

MID TRENT CANCER NETWORK

BASELINE REPORT OUTLINING CURRENT KNOWLEDGE
OF HOW PATIENTS, CARERS AND HEALTH
PROFESSIONALS FIND OUT WHERE TO GATHER
INFORMATION MATERIALS AND THEIR EXPERIENCES
OF ACCESSING AND RECEIVING INFORMATION

APRIL 2007

1.0 Introduction

This report presents a summary the key pieces of work undertaken to date across the network to establish current experiences and needs of patients and carers in relation to information. This provides a baseline, at this point in time, for the Mid Trent Cancer Network in relation to the information needs of patients and carers. The data has been drawn from a number of sources:

- Mid Trent Cancer Network HNA 2004
- Research report for Cancerbackup – Evaluating the ‘Cancerbackup Network Information Project 2004-2006’: – users’ experiences of patient information delivery across a cancer network
- Feedback from a conference held in June 2004 exploring the implications of implementing the NICE supportive and Palliative Care Guidance
- Network report providing feedback from patients and carers on patient information, support and communication issues
- Views from patients and health care professionals gathered at Information Prescription Stakeholder Event – March 2007

Information and insight from each of the sources is presented below

2.0 Health Needs Assessment for Palliative and Supportive Care (HNA) - Sept 2004

A network wide HNA for palliative and supportive care was undertaken in September 2004. One aspect of this was gathering views on the information needs of patients and carers. This was done as part of face – to – face interviews with patients and carers and as part of discussions with health care professionals.

The reported presented general views across the whole network and locality specific views from the three geographic clusters at the time:

- Central Nottingham
- Greater Nottingham
- Lincolnshire

Details of the themes that emerged and the recommendations made in relation to patient and carer information are outlined below

2.1 Network wide views

Emerging key themes

- **The network needs to continue to explore the options for accredited information accessible on the network website**
- **There is a need to develop network wide information leaflets on common sites**
- **There is a need to develop a detailed directory of services available to those with palliative care needs**

At the time it was reported that the Network Palliative Care Group, Patient Information and Communication Strategy, was exploring the possibility of the Network Website becoming a front-end where patients can access ‘accredited’ information.

Across the network it was reported that there was a lack of well written, consistent information to give to patients.

Patients undergoing chemotherapy and radiotherapy reported that they valued the excellent detailed and comprehensive written information that they received. They reported that they got this each time they underwent therapy, so that no assumptions about prior knowledge were made. In contrast no patients reported being given any written information about their specific cancer. None reported being given written information about the expected course of their disease. Many reported that they rely on either themselves or family accessing the internet, thus they may access data that is less than reliable.

However, this was reported as often changing once they accessed specialist palliative care services.

"Woman with ovarian cancer. I now know what's happening to me and understand what will happen in the future which I didn't know before."

"92 year old lady with breast cancer. Its being really good talking to people about the cancer and what's going to happen I haven't been able to do that for the last 7 years."

Many commented that to deliver consistent high quality information across such a broad spectrum of potential diseases good IT support is required.

There was also a sense that both professional and users and carers were not aware of what services were available. Many professionals requested a detailed directory of what services were available in their area, and details of how to access them.

2.2 Central Nottingham Views

There were several initiatives identified looking at patient information. It was reported that the network were developing an information strategy. The kite marking of the Coalition for Cancer Information (C4Ci) is seen to be a useful tool and the development of the Patient Held Record viewed as important. More specifically the Newark & District Macmillan Service were reported as providing advice and information provision to patients and carers on cancer and palliative issues. However it was reported that there is no standardised information pack that all patients diagnosed with cancer can receive.

Areas Identified for Further Work

- **Data on patients actual needs for information**
- **Development of comprehensive, accredited information across the full spectrum of palliative care, incorporating information provided by site specific specialist nurses.**

2.3 Greater Nottingham views

It was reported that information is now more freely available than before. Resources such as cancer BACUP web site are valued. It was reported that PALS and PPI are both helping to take this forward. There are now also carer support groups. However the dangers of poor quality information on the website and elsewhere were recognised.

Areas identified for further work

- **Better funding for this area of work. Leaflets are expensive and not budgeted for.**
- **Need a directory of available services.**

- **A Website with accredited information and guidance.**

2.4 Lincolnshire Views

Across the locality there was a real desire to improve this. It was reported that there are recognised pockets of good practice with Specialist/Macmillan Nurses e.g. work is underway at Lincoln County with the colorectal MDT. It was also reported that work is also in hand in Boston and Lincoln to improve patient information between primary and secondary care. A core group of leaflets have been developed for either health care professional or patients on bereavement, caring for relatives and grieving. Therapy services information leaflets are available. Boston and Lincoln have an information facilitator. There is a patient held record pilot at ULHT. GIFTS hospice has an information resource centre.

