

| <b>INFORMATION PRESCRIPTIONS PILOT PROPOSAL - Durham</b>   |   |
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| <b>Proposed Pilot Site</b>   | Three primary care practices in the district of Easington, working with the district's recently established Cancer Information and Support Centre located in Peterlee Town Centre.  |
| <b>Title and Address</b>   | Macmillan Cancer Information and Support Centre,<br>20 Upper Chare, Castle Dene Shopping Centre, Peterlee,<br>County Durham, SR8 1BW.   |
| <b>Contact Name, telephone, e-mail and fax number</b>  | Fiona McQuiston, Cancer Information Support Worker<br>0191 5874500<br><a href="mailto:fiona.anderson@cdpct.nhs.uk">fiona.anderson@cdpct.nhs.uk</a><br>Fax: 0191 5874508   |
| <b>Please outline proposal for introducing information prescriptions and areas that you are proposing to cover(see section 9 of criteria document)</b> | <p>The project will seek to explore whether the introduction of information prescriptions, within a socially deprived area, will improve the take up of vital information and support for cancer patients and their carers.</p> <p>It will also seek to develop approaches that take into account the unique problems faced by residents in Easington district and the impact of health inequalities and health literacy (the capacity of an individual to obtain, interpret and understand basic health information and services in ways which are health enhancing).</p> <p>The proposal is intended to provide clear and identifiable guidance, systems and processes to support GP practice staff/ primary care health professionals to enable patients and carers to gain timely access to appropriate information and support.</p> <p><b>Background</b></p> <p>Detailed below are some of the significant indicators of social deprivation in the area and resulting impact on health inequalities:</p> <ul style="list-style-type: none"> <li>• Within Easington ten of the 20 wards have the worst health in England</li> <li>• 37.2% of households in the district do not have a car</li> <li>• Significantly fewer 15 year olds achieve at least five good GCSE passes than the England average</li> <li>• Unemployment rates are higher than the national average</li> </ul> |

- The average resident worker earns 21% (£74 per week) less than the national average gross weekly wage
- With the exception of one area, the district has the lowest average house prices in the Strategy Health Authority area – the national average is £187,200 to Easington's £85,197
- Standard mortality rates for most cancers are above the national average, for example:

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| Lung Cancer:       | Men   | 139 |
|                    | Women | 160 |
| Stomach Cancer:    | Men   | 285 |
|                    | Women | 122 |
| Colorectal Cancer: | Men   | 115 |
|                    | Women | 108 |

Source: *Miserable Measures*. County Durham and Tees Valley Public Health Intelligence Unit. April 2003.

*Delivering Health Improvements in County Durham and Darlington: Easington Supplement of the Annual Report of the Director of Public Health, 2005/06*. County Durham and Darlington Primary Care Trust, (2006).

In addition, the district has no acute trusts or hospices within its boundaries. People with cancer and their families have to travel substantial distances to receive diagnostic investigations, treatment and monitoring from (a possible) two Cancer Treatment Centres and five Cancer Units. The transport infrastructure is poor and this situation is further compounded by low rates of car ownership. Consequently, the majority of local people consider their GP to be the most useful and accessible source of information and support. However, within an area of high social deprivation, poor educational attainment and low health literacy, supporting people is a considerable challenge for community based healthcare professionals.

The combined impact of the above led the former Easington Primary Care Trust to establish a Specialist Palliative Care MDT and successfully bid for Macmillan funding to establish a community based Cancer Information and Support Service (CISS) and Centre. The Centre became operational in February this year (2006). A core component of its work is to assist patients and carers to receive information in a format that is right for them. It also provides support to enable people to understand, interpret and act upon the information provided.

Therefore it is believed that the involvement of the Centre to support primary healthcare professionals to roll out information prescriptions would be invaluable.

### **Pilot Overview: Aims and Objectives**

The pilot would develop a hub and spoke model of information and support services. The proposed service would build on current good practice within local teams, such as primary care health teams, the specialist palliative care team, the Cancer Information and Support Service and library services (as well as all other disciplines represented on the project's Steering Group).

Based within the primary care setting, work would focus on supporting primary healthcare professions (e.g. GPs and district nurses) to generate and issue information prescriptions. A process that will be informed by training, developing supportive resources and utilising identified information directories.

To ensure patients/carers receive support to access information they will be signposted to, or advised as to, how they can gain assistance from the existing Cancer Information and Support Centre and/or the proposed outreach services. The outreach services will be developed within the GP practice sites and consideration will also be given to exploring links with community library services. Outreach services will be developed using the principles and resources. In this instance, outreach services does not relate to home visits but developing "micro" Cancer Information and Support Services within other community venues e.g. GP practices.

