

Chronic Conditions Management Demonstrators Evaluation Report

Proposed Introduction of Cancer Key Worker Role; a Qualitative Scoping Study of Cancer Staff in Cardiff

December 2010

Prepared by:
Opinion Research Services
The Strand, Swansea

Contents

Contents.....	2
Glossary and List of Abbreviations.....	3
Executive Summary	4
Introduction.....	7
Results	9
Awareness, Understanding and Interpreting the Initiative.....	9
Views on the Introduction of the Initiative	10
Current Practice	12
Identifying the Key Worker.....	15
Patient Journey.....	19
Patient Expectations	21
Challenges and Fears.....	24
Summary and Key Learning	26
References	28

Contact for further information

Ruth Jordan
Cardiff CCM Demonstrator Lead,
Ruth.Jordan@wales.nhs.uk
029 20742262

Sian Morrison-Rees
CCM Demonstrator Principal Researcher
Sian.Morrison-rees@wales.nhs.uk
01443 233516

Glossary and List of Abbreviations

Glossary

Cancer key worker: A key worker/navigator is important for patients to be able to refer to when needed. The key worker may change over time and as a patient moves from hospital based care and follow up to home or community based care. The choice of key worker will depend on each patient's needs. For patients undergoing initial or follow up treatment the cancer site MDT are best placed to agree the key worker. For cancer patients also having to deal with other diseases the GP/primary care team may well be the most appropriate to co-ordinate care. For those at the end of life a member of the palliative care team may be the most appropriate key worker.

Cancer Site: Refers to a type of cancer (e.g. breast) rather than a particular place or hospital.

Abbreviations

AHP	Allied Health Professional - professions that include Dietetics; Speech and Language Therapy; Physiotherapy; Occupational Therapy
CCM	Chronic Conditions Management
CCMD	Chronic Conditions Management Demonstrators
CSN	Cancer Specialist Nurse
MDT	Multi-Disciplinary Team
SLT	Speech and Language Therapists
WAG	Welsh Assembly Government

Executive Summary

An emphasis of the National Standards for the Rehabilitation of adults is that cancer is now to be classified as a chronic life threatening disease as opposed to a terminal illness, survivorship is now of greater importance in everyday life with the rates of survival increasing, currently estimated at 46%. This needs to be addressed and the challenge is to make the shift of care to managing cancer as a condition and leading as healthy a life as possible. One of the main priorities in the cancer rehabilitation standards is the development of a key worker for individual patients diagnosed with cancer.

In line with current policy and strategic developments, the cancer key worker initiative seeks to ensure that all patients living with cancer:

'could be allocated a 'key worker/navigator' to ensure more appropriate timely collaboration between primary care, secondary care, tertiary care and the voluntary/third sector throughout the cancer continuum. These key workers could develop and maintain patient navigation systems/care management plans that could facilitate optimum care for cancer survivors'

The cancer key worker role would involve¹:

- Orchestrating assessments to ensure patients' needs are elicited
- Ensuring care plans have been agreed with patients
- Ensuring findings from assessments and care plans are communicated to others involved in a patient's care
- Ensuring patients know who to contact when help or advice is needed, whether the 'key worker' or other appropriate personnel
- Managing transitions of care.

Recognising cancer as a chronic condition, the CCM demonstrators have conducted studies in order to assist the development of the role/functions of cancer key workers through investigative work at each of the three Demonstrator Project sites to inform the wider implementation of the cancer key worker in 2011.

Each of the three Demonstrator sites have investigated a different aspect of the cancer key worker role, with Carmarthenshire CCM demonstrator testing the fit of the 'cancer key worker' in the emerging Community Resource Teams (CRTs) and North Wales testing the role of the cancer key worker with the third sector, a more detailed description is available in CCM Demonstrator Evaluation Paper 6 - October 2010: The Cancer Key Worker Role: Advanced Learning (www.ccmdemonstrators.com)

The Cardiff CCM demonstrator has linked with the South East Wales Cancer Network, and the Cardiff cancer teams to develop a scoping study investigating the role/function of a cancer key worker. The focus is on:

- expanding the understanding of the role of the cancer key worker
- exploring the extent to which this function is already being carried out
- identifying the challenges faced to meet patients' needs

¹ Paul Williams Letter/Guidance, 2010.

This study will allow lessons to be learnt and shared with the NHS ahead of full implementation of the initiative for all cancer patients by the end of March 2011.

Methodology

ORS (Opinion Research Services) were commissioned to collect and analyse the views of NHS staff within Cardiff and Vale on the cancer key worker initiative. Through collaboration with the South East Wales Cancer Network and Cardiff cancer teams an interview schedule was designed to focus on:

- *Awareness of the cancer key worker development work*
- *Extent to which cancer key worker role/function is currently provided, and by whom*
- *What the cancer key worker does/should encompass*
- *What the patient might hope/expect/require from the role*
- *Patient handovers – how key worker responsibility should be managed*
- *Challenges of delivering a cancer key worker role*

ORS conducted the in-depth, semi-structured telephone interviews with 28 cancer related staff in September and October 2010. Participants included relevant senior managers, cancer leads, clinical nurse specialists, Allied Health Professionals and 'other' clinicians.

Findings

Overall, there is awareness of the initiative, particularly amongst Senior Managers and Cancer Leads. That said, there is a general lack of understanding about the initiative and what the key worker role entails.

In general, most healthcare professionals view the initiative as much needed and timely and one that will have a positive effect on the patient journey. Those health care professionals who are less positive feel that it will not alter the current situation whereby those who require support most do not access it.

Many patients are supported through their cancer journey by a key worker or someone they can contact. Some cancer sites already have a key worker system in place which reportedly works well. In areas where such a system is used it is typically not formalised, not written down and takes the form of a team approach rather than a named individual. There are some models of good practice in other clinical areas. It will be difficult to implement the initiative at some cancer sites as many will not have CSN staff and the patient journey will be short in comparison to others.