Patients reported that there is a good information pack available from the specialist nurse in ULHT but not everyone gets it.

There is no patient information strategy and all the work is ad hoc. There is variability about who receives what information and when. It was reported that different staff are using different leaflets.

Areas identified for further work

- **Learn from the best practice and adopt a strategic, planned approach to ensure that all patients have access to information no matter where they are in the pathway of care.**

3.0 University of Nottingham Research Project - October 2006 - Evaluating the 'Cancerbackup Network Information Project 2004-2006': – users' experiences of patient information delivery across a cancer network

The Cancerbackup/Mid Trent Patient Information Project began in October 2004 and as part of that project an evaluation of user experience was commissioned. The evaluation was based on three qualitative interviews with patients and relatives over a year from the point of initial diagnosis and treatment. Twenty seven patients had a first interview, seventeen took part in a second interview, and six completed a third. Patients (and their nominated relative) were recruited from two identified Cancer Network sites treating those who had been diagnosed with Head and Neck or Lung cancer. These sites represented a pathway that had information mapped (lung) and one which had not (Head and Neck). A satisfaction with information questionnaire was also completed at each of the interviews. Four patients provided additional data from diaries documentation details of information events occurring between interview sessions.

3.1 Findings

A total of 50 interviews, 40 completed questionnaires and 4 diaries were analysed. The interviews raised a multitude of complex issues and interesting aspects of information delivery and presentation. The points that were highlighted in the report were:

- That there was a wide variation in information needs of different individuals, with some individuals stating that they would like a great deal more information than others. Advance information about tests and procedures, the nature of side effects of treatment and how to manage subsequent care were appreciated. However a marked ambivalence and even resistance towards information was also commonly

expressed. Trust in professional expertise and a preference for maintaining uncertainty appeared to be being pursued as alternative strategies to seeking information as a means of coping with serious illness.

- As part of the evaluation it was discovered that the protocol for delivering information to patients and carers in the lung group was not being implemented in the way it had originally been envisaged. A composite pack of information was handed to patients at the start of the treatment, rather than individual items being provided selectively at appropriate points throughout the process of care. As soon as this was identified by the project steering group appropriate training and intervention was implemented.
- Many respondents from the lung group expressed concerns about
 - The volume of information received
 - The repetitiveness of information received
 - The appropriateness or relevance of the information to their particular medical condition; and
 - The appropriateness of the information to the particular stage they had reached in their illness.
- Respondents in the head and neck group rarely commented on the volume of information they received, despite the fact that they received much less than was available to most lung cancer patients, and they did not identify any repetition. They did express concern that information was too general and not specific enough to their own medical conditions. There was less concern about information being provided at an inappropriate stage.
- Respondents in both groups had a clear preference for verbal rather than written sources of information. Written information was valued as a supplement, but not viewed as a substitute, for fact-to-face discussions with health professionals.
- Respondents in both groups expressed a preference for selective, personalised and tailored information provided at appropriate stages in their illness trajectory. They were not interested in general information which had no personal application.
- Patients' and relatives' information needs differed. Relatives valued information which helped them form their own understanding of the illness. The noted that they did not always receive this kind of information.
- Most respondents reported high levels of overall satisfaction with the information they had received. However a number expressed uncertainty in not knowing what to expect or demand from information delivery. For some there was awareness of having no comparison against which to gauge their level of satisfactions, which was assessed within a context of generally low expectations.
- Much of the pack of information was directed at patients' medical or clinical needs. Respondents would have liked more practical and lifestyle information (e.g. about travel to the hospital, or diet). The pack contained several publications providing advice concerning patients and carer adjustment to cancer and its impact on psychological wellbeing and interpersonal relationships. However these did not relate to any concerns expressed by respondents in the interviews and do not appear to have been useful to them.
- Patients often reported frustration over the consequences of inefficient administrative routines and poor inter-professional and inter-agency communication. This translated into the experience of cancelled and missed appointments, delay in

learning results of tests and in administration of treatment and difficulties in making effective contact with professional support. Lung cancer patients in particular felt unprepared about the post treatment plans for follow up and monitoring.