### **Aims:**

- To develop robust information prescription processes and mechanisms to support the dissemination and delivery of timely, personalised, health/social information to patients and carers, within a socially deprived area.
- To address the specific health information and health literacy needs associated with living in a socially deprived area.
- To ensure that patients and carers are signposted to the most appropriate support services to assist them to understand and interpret the information they receive and to address the emotional and social needs associated with living with cancer.
- To signpost service users to the district's Cancer Information Support Centre and its outreach services as a recognised support agency within the information prescription process.
- To identify and develop accessible information resources/directories to support effective information-giving which relates directly to a person's care pathway.

**Objectives:**

- a. To establish a Steering Group that will oversee the pilot and will include all partners involved in the delivery of services related to cancer and palliative care in Easington
- b. To enhance working relations between GP Primary Health Care Teams and the community based Cancer Information and Support Service (CISS) through the establishment of clear shared working protocols.
- c. To ensure transparency of services available for all patients.
- d. To recruit a Project Worker to oversee all developments in relation to the roll-out of the pilot.
- e. To establish dedicated information and support outreach sessions within two or three GP surgeries, overseen by the CISS.
- f. To identify and ensure the content of information prescriptions are patient-centred, appropriate and accessible and that recommended information relates directly to Patient Information Pathways and work undertaken by the Northern Cancer Network Cancer Care Alliance and Improving Outcomes Guidance.
- g. To assist health professionals to work to a clear assessment framework of patients' information needs, through education and the development of a staff toolkit/handbook.
- h. To ensure primary healthcare professionals signpost patients and carers to the Cancer Information and Support Centre for assistance if they require support with health literacy needs.
- i. To review and evaluate the impact of outreach services on the take-up of information prescriptions, especially within more isolated geographical areas.
- j. To develop the information prescription process for all cancer types.
- k. To update and agree a directory of relevant voluntary and community organisations.

- l. To develop an information prescription template in partnership with the pilot sites and Macmillan Cancer Support.
- m. To investigate the potential role of community library services in the scheme through, free access to I.T., infrastructures, mediated book selection, and use of library buildings for events and promotions.
- n. To identify and develop varied health information formats, i.e. the use of pictorial and audio-visual materials to ensure information prescription is meaningful to all cross-sections of the community.
- o. To monitor the impact of information prescriptions on patients' and carers' experiences of living and coping with cancer (as outlined below).

#### **Impact for Patients and Carers**

Involvement in the pilot would provide an opportunity to explore:

- Improved take-up rates of information from specific geographical areas within the district, using existing Cancer Information and Support Service figures as a benchmark
- The impact on relationships between patients and their healthcare professionals
- The different information needs of carers and patients
- Whether the supported use of information prescriptions can lead to changes in attitudes, i.e. a movement away from being passive and deferential to an active partner in one's healthcare
- Whether information prescriptions can initiate a more holistic approach to care within the primary care setting
- What is of key importance and benefit to patients/carers? - access to written information only? or written information delivered *with* support?

#### **Impact on Health Care Professionals**

The pilot will seek to:

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|  | <ul style="list-style-type: none"><li>• Assess the impact of information prescription on consultation and practice administration time</li><li>• Highlight the advantages and disadvantages of the chosen information prescription's template</li><li>• Increase confidence in dealing with patient information needs</li><li>• Establish the impact of information prescriptions on services e.g. increased uptake of services.</li></ul> |
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The pilot and subsequent evaluation gives Easington a unique opportunity to identify where information and support gaps are and to re-design information delivery accordingly. It may also provide information to the Networks regarding the patient experience pertaining to the information agenda and assist the provision of equitable services across Networks.

**Please provide a brief description of your proposal to:**

**Work with stakeholders and partners**

The key stakeholders and partners involved are:

**Partners**

- Macmillan Cancer Support
- County Durham Primary Care Trust

**Potential Stakeholders**

- GP Practices and Staff
- Community Nursing Teams
- Macmillan Specialist Palliative Care Team
- Clinical Lead Cancer Services
- Primary Care, County Durham Primary Care Trust
- Finance Department, County Durham Primary Care Trust
- IT Department, County Durham Primary Care Trust
- Communications Department, County Durham Primary Care Trust
- P.A.L.S., County Durham Primary Care Trust
- Cancer Information and Support Service Steering Group
- Cancer Information and Support Service Volunteers
- Patients and Carers
- Northern Cancer Network
- Cancer Care Alliance
- Acute Trust Clinical Specialist
- Cancer Information and Support Services based within Acute Trusts
- Durham County Council Library Services

It is proposed that partners and stakeholders will be engaged in the roll-out and development of the pilot on several different levels. Consultation with the above stakeholders would have to take place. This would include an introductory Information