Many interviewees (particularly CSNs and AHPs) feel they are currently carrying out the role of a key worker. Although guidance suggests that the appropriate person is not necessarily the CSN, most of those interviewed feel that CSN, AHPs (including SLTs), are best placed and therefore most suited to become key workers. Indeed, there is a willingness amongst those CSNs and AHPs to become a key worker. Interviewees also identified those who would not be suitable: these included cancer leads, consultants, doctors and senior managers.

In most cases the patient journey is identified in the initial MDT meeting. The initial key worker is easily identifiable and is usually a CSN. However, referring on after treatment is not so clearly defined. For many patients the journey will continue if there is a chance of relapse and the key worker will remain a health care professional within the cancer site.

Many interviewees argued that a key worker within the community would be helpful after treatment has come to an end. However, it was argued that in order for them to do so they would need to have a contact list of those in the geographical area that would be willing to become a key worker. There was a concern about how this could be monitored.

The patient will expect and require: information via signposting; a named contact; and time. Not every patient will want or need to keep in touch with their key worker. However, having a named contact will provide reassurance to the patient.

The main challenges noted by interviewees included: resources and time; infrastructure; support and recognition; the problems associated with different cancer sites and changing what already works.

Key Learning

The function of the key worker system is already being practiced in many of the cancer sites, although not formalised in many areas, and consequently the new cancer key worker initiative should support and enhance areas of good practice. The initiative should aim to build on, rather than change, what is currently being practiced by staff in order to capture the willingness and enthusiasm of those currently fulfilling the role.

More information about the initiative should be made available to those who are most likely will become a key worker. The role needs to be clearly defined in order that people understand what it involves. It does however need to retain a degree of flexibility, and due to the differences between the needs of patients on differing cancer pathways.

Time is also a crucial factor. Managers must understand that key workers will need to dedicate time to this role in order for it to be fulfilled to a high standard. In particular, if it is an addition to their existing role, this must be recognised and time allotted accordingly.

An individual cancer site assessment needs to be completed for each area, to ensure that the individual needs of the patients are going to be adequately met and additionally to ensure that those without current capability to fulfil the role are provided with the requisite support.

Cancer Care Standards, which state that cancer patients should continue to be followed-up for five years was clearly familiar to staff as was the pathway of care. The patient journey was, however, more complicated and less clear when discussing the end of secondary care and referral back into the community. This is an area that will require further evaluation and attention during the implementation.

Introduction

The Policy background

The provision of high quality cancer care is a top priority for the Welsh Assembly Government, from prevention through to rehabilitation and palliative care. The Cancer Services Co-ordinating Group (CSCG) cites widespread support during the consultation phase for cancer key worker.

The population of Wales is ageing and the prevalence of cancer is therefore increasing as cancer is predominantly a disease affecting the older population. Additionally, earlier diagnosis and more effective treatments have resulted in more people living with their cancer. As a result, cancer is classified as a chronic life threatening illness rather than a terminal disease².

Cancer survival continues to improve in Wales, with overall survival rates increasing from 24% 30 years ago to the current level of 46%. By the end of 2006 a total of 116,086 people that had been diagnosed with cancer in the previous twenty years, were either cured or living with their cancer. This gives a prevalence rate of 3,914 per 100,000 people in Wales and accounts for 3.9% of the population.³

The Health and Social Services Committee undertook a review of cancer services in Wales in 2007 and amongst its recommendations highlighted the need for the development of cancer rehabilitation standards.

All cancer patients will have rehabilitative needs throughout their care pathway. These standards will need to inform the development of site specific rehabilitation pathways which are integral to all services. Cancer rehabilitation can be defined as a process that assists the person with cancer to obtain maximum physical, social, psychological, and vocational functioning within the limits created by the disease and its resulting treatment.

The Cancer Services Co-ordinating Group (CSCG) was tasked with developing these Standards. One of the main priorities in the cancer rehabilitation standards is the development of a key worker for individual patients diagnosed with cancer.

Each patient diagnosed with cancer should have a nominated key worker to coordinate their care for the duration of their treatment in hospital and in primary care through their GP, in recognition that people living with cancer have on-going needs following the end of their main treatment.

The key worker for each patient will be the most appropriate NHS worker, depending on where the patient is in their cancer treatment. The patient will know who to contact at all times should the need arise. Although the standards are aimed at adults, this will also be a requirement for paediatric cancer patients.

In April 2010, the minister for Health and Social Services agreed the publication of the cancer key worker. Each Local Health Board should have this in place by the end of March 2011:

I see the development of a key worker role as central to improving care as many cancer patients feel that once they have finished their main treatment,

² World Health Organisation (2006) *Disability and Rehabilitation action plan 2006-2011*

³ Welsh Cancer Intelligence and Surveillance Unit, Velindre NHS Trust, Cardiff (2008) *Cancer in Wales, 1992-2006: A Comprehensive Report*.

whether that is an operation, radiotherapy or chemotherapy, that they are abandoned. This will no longer be the case⁴

In order to aid implementation, from April 2010 the three Chronic Conditions Demonstrator sites will allow for lessons to be learnt and to be shared with the NHS ahead of full implementation for all cancer patients by the end of March 2011.

Methodology

The CCM Demonstrator National Team and the Cardiff CCM Demonstrator Lead in collaboration with the South East Wales Cancer Network and Cardiff Cancer teams discussed and designed a questionnaire/topic guide to focus on:

- Awareness, understanding and interpreting the initiative
- Views on the introduction of the initiative
- Current practice
- Identifying the key worker
- Patient journey
- Patient expectations
- Challenges and fears.

ORS (an independent social research company) were commissioned by the CCM Demonstrator programme to conduct and analyse the interviews.

The interviews were semi-structured (using a topic guide) to ensure the key questions were addressed whilst also enabling respondents to bring their own suggestions, concerns and recommendations to the research. Interviews lasted between ten and thirty minutes depending on the interviewee's knowledge of the issues and the amount of time they had available. Clear themes emerged and therefore thematic reporting best reflects the outcomes of the interviews.