3.2 Conclusions

Overall it was reported that the study highlights three key points:

1. The variability of patient preferences and responses to information and the resulting difficulties involved in developing appropriate and sensitive professional and service responses which can adequately and appropriately address these.
2. The extent to which patients and carers prefer tailored information to be communicated directly by the health professionals involved in their care and treatment.
3. The distress and frustration occasioned by administrative inefficiencies and bureaucratic unresponsiveness: this was the area in which respondents experienced the greatest information deficit.

4.0 Feedback from the NICE Supportive and Palliative Care Conference in 2004

A conference was held to identify the implications across the network of implementing the NICE supportive and palliative care guidelines. During the conference participants were asked to consider four key questions:

1. What information, support and resources will you need to implement NICE recommendations?
2. What will hinder successful implementation?
3. What are the gaps in existing services?
4. What do you think the key priorities for development are?

4.1 Key themes that emerged in relation to information for: What information, support and resources will you need to implement NICE recommendations were:

- Devise a patient held record
- Stop using jargon
- Information should be non-repetitive – duplication should be avoided

4.2 Key themes that emerged in relation to information for: What will hinder successful implementation were:

- Lack of patient understanding / hearing
- Back up the verbal and written
- Written information is often seen as a replacement of verbal communication, which are often too generic and not personalised enough
- Communication skills training
- IT systems do not link
- Lack of carer support

4.3 Key themes that emerged in relation to information for: What are the gaps in existing services were:

- Lack of resources – staff time

- Information/communication is not necessarily available when patients want it
- Insufficient communication links between primary and secondary care – sharing of information
- IT solutions not available
- Void and communications / information to those other than white middle class
- Overarching policy – what should be provided and copied into permanent record
- Timely information – admin support to check
- Responsible person for completing the record – recommended that the person who gave the information best
- Accurate information available at each visit – confidence in the system
- Multi profession notes – easy access to standardised key points of information
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**4.4 Key themes that emerged in relation to information for:
What do you think the key priorities for development are were:**

- Engaging with ethnic /disadvantaged groups
- Establishing what patients need to know and providing it
- Health care professionals having the resources and being able to identify when patients need the resources
- Patient held record – future IT/MDT notes
- Central resource to provide signposting for information
- Sharing the information between hospitals
- Internet
- Understanding what primary and secondary care can offer each other
- Equity of information and standard of giving
- Flexible working
- Call centre approach – stranger may be in a better position to give info – sign posting patients and making sure call is referred
- Patients should meet patients – need to facilitate this - directory

5.0 Report providing a compilation of feedback from patients and carers on patient information, support and communication issues (2006)

A report was compiled in January 2006 to provide a single document with all of the feedback and comments received into the Mid Trent Cancer Network over the previous 18 months from patients, carers and members of the general public in relation to patient information, support and communication. This was done with the purpose of informing the development of patient information, and support and communication infrastructure.

The analysis and conclusions were as a result of a number of information sources – some of which have been detailed earlier – but included:

- The Mid Trent Cancer Network HNA
- Focus group feedback on implementing the NICE Supportive and Palliative Care Guidance
- Development of the Mid Trent Cancer Network Supportive and Palliative Care Target 10 Action Plan
- Feedback from the Network patient and public partnership group first annual conference

Key themes and recommendations made as a result of this analysis were:

- **Education and training**
 - Communication and information-giving skills training for health care professionals

- The development and roll out of advanced communication skills training for senior clinicians

- **Information and Communication Resources**

- The development of agreed patient information pathways
- The development and provision of high quality, consistent patient information
- The development and roll-out of patient information protocols and procedures
- Information to be accredited and accessible through a variety of media and sources including the mid Trent Cancer network website
- Update and rollout services directories
- The development and rollout of patient held records across the Network (consideration also being give to this being rolled out across the Trent Region and all long term conditions)
- Need for engagement of commissioners to ensure that patient information and communication services are properly funded
- Need for engagement of commissioners to ensure that patient information and communications services are properly funded
- TO ensure that there are appropriate facilities and access to patients and Resource Centres that are open flexible hours
- Development of IT infrastructure to support patient information and communication developments

- **Changing culture and new ways of working**

- Consultants writing to patients with copies of letter to GPs
- Staff working appropriately and flexibly

- **Key 'watch' words**

- Consistency, equity, accessibility, availability, choice, informed, supported

6.0 Views from patients and health care professionals gathered at Information Prescription Stakeholder Event – March 2007

Mid Trent Cancer Network held a stakeholder event on 27th March to start the debate and discussion with key stakeholders regarding the network approach to developing information prescriptions. Prior to attending the stakeholder day participants were asked to respond to nine areas with regard to how information is currently accessed. The areas participants were asked to respond to are outlined below and then the responses to each question provided.

