed as these are a very good way to gather active service user views. To be at their most effective these groups should include patients of different ages, diagnoses and socio-cultural backgrounds.

To secure the breadth and depth of information needed to properly inform service planning and delivery there is a need in Wales for a regular survey similar to the VOICES survey. This, together with real-time information, patient concerns and facilitated feedback would:

- Provide a detailed insight into current end of life care
- Provide respondents with the opportunity to comment across all aspects of care in a way that can be effectively analysed
- Inform service change and improvement in the short, medium and long term
- Identify inequity in service
- Enable identification of best and poor practice
- Inform benchmarking
- Provide links to outcome and quality of care indicators
- Provide a rich mix of patient stories

As more people are placed on a palliative care register which is a key aim set out in the Welsh Government’s End of Life Care Delivery Plan, it will be possible to undertake properly representative surveys of people who are themselves receiving palliative and end of life care services. This will add a further and important dimension to the information that would be available to inform service planning and delivery.
6. Recommendations

As is made clear in the Welsh Government’s Framework for Assuring Service User Experience, no single method of gathering patient experience information can be effective on its own. This is no less true for palliative and end of life care than it is for other health and care services. If we are to develop high quality evidence based and patient centred services for terminally ill people in Wales we must have a variety of measures at our disposal:

- Real-time surveys
- Retrospective surveys, such as VOICES
- Proactive/reactive surveys, e.g. of the type used by NHS Basildon and Brentwood CCG and Thurrock CCG to assess the local communities’ views on what counts as excellent end of life care
- Balancing measures, such as patient stories and patient, family and carer groups

We are making the following recommendations:

1. Wales introduces an annual VOICES type survey, with the inaugural survey conducted early in 2015. It is important that the free text analysis is released at the same time as the quantitative analysis. The results can then feed into the Welsh Government’s next End of Life Care Delivery Plan.

2. A real-time survey should be retained; however, its structure and distribution needs to differ significantly from the current approach:
   - It should collect patient characteristics such as diagnosis, age, gender and ethnic origin
   - It should use a simpler scale which has each point clearly described for the questions asked
   - There should be greater encouragement to complete the survey to secure larger numbers of responses
   - A record should be kept of who has been given a real-time survey form

3. At the point when numbers of people across all disease groups on palliative care registers has reached a level where statistically valid data can be secured an annual ‘snapshot’ survey of people on palliative care registers is undertaken.

4. Patient concerns data should be utilised as a valuable tool for reviewing end of life care services by all Health Boards. The Welsh Government should give clear guidelines on the exact definition of a concern or complaint relating to end of life care in particular and advice on monitoring. This would insure standardisation across the Health Boards. Standardised processes of reporting, recording and theming this data should then be developed to allow for important benchmarking and comparisons to take place across Wales.

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8 See website for more information: http://www.basildonandbrentwoodccg.nhs.uk/news/124-end-of-life-care
9 The current End of Life Care Delivery Plan runs to 2016
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