Participants:

28 interviews were undertaken. Seven Cancer Leads, ten Allied Health Professionals (including two managers), four Cancer Nurse Specialists, four 'other' clinicians and three senior managers were interviewed. They all had experience of working with cancer.

⁴ <http://www.wales.nhs.uk/news/16314>

Results

Awareness, Understanding and Interpreting the Initiative

Overall, there was awareness of the Cancer key worker Initiative amongst health care professionals. However, this awareness varied across the different types of staff, with many interviewees requesting additional information (including a definition of a cancer key worker in the preliminary stage of the interview). In addition, even for those who were aware of it, there was a recognised lack of understanding of the initiative and, in particular, the definition of a key worker. Some interviewees found it difficult to pass comment when the definition of the role is currently so vague. Due to the apparent lack of definition, interviewees offered their own interpretation of what they feel the role will involve.

Findings:

Due to their attendance at Cancer Leads meetings and reading paperwork from WAG and the CCM Demonstrators Steering Group, Cancer Leads and Senior Managers tended to be more aware of the initiative than others:

I have read the various paperwork and documentation and I discussed it in a Cancer Leads meeting four weeks ago

I am aware of it. I know it crops up at the Cancer Leads meetings

Those (such as CSN and AHPS) who are more likely to become a Cancer key worker under the current guidance are less likely to be aware of the initiative:

I am not aware of it. I have spoken to people and they think it is from the trust

No I had no information prior to the interview. I am not sure what is going on

Others found it very difficult to discuss the role as they felt it is currently too vague:

I haven't seen a job description because there is no job description. It is just a role onto another job that someone is already doing. Is a health professional going to have 200 people they are supposed to be key worker for, will they know all about those people and are they going to be proactive and contact them so clearly nobody has got time to do that within their current role

Those who felt the definition is too vague offered a number of interpretations as to how the initiative should work or what they felt the role should encompass:

There are two ways of doing it. One where we have an electronic system where a patient coming through the door will be registered and everything that happens to them is recorded along the patient pathway. A single person can sit at the desk and monitor patients as they pass through the pathway

There is a little bit of vagueness, I would rather one person managing IT and take care of the patient pathway. That would be my suggestion. The hands on could be too difficult. If it is a two way approach it lends itself to the switchboard which is manned and can provide timely advice to the patient,

they can inform the patient where they are in the pathway and can change an appointment for them if they need to. I have seen a model like this in Brussels in a cancer unit, I was taken to where they start the tracking process, to a person behind a screen and so the patient always knows where they are along the pathway. It makes a huge difference. They don't need to worry about doing it a piecemeal way

Conclusions:

- There is a lack of awareness of the cancer key worker Initiative, particularly amongst:
 - Cancer Nurse Specialists
 - Professions Allied to Medicine
- These professionals are likely to be affected by the introduction of the cancer key worker initiative.
- The definition of the role is currently vague, undetermined and lacks fine detail.

Views on the Introduction of the Initiative

All interviewees, either as a result of prior knowledge or through a definition and explanation at time of interview, formed an overall opinion of the initiative. These opinions can be separated into those who welcome the initiative and feel it will have a positive effect on the patient journey, and those who feel it is an unnecessary and unhelpful intervention.

Findings:

For those who view the initiative positively, the introduction of a key worker role is long awaited, much needed and an essential part of a patient's journey. They argued that the initiative will ultimately benefit the patient by providing continuity of care through a named contact at a very emotional, stressful and complicated time. Importantly, for some it is an opportunity to build a bridge between the primary, secondary and tertiary care sectors through which the patient will travel:

It is a very emotional, stressful time. Information they are given they may not remember two years down the line. They are left alone at the end of it. It varies according to the journey of the patient

I think it is essential to have a named contact that could change depending on the patient's journey. Some patients are hesitant about talking about medical conditions

It is a good ideahaving somebody to contact once they are discharged

If someone is appointed as a key worker the patient gets better treatment. It should work for the patient, depending upon the key worker. They need to take an overall look at the patient and decide what is best, not be biased in one area or the other and decide what the patient is or isn't getting

It is a positive thing. It is useful to have a named contact that they can ring and call. Lots of patients know my face and it is good to have continuity rather

than explain things over and over again. They feel like nobody understands them

It is a very good idea for continuity of care. There is a natural tendency for the chain to be broken down. So many cases of losing track of them

It is a fabulous idea for the patients. It is a complicated journey

Personally and professionally it is an excellent initiative. Patients who have cancer really need somebody they can turn to. People really need somebody that will do that

It is a long needed initiative. They would look at the qualitative path way of the patient's care. It is unsure as to what is hit and miss at the moment. This forces the LHB to ensure that patients have this in place by March 2011

It is quite important for the patient. I used to work as a district nurse and we used the key worker role. It could be a supporting and signposting role

Some interviewees discussed how their cancer site is currently in the process of considering methods to improve the patient journey and saw the key worker as an effective solution:

Overall I think it is a good move. We have all been thinking of this. When cancer is diagnosed until they have been treated they have hospital contact and a lot of input into their needs. There is a huge support system. Once finished they are in follow-up mode. They have contact with a breast care nurse but only on a SOS basis

We have been talking about this before it has come out. Under the NICE guidelines there should be an identifiable key person to coordinate and decide with the patient on a formal care plan. Written documentation which will outline the pathway. This will be in the patients hands and will go to the next key worker. At the moment it is done by word of mouth

A few interviewees were less supportive of the key worker initiative. One interviewee argued that the initiative will not help those who need it and another felt that the current system should not be replaced. One interviewee suggested that the initiative is merely a 'gimmick':

I don't think people who struggle would be the ones who benefit. A lot of the people I see have nothing but praise for their cancer nurses and those are the ones that have pushed or made the effort to seek help and would have done so if they did not have a Cancer key worker the people I see would have benefitted because they would have pushed regardless. It is the disenfranchised and the poor, unemployed, uneducated and non-English speakers; those people who won't know how to get help and won't know where to go to get help. They won't search on the internet, they won't know that they should have a cancer key worker and it will just be another piece of paper which will go in the bin. These are the people, I feel, who will continue to be unsupported

There should be no need for a key worker. It should be the GP or the MDT

I am slightly sceptical. Anything that improves the service I am in favour of. The patient experience is very important. I am behind that if it is the case but I think it is just a gimmick and I don't think it can work.