Sixteen responses were received.

The nine areas covered were:

1. How do patients, carers and healthcare professionals currently find out where to gather information materials?
2. How do you know were to get this information?
3. What information sources do you currently get information from?
4. What types of information materials do you currently gather – give some examples
5. What would an information prescription mean to you?
6. What should be included in an Information prescription?
7. Who should give out the information prescription?

8. What problems or issues do you foresee with the use of information prescriptions?
9. How would an information prescription improve the information given to patients?

Participant's responses were as follows:

How do patients, carers and healthcare professionals currently find out where to gather information materials?

- Internet: Doctors surgery, hospital, resource centre, library
- Internet, CancerBacup, Library, Bookshops, Macmillan
- Informed by nurse specialist
- Hospital information literature
- Support groups
- GP surgery
- Hospital consultants or Dr dealing with the medical complaint
- Hospital specific info written by clinicians
- From other patients
- PALs services
- Leukaemia care
- I don't know

How do you know where to get this information?

- By using search engine on the internet x3
- Ask people
- Literature search
- Library x4
- Cancer Bacup and other cancer organisations x3
- Support Group
- Most of the time don't know where to go – we need to be given 'start off' points
- Trust base patient information teams
- Local pensions and benefits office
- I don't know how to get specific information but I might pick up a leaflet at GP surgery or hospital clinic

What information sources do you currently get information from?

- Internet x2
- Resource centre
- Library
- People, friends, other people with cancer, the cancer support group
- Cancer organisations – Macmillan – coping with cancer
- Macmillan guide to cancer services
- Cancer Backup dietary info
- National adverts
- Hospital
- Support group
- Social Security
- Leaflets if and when obvious and area available

What types of information materials do you currently gather – give some examples

- Magazines
- Leaflets x4
- Posters
- Cards

- Articles
- Booklets
- Books
- Videos
- Preventative medical opinions to optimise my remission
- Alternative therapy to help my condition remain in remission
- MDT decides what is needed
- Spoken written opinion
- Info pack from first hospital visit
- Site specific treatment letters
- DVD's

What would an information prescription mean to you?

- To be able to point patients and carers to how to get the information they need
- A set of information specifically designed and put together for use e.g. currently having investigations for post menopausal bleeding and reasons for this – whether it is likely that it will be cancer or not
- A source of additional information and help
- I would like it to mean, that from the day of diagnosis, the relevant support groups and voluntary organisations, agendas and information are made freely available
- Potential to sign post patients to specialist information from a variety of sources
- Educate professionals about what is available
- Use as an audit tool
- Would mean very little to me – seems like meaningless jargon – might mean I learn a lot which could frighten me
- I don't know
- A comprehensive report on the condition and treatment pattern and side effects on one sheet of paper in layman's terms
- Be able to direct patients better
- Enable better communication and update of the patient
- I personally found that just carrying on as before wasn't enough I personally wanted to make changes to my life to take control and feel I was positively impacting on my future and information prescription hopefully would have helped me do this
- It would mean that the people affected by cancer would begin their journey with the means to access the information they desperately need
- You could get all the information in one place
- Accurate information, a pathway to follow, how and when to ask further questions, a ready reference
- Easy access to my condition, what to expect and when and how to ensure this happens

What should be included in an Information prescription?

- How to contact groups so that patients can contact others and don't feel so isolated
- Who to go to
- Where to go to for help
- What happens for example at screening tests or treatment and the consequences
- A clear pathway through my journey
- All information – including the 'bad' symptoms that may occur and the necessary equipment, medication and nursing procedures that may be required as well as the long lasting medical conditions the treatments may leave
- Emphasis on non clinical information
- Complementary therapies