Conclusions:

- Most health care professionals view the initiative as much needed and timely and one that will have a positive effect on the patient journey
- Those healthcare professionals who are less positive feel that the initiative will not alter the current situation whereby those who require support most do not access it.

Current Practice

Most healthcare professionals discussed how the initiative fits with current practice. There were two main issues reported in this area; firstly there are areas which already have a key worker type role in place; and secondly there are cancer sites where no similar initiative currently operates and where there are perceived difficulties in implementing such a system in future.

Findings:

A number of those interviewed work in cancer sites where, they argued, the key worker approach to the patient journey already exists. For instance:

We may not have it written down on a piece of paper but we could do that pretty quickly. We function very well as a department and it is clear when the patient starts treatment. It is pretty clear

Below are examples of cancer sites where the key worker system is already being practised.

Urology

In Urology, Cancer Leads, CSN staff and others argued that a key worker is already integral to the patient journey. Interviewees highlighted the CSN as the current key worker. However, they argued that whilst an individual usually becomes the key worker, this is supported by a team effort:

In Urology we are currently able to provide a key worker. We have an innovative structure and we have a number of nurses employed in a team and we have four nurses that can be described as key workers. One individual is named but we have a team approach which acts as a rapid approach. It is a model of good practice which we have been able to implement from different sources of investment. There are not many areas which have that type of infrastructure

We already do it. We have answerphones and beepers. We try to get back to them. We contact. We speak to relatives. We deal with all sorts of things, what will happen next, we organise appointments. We try and stay with them along the pathway

We have two MDTs for that. We have an excellent CSN team and cancer team. They are not named as a key worker. The advantage is there is a

group of four. In general we get them to see the same person but it is useful if anyone is on sick or on leave. The CSN's are the core of the MDT, they have a good knowledge base and they see them all through the process. They are more available than the consultant

Haematology

The key worker system is also being practiced in Haematology. Interviewees argued that since treatment does not necessarily come to an end as the chance of relapse is high, the cancer site is always accessible to the patient and thus there is no real handover of care. The cancer site then continues to be a key point of contact:

I have to say in Haematology it won't make that big a difference because we already do it. We already have people who fulfil the role of what a cancer key worker is so I have been looking at the changes that we would have to make and I don't think it is that much. On the whole this might not be the same for other tumour sites that aren't as well staffed as we are. It is important that the patient has a key point of contact and an advocate they can turn to when they need to find out what is happening or they have a concern

There are good examples of this within Haematology where patients will come back and forth and they have got good information systems there

We don't discharge many people in Haematology because the acute conditions like leukaemia unfortunately have a significant chance of relapsing

Head and Neck Cancer

Those interviewees involved in the treatment of head and neck cancer discussed the informal use of a key worker as part of their current practice. They described how patients are given an information sheet at the start of their treatment which contains contact details of their CSN, who is thought of as the key worker. Most interviewees also discussed how, after treatment, they remain a key worker as they very rarely discharge a patient who continues to need help:

We have an information sheet, it tells you who to contact. I tell patients at every review meeting. If they want me, a message will be passed onto me. It would work if they named me

It is already being done...it is not actually written down. Although we don't specify any particular person and that is a good idea. Most patients do get follow up care currently

They need lifelong good dental care and I see patients every three to four months after treatment as finished. I know after five years they are discharged but I rarely stop seeing someone. These people need specialist oral care and as a result of their treatment they may not be still with a community dentist

We have a MDT and we already provide it through our CSN who follows each patient through. The patient knows who we are. The CSN is the key worker. They coordinate the pathway and follow them through the pathway. They

build up a rapport with the patients and we communicate effectively with each other

Although most interviewees argued that having a named contact would not affect the success of their current system, one interviewee felt that having one named contact would be too rigid and would not benefit from team support:

The key worker could have a negative effect on the team work. How would they know how to choose the key worker?

It is sort of going against what we do because we work as a team and it doesn't come down to one person. I think it might restrict the open access that they have to us all. Some people may prefer to see one person but we have worked hard to get a good multi-disciplinary team

Paediatrics

Those involved in paediatrics described how they currently use their own outreach nurses as key workers when patients finish treatment and are discharged into the local community:

In Paediatrics we have nurses who are key workers

Paediatric outreach nurses. They pick up patients once they have been discharged. They are managed by a lead nurse and they are locally managed. Patients have a contact number and they have their mobile number. When they are inpatients are managed by the nurses on the ward. We have a psycho social team which supports the key worker. I wouldn't regard those as key workers as they need to have an understanding of the condition. Unless they had a purely social problem their role would be purely supportive

A CSN involved in breast care and a number of Physiotherapists also argued that the patient journey is currently supported by a key worker:

Breast Care

We are privileged. We have always had a cancer key worker. When they are diagnosed they have an allocated nurse from biopsy, same nurse who is there when they get the result, it is the same nurse who discusses the treatment with the family, the same nurse that sees them on the ward to when then get back home in the community. We just called it an Allocated Specialist Nurse. It is different. We don't know who that person will be

Physiotherapy

It links in well with what we do already. We link in with the family and are the link to the questions they want answered. The patients see us as very holistic and patient focused and we have time to build up a rapport whereas the nurses don't have the time to do that. I link into the palliative care team so I have a lot of access to information including their care package and what agencies can be involved in supporting them

Other clinical areas and models of good practice

Others identified clinical areas such as Cardiac and Stroke Rehabilitation where a key worker approach is used:

Cardiac is so well structured, it is possible to do this and cancer is also a major illness. It is a completely fluid system. There are four phases: intervention; immediate recovery; outpatient rehabilitation of 6-8 weeks; and community based (leisure centre) instructors and access to a nurse. If this structure was used to treat cancer it would be easier to put in place a cancer key worker approach because there are defined stages

I have worked in stroke and neuron rehab before where they have had the key worker role. If you have got the right person it works well

Different cancer sites

A smaller number of interviewees identified different scenarios and cancer sites where it is less conceivable that the initiative could operate without major difficulties. The main problem involves a lack of CSN staff and capacity to cope with the volume of patients:

I don't know if Velindre has the infrastructure to support a key worker considering the large volume of cancer patients they have to cover. This could be the same with the smaller cancer sites like Thyroid. In some areas good models exist. Our CSN covers clinical care but in other areas different types of key workers will be needed. For instance palliative care will support rather than clinical care

I doubt that all cancer sites and specialities would be able to do this.

Many comparisons were made between one cancer site and another. One cancer lead discussed how a key worker approach would be easy to introduce for a patient who has, say, acute leukaemia. The patient will receive intensive treatment, will get to know the people involved in their care very well and will receive follow-up care. The participant argued that this is very different for other patients who have a different type of cancer:

A lot of cancers are less intensive and [there is] less chance of recurrence. In these instances they will be referred back to primary care and this is a very different situation and I think in that setting, for the cancer nurse to remain the key worker for thousands of patients that pass through, that is probably the wrong way of doing it

Conclusions:

- Many patients are currently supported through their cancer journey by a key worker or someone they can contact.
- Some cancer sites already have a key worker system in place which works well.
- In areas where such a system is used it is not formalised, not written down and takes the form of a team approach rather than a named individual.
- There are some models of good practice in other clinical areas.
- It will be difficult to implement the initiative in some cancer sites.

Identifying the Key Worker

As discussed previously, many interviewees felt that the key worker initiative reflects current practice within their cancer site. As a result many felt that they are currently fulfilling the role of a key worker.

Interviewees discussed who could, ideally, become a key worker. Many (including CSNs) suggested that a CSN could fulfil the role alongside other members of the MDT. Some felt that the role can only be fulfilled by a person who has a medical background, knowledge of the disease and the care pathways involved. Others suggested that as long as the person knows who to signpost to, it 'could be anyone' with interpersonal skills.

Cancer Leads, Senior Managers and 'other' clinicians felt that they are not in the best position to fulfil the key worker role.

Findings:

Current key workers

Most of the CSNs and AHPs interviewed felt that they are currently fulfilling the role of a key worker and described how they do this:

CSN

Our office is based in the outpatients department so we are right at the heart of things and most of our patients are referred to us as early suspected referrals before the doctor even sees them. We see a lot of the urgent suspected cases. We have already made contact with the patients. When the patient is diagnosed with cancer they may come to us for the diagnosis

A specialist nurse in any discipline - she is the key communicator and in the prime position...It has to be someone with good communication skills or can manage the care for that patient and more importantly someone they gel with, but nurses may answer that can only be possible if there were more of us

AHPS

I am a key worker. We work holistically, sharing information and working alongside the Cancer Specialist Nurse, Dietician and Speech and Language Therapists. Naturally you get one person who acts as a key person: more often than not it is usually the Cancer Nurse Specialist. If someone asked me who the current key worker is I would say our Cancer Specialist Nurse. If I don't know something about a patient I will ask her because she does both sites, including Velindre. I know she knows what is going on. We communicate very well and I feel that from the patient point of view they can contact us and we can find out what is going on. For oral care I am a key worker. I am involved in patient oral care and I follow the patient through from diagnosis to the ward to Velindre and they still have contact with me through follow-up at outpatients dental treatment. I am there throughout the treatment as are the other key members of the team who they can contact. I would follow these people up in outpatients. Prevention of any further dental problems. All the patients who come through the MDT who haven't got dental services outside. The problems don't go away after radiotherapy. These people need specialist oral care and as a result of their treatment they may not be still with a community dentist

For a lot of patients I have a key worker role. I meet with the family and I have a key role and arrange any equipment that is required. I coordinate the discharge planning meeting, getting everyone together who is involved

Ideal key workers

The majority of interviewees cited the CSN as the 'ideal' key worker. It was argued that CSN staffs have the necessary skills and placement within the patient journey to fulfil the role:

We rely on the CSN as a key worker. They will say to me 'someone has a problem over there' and we will arrange an appointment to see us

A CSN is and would be the cancer key worker. They coordinate, liaise with other professionals and with the patient and they keep tabs on the patient. 70% of the patients come from outside Cardiff and Vale. The CSN liaises with GPs, other specialities and other hospitals

The CSN discuss it at their MDT. She is the key worker and will control all the way along.

CSN... they have a lot of empathy

The CSN does take a key role, especially in the initial stages

The person we have who fits closest to the role are the four Specialist Nurses. I know the documentation states that the responsibility changes through the treatment and I think this is pretty simple for us. The main Specialist Nurse would be the ideal key worker for the patient all the way through

Although most identified the CSN as the most suitable key worker, some participants also thought the role could be undertaken by a variety of other health care professionals:

In the community it could be an allied healthcare professional like a Physio or a Social Worker

A Physio could be key worker. Nursing staff know the system. A Dietician knows all about energy levels. District Nurses are involved in wound management and looking after drains

People traditionally think that the caseworker should be a nurse. It doesn't have to be a Specialist Nurse. It could be a Therapist. It could be any health care professional, nurse or social care. It is the person most appropriate for the patient to meet their needs and this can change over time

Limitations

Other interviewees identified limitations on who can fulfil the key worker role and attempted to identify certain characteristics that a key worker should have. Some argued that they must have a medical background, a working knowledge of the disease and a certain level of experience and skill:

I don't know how it can be somebody who isn't familiar with cancer. They would almost be as much in the dark as the patients

The issue is the skill mix. If you have more junior staff, they need a scope of knowledge and experience to be able to fulfil the role adequately. They have got to have a good understanding of issues that you are dealing with. I don't just mean the medical interventions but it is broader and includes the voluntary services, social care, all that sort of stuff that I wouldn't have a clue on. This would very much come under a cancer key worker role; I don't think we have the resources or the up to date knowledge to provide to patients and families

It will have to be somebody with the relevant amount of experience, knowledge and skills. They will need to know who to contact and to understand what their needs are

I don't think it could be a healthcare support worker. I don't think they would have the depth of knowledge and experience and skills. Their amount of knowledge would not be enough. The patient will have expectation that their key worker will be somebody who will be senior enough to have that information or will know where to get it

A person has the background of the pathologist for the knowledge base. If it involves interaction, if the patient is going to call you up to give advice, you would need a CSN. I noted that was the favourable person, but they would have to have good training about the whole of the cancer process. They would have to be an empathetic person. It couldn't be a clinician. You need an observer level person who is trained in pathology of diseases and cancer in particular and knowledge of cancer treatment and complications. It is hands on versus the knowledge base and the tracking issue

It depends on the qualifications of that person, like a breast care nurse. Community nurses don't have the experience of breast care nurses. It is trying to find the person and finance them and the appropriate person who has a degree of medical qualifications

A few participants also identified healthcare professionals that could not and should not become key workers:

Not nurses on the ward, they work shifts, and not consultants

(Senior Manager) I don't have clinical input so I am not a key worker

Not a Clinician or a Doctor. They are renowned for having bad patient skills and the patient associates them with the one who gave them bad news. They would probably delegate it anyway

(Lead) Due to the nature of my position I cannot be a key worker as I am not at the end of the phone. The breast care nurses all have mobile phones

which patients can contact, and answerphones where they can call back within 24 hours

Conclusions:

- Interviewees, particularly CSNs, and AHPs feel they are currently carrying out a key worker role.
- Interviewees argue that CSN, AHPs (including SLTs), are best placed and therefore most suited to becoming key workers.
- There is a willingness amongst CSNs and AHPs to become key workers.
- Interviewees identified those who would not be suitable. All Cancer Leads argued that they could not fulfil the role of key worker.

Patient Journey

The current system for referral (and hence the patient journey) was clear to most interviewees as they discussed the beginning and end of their involvement. Many felt that identifying an appropriate key worker at the start of the patient journey would be relatively easy.

A significant proportion of interviewees discussed the end of the treatment phase, whereby they feel the patient is still, informally, in their care. They argued that a formal key worker handover could be detrimental to the patient.

Interviewees also raised the issue of whether the key worker should change. A number of interviewees felt that he or she should change - but discussed the difficulties associated with this.

Findings:

Most interviewees discussed how the beginning of the clinical pathway is easily identifiable, with a clear role for the MDT and the CSN. With the exception of cancer sites that do not have CSN staff, it was agreed that a key worker could be identified within the initial MDT meeting. It was suggested that a care pathway can be mapped out at this stage, and it is thus easy to identify key workers at the beginning of the patient journey:

The beginning of the pathway is easy, it is when diagnosis starts

They are referred by the GP and come to the diagnostic clinics where they are seen at the nurse-led clinic. At the start they are given a contact card and usually all the tests and appointments are booked at that point. The CSN are initially involved and through the diagnosis. The CSN is involved in the MDT. At the clinics they are seen by a Surgeon and Oncologist and a CSN

I see them at pre-admission clinic with the Cardiac Nurse. We go through what they should expect and about the drains and pain management and we do a functional assessment and we take them off the wards to do that and that is when they start talking about family issues. If they were working, we talk about benefits and make sure they are aware of what help is out there for them

Discussing the patient journey was, however, more complicated when discussing the end of secondary care and referral back into the community. Many discussed the Cancer Care Standards, which state that cancer patients should continue to be followed-up for five years. That said, the majority of interviewees discussed how they practice a flexible approach to follow-up, with some arguing that patients with certain types of cancer are rarely discharged:

It is a clear role from the first patient contact and when patients die. They are followed up for a long time. The CSN will follow this up and develop a good rapport with the patient

There is no certain cut off period. If people want to come back after I have stopped seeing them, that is OK; there is an open door policy. They are followed up for five years and the patient is reassured that the door is not closed. We continue to see them on a yearly basis and we never tell them that it is finished. They become like a family member

We are fortunate in breast and we have a Breast Care Nurse in the community who the patient can go to if they have a problem, same as the Oncologist in Velindre. That doesn't happen in every tumour site

We don't discharge many people in Haematology because the acute conditions like leukaemia unfortunately have a significant chance of relapsing....so even five years down the line we are seeing them every six or twelve months so they stay within the system. We also have a lot of diametrically opposite conditions like chronic lymphocytic leukaemia where patients can be under follow-up for twenty years with no treatment...

Therefore, a number of interviewees argued that in many cases there is no formal identifiable end to the patient journey. Many patients, who are theoretically discharged to their GP, are told that they can contact the cancer site if there is anything they want to discuss after their treatment is finished.

A few interviewees discussed the lack of anyone to refer onto within the community:

At the end there is no formal process. Patients who go to Velindre can still contact us. There is no formal discontinuation of care. If there is a formalised process whereby you have to have a tick box then it will add a new scenario. If we have to provide a key worker at the start and end points it will add another level of bureaucracy

There is nowhere else to refer onto. We man the follow-up clinics. So theoretically any patient who has gone through the SLT can be seen there. That is self-limiting. If someone comes out of that system after five years we don't have resources to pick them up if they have on-going needs. Unless they have an identified surgical need that would take them back in the new patients' system. So technically they are in the ether. The normal way they could come back is through the GP. Five years is the cancer standard. It then goes to the GP. If a new problem develops they can access referral via the GP

Some interviewees usually refer onto a GP, and felt that this works well:

A breast cancer patient will have treatment but then will be followed up for five years. Are they still in treatment? Or if they may be taking Tamoxifen for ten years are they still in treatment? In which case logically the GP would be the key. Theoretically the primary carer should be the key worker; they should know the person, the family

Other interviewees argued that the referral process depends entirely on the patients' needs at the time:

At the end of discharge we give them information and the do and don'ts. We tell them they can always contact us and some do. After that it depends on what they need. Who I hand it over to depends on their needs. If they don't have any physical needs they would be discharged to their GPs. We don't have much follow-up if they don't have identified needs. For social needs we direct them towards websites such as Tenovus, Macmillan and Marie Curie. For younger patients we talk to the parents

The end of their care depends upon the patient's needs at the time. End of life they will go to the palliative care team. If they have continuing physical needs they will go to the GP and District Nurse or other MDT workers out in the community

Some interviewees discussed how it would be useful to be able to refer patients onto people within the voluntary sector. However, interviewees discussed the requirement that key workers should have the relevant knowledge of cancer. Also, some argued that in order to be able to include these key workers as part of the patients journey they would need to be identifiable through a list of available key workers in a geographical area:

There is a geographical issue. We serve the whole of South West Wales, we discharge some patients back to the district general hospital and there is some handover there. One thing we need to think about is when we are referring we need to have a named contact

Conclusions:

- In most cases the patient journey is identified at the initial MDT meeting.
- The initial key worker is easily identifiable and is usually a CSN
- Referring on after treatment is not so clearly defined. For many patients the journey will continue if there is a chance of relapse.
- Many interviewees argued that key workers would need to have a certain level of knowledge. However, some health care professionals were happy to utilise key workers within the voluntary sector after the patient had finished treatment.

Patient Expectations

Patient expectations were discussed by all interviewees who identified a number of different areas they thought a key worker should cover.

Findings:

The challenges faced by patients under the current system were well articulated by many participants, who argued that the key worker must have a number of qualities and perform a number of tasks.

Information

Most interviewees discussed how the patient will require a range of information. This includes information relating to their treatment, social issues, employment and benefits and the future. Most argued that it is important that the key worker is able to signpost the patient to relevant sources:

The patient expects to be given time, clear information, how the diagnosis will impact them and how the treatment will affect them and what will happen to them in the future. They will want this in verbal and written communication and have it in a respectful way. They expect an expert, knowledgeable service which they have confidence in. We see patients when they are first present and we have to deal with the shock of the first diagnosis and be there for them

Information, clarification and a shoulder to cry on. Information also involves financial and personal; it isn't just medical. For instance some patients may be hard to manage; there could be a family problem that the CSN knows about

A main contact number to deal with outstanding issues. If it is a non-clinical issue they should be able to signpost them to someone who can help

Information about their own management. What will happen next and inform them of each stage. They are very keen to know about the timeline. How long will my treatment last, knowing how they will feel, their personal status. It is enormously important that they have the knowledge

Information and to know when they are going home. They want to know the answers. The key worker should be signposting and having family contact. We do this currently. I do take phone calls even when they are discharged

Information about benefits, assistance with filling out forms, help to make appointments, where they go for things. Many of our patients have social issues

The key worker should make sure they know what is available. People give up. They need to be prepared to follow things through

Some interviewees argued that in order to provide this information the key worker must be someone with knowledge of the illness, although one participant suggested that the signposting role will, in future, be supported by an information officer:

An Information Manager is going to be appointed to the health board. It is a new initiative. We put a bid in with Macmillan for a Band Level 6 information post for three years. Because it is Macmillan it is predominantly cancer. I met with Tenovus and they are quite interested in providing information on benefits. This is important. You have to put bread on the table. Using the charities will enable the key worker. They will be able to direct the patient to them

A named contact

Many interviewees argued that having a named contact will provide much needed reassurance to patients during what is a difficult period:

To have a named person and reassurance. Somebody to have confidence in and signpost

They just need somebody they know who will listen and help them sort things out. If they have a named person, they don't have to ring you but at least they know they have someone they can if they have got problems

Time

Other interviewees felt that allowing patients time is an essential part of the role:

They need time to talk things through

Flexibility: Meeting patients' individual needs

Some interviewees argued that patient expectations and requirements will differ according to the needs of the individual:

Expectations are very different. Some want an input, some want reassurance.

Only one interviewee felt that patients should not expect anything more than they receive currently. Conversely, a few participants argued that this study should discuss patients' expectations and requirements:

We need to have liaison with patients to find out what they want. Perhaps we are running away with it. A good place to start is the Community Health Council. We have just done a survey with them looking at Haematology and Urology and the patient pathways and communication and information. We may think we know what a patient wants

Conclusions:

- The patient will expect and want:
 - Information via signposting
 - A named contact

- Time

- Not every patient will want or need to keep in touch with their key worker. However, having a named contact will provide reassurance to the patient.
- Patients need to be consulted to clarify what they want from a key worker.

Challenges and Fears

Most interviewees were positive about and supportive of the key worker initiative.

Many felt that the initiative will not change the way they currently manage the patient journey. However, others discussed potential challenges and fears.

Findings:

Participants' perceived challenges and fears were as follows:

Resources and Time

The majority of interviewees suggested that the key worker role is a considerable commitment and that finding sufficient time and resources will thus be the main challenge:

Time is the biggest one

The barrier is time. If I get a new acute patient it takes several hours to inform them. You have to be flexible. People land on your door and you have to deal with it immediately. It relies on good will and conscientious staff and teamwork

Resource and the availability of staff to fulfil the role. I am not sure that all sites can provide the staff and skills

Time is the first challenge

Many felt that resource and time pressures could mean the initiative has a negative impact upon already understaffed cancer sites:

It could be a huge extra burden on staff

Infrastructure, Support and Recognition

The need for infrastructure to support the initiative was expressed. This would include Senior Managers etc supporting and empowering the key workers. There should also be someone to oversee and monitor the key workers, a support group for key workers and a clearly defined job specification:

There needs to be organisation and it needs to be well set up with support infrastructure. Everyone should have an appropriate role with a job specification. They should have a peer support group with a key workers' group association

The management should appreciate the role and the role should be given some status and become a respectable position

How many people they have got and how many patients they have and the infrastructure

It has to be agreed at the MDT level and how do you monitor this? If the key worker is on leave they will need a cross key worker who can stand in. There will need to be a key worker who oversees other key workers, to check that patients are not just abandoned. The directorate and cancer site has to monitor it, own it and audit it

Different Cancer Sites

As discussed previously, interviewees noted that whilst the key worker role could work in some cancer sites, it is not reasonable to expect it to work everywhere:

In some tumour sites you haven't got a CSN. Dermatology is one. They see 1000 patients a month. You have to be realistic. Some patients may be very demanding and others may not need a key worker. Dermatology is a one stop shop. A patient goes there and will be treated on the day and that is it. With lung cancer it is totally different. Inevitably they will go on to palliative care

Changing what works

A few interviewees felt that the introduction of the initiative could have a negative effect on what they currently provide to patients:

What I am anxious about is that if we are labelling the key worker within current roles it doesn't change things, as it is working very well. I don't want them to be committed to reams of paperwork. I don't think as a department we will be doing anything differently because we have people fulfilling all the roles and there is always someone who is contactable. I don't want to burden these specialist nurses who are doing a wonderful job with pointless paperwork and tick fifty boxes. I am pleased that this is being brought in but would not like it to be something that changes what works well

Conclusions:

- The main challenges are:
 - Resources and Time
 - Infrastructure, Support and Recognition
 - Implementing the initiative at different cancer sites
 - Changing what works

Summary and Key Learning

It was found that there is a general lack of awareness amongst AHPs and CSNs of the cancer key worker initiative, the workers who felt that they would most likely be affected by the initiative. The initiative was supported by the majority in principle with a willingness to perform the role. Those health care professionals who are less positive feel that it will not alter the current situation whereby those who require support most do not access it.

With respect to current practice, it was commented that the key worker function/role is very much performed already in several cancer areas where applicable and was working well. Staff reported examples of good practice and described that many patients are supported through their cancer journey by a key worker or someone they can contact. Some cancer sites already have a key worker system in place staff reported as working well.

The systems described though have not typically been formalised, and staff

In areas where such a system is used it is typically not formalised, not written down and takes the form of a team approach rather than a named individual. There are some models of good practice in other clinical areas. It will be difficult to implement the initiative at some cancer sites as many will not have CNS staff and the patient journey will be short in comparison to others.

It was felt by many interviewees (particularly CSNs and AHPs) that they are already functioning as a key worker and most of those interviewed feel that CSNs or AHPs (including SLTs), are best placed and therefore most suited to become key workers. Interviewees also identified those who would not be suitable: these included cancer leads, consultants, doctors and senior managers.

In most cases the patient journey is identified in the initial MDT meeting. The initial key worker is easily identifiable and is usually a CSN. However, the role of key worker following referral referring on after treatment is not so clearly defined. For many patients the journey will continue if there is a chance of relapse and the key worker will remain a health care professional within the cancer site.

Many interviewees argued that a key worker within the community would be helpful after treatment has come to an end. However, it was argued that in order for them to do so they would need to have a contact list of those in the geographical area that would be willing to become a key worker. There was a concern about how this could be monitored.

The patient will expect and require: information via signposting; a named contact; and time. Not every patient will want or need to keep in touch with their key worker. However, having a named contact will provide reassurance to the patient.

The main challenges noted by interviewees included: resources and time; infrastructure; support and recognition; the problems associated with different cancer sites and changing what already works.

Key Learning

The function of the key worker system is already being practiced in many of the cancer sites, although not formalised in many areas, and consequently the new cancer key worker initiative should support and enhance areas of good practice. The initiative should aim to build on, rather than change, what is currently being practiced by staff in order to capture the willingness and enthusiasm of those currently fulfilling the role.

More information about the initiative should be made available to those who are most likely will become a key worker. The role needs to be clearly defined in order that people understand what it involves. It does however need to retain a degree of flexibility, and due to the differences between the needs of patients on differing cancer pathways.

Time is also a crucial factor. Managers must understand that key workers will need to dedicate time to this role in order for it to be fulfilled to a high standard. In particular, if it is an addition to their existing role, this must be recognised and time allotted accordingly.

An individual cancer site assessment needs to be completed for each area, to ensure that the individual needs of the patients are going to be adequately met and additionally to ensure that those without current capability to fulfil the role are provided with the requisite support.

Cancer Care Standards, which state that cancer patients should continue to be followed-up for five years was clearly familiar to staff as was the pathway of care. The patient journey was, however, more complicated when discussing the end of secondary care and referral back into the community. This is an area that will require further evaluation and attention during the implementation.

References

All Wales Alliance for Research and Development in Health and Social Care (AWARD) (2007) *Chronic Conditions Management Programme in Wales: Framework for Research and Evaluation 2007 (final - December 2007)* Available at:

http://www.awardresearch.org.uk/documents/CCM_final_FfRE_Dec_07.pdf

Cancer Services Co-ordinating Group Report (2010) *Living With and After Cancer*

Welsh Assembly Government (WAG) (March 2007) *Designed to Improve Health and the Management of Chronic Conditions in Wales: An integrated model and framework*. Available at: http://www.wales.nhs.uk/documents/Chronic_Conditions_English.pdf

Welsh Assembly Government (WAG) (Jan 2008) *Designed to Improve Health and the Management of Chronic Conditions in Wales: Service Improvement Plan 2008-2011*. Available at <http://www.wales.nhs.uk/documents/serviceplane.pdf>

Welsh Assembly Government (WAG) (March 2009) *National Standards for Rehabilitation of Adult Cancer Patients*

Williams, P (2010) Letter on the Rehabilitation and CSCG Report on the needs of those living with Cancer