- Clinical information **should** all be given by relevant health care professional with explanation
- Principle clinician name, CNS name, demographics, name, NHS no, date, GPs number, free text, next appointment, diagnosis, operation, treatment pattern, side effects and treatment, diagram of where cancer is
- Any or all of the current details relating to my disorder, treatment and care and my rights to treatment and care. Also any alternatives available to me – what my choices are
- Alternatives, diagnosis, prognosis, other patients experiences
- Web sites, phone numbers, support groups, specific info for patients, social information
- Contact numbers of health professionals, numbers of support groups, bullet points of what to do in a crisis
- Out of hours contacts
- What happens after diagnosis – warts and all! Information about surgery/treatment (possible side effects) lifestyle changes. Options for treatment – information resources such as Cancerbackup and complimentary therapies – more information on effects of drugs
- It should be individualised and should provide a guide to enable them to understand the name of their cancer and the treatments they have to consider
- Contact name and number for questions as they arise after I have had time to consider what has been given verbally and in writing
- Outline of conditions, where to get more information and where form. Contact numbers, benefits advice, transport and parking information, local support groups – names and titles of key staff.

Who should give out the information prescription?

- Dr's, nurses, community nurses, practice nurses
- Cancer support groups and trained lay people as well as Nurse and doctor – all setting really – physio – OT radiotherapist etc
- Consultants or CNS or person responsible for future treatment or care
- There should be an information technician for each condition.
- Could be filled out by all – including chaplains etc
- Specialist working in information centre with access to large amounts of information
- Someone qualified to do so – not everyone will want this information – please remember to ask - please take care about informing people about their health – it's theirs!
- Person involved with diagnosis and treatment path
- ?OOH, key worker
- Anyone
- This will depend but I believe everyone working in health care should know how to guide people to a reliable source of information
- Needs to be an opportunity to come back with questions regarding the information
- Anyone but I should be able to contact them afterwards if I have any questions

What problems or issues do you foresee with the use of information prescriptions?

- Information not being in plain English
- Language
- Too much
- Being frightened and no one to talk to
- Information must be regularly updated according to reactions to treatment or progression of my disease

- The need to be approachable at all times
- The need to be keep informed of each patients needs and requirement, as the condition progresses
- These should not take the place of a consultation or information being given by the specialist – information prescriptions should be supplementary
- People should not be forced to have information – this can cause anxiety
- Fitting in with care pathways/ information pathways
- If not used in little blue book – other info may be overlooked
- Too much information, too soon
- Training need
- Jargonised
- How the professional / person decides what information they want plus how much extra consultation time will this take up
- Staff of all grades being reluctant to adopt this procedure. – I.N.M.J syndrome or too busy!
- Patients and carers with paper overload
- Information needs to be written in laymen's terms
- Loss of paperwork

How would an information prescription improve the information given to patients?

- They would feel they are not alone. They could get in contact with support group if necessary
- Know what happens when, who is involved – how to plan for the future
- It would lead them forward to areas of help that they may not be aware of
- At diagnosis you are 'in shock', an information prescription would be really helpful with contact numbers to get information once the trauma has subsided.
- Provide a more holistic approach
- **MIGHT** improve their quality of life/death
- Standardisation, making sure it was not forgotten
- It would be very useful as when diagnosed with cancer one doesn't absorb all the verbal information given. IF you were able to take an information prescription away to keep it would be wonderful
- Keep staff better informed of resources available
- Feel more confident
- I think it would allow patients more choices and make them feel more in control and actively part of their own care.
- The term prescription gives an official recognition to this very necessary part of the patient's treatment and ongoing aftercare.
- People have a RIGHT to know – anxiety and uncertainty are painful and unhelpful and the lack of information can be potentially dangerous
- A patient would then be able to understand their illness
- There should be one sources for all information required and needed

7.0 And finally

No attempt has been made to analyse these pieces of information as a whole as each has been undertaken with differing purposes and drivers in mind. However there are some strong messages that emerge that can be taken forward in developing information prescriptions including:

- Both patient and carer's information needs must be considered – they are different
- Written information should not replace verbal or face to face contact

- Patients want information that is specific to their cancer and their journey
- Good information relating to diagnosis, treatment, treatment choices, side effects and, prognosis are important but so is information on lifestyle and practical issues including benefits, parking, appointments, contact details of professionals, how to manage the bureaucracy of the system
- Information should be a choice
- Patients and carers need to know what questions to ask – they need to know what they don't know
- The information needs to be good quality and reliable
- An information prescription could be a tool to help facilitate and navigate the journey better for both patients and the health care professional
- There needs to be a process of giving information but then a process for how a person can access someone to talk if they have any questions
- The information prescription should include some basic details about the diagnosis, treatment choices, and next stages and key contact numbers for named clinicians. It should also be used to sign post to other appropriate information as agreed by the patient or carer and person giving the prescription at a specific point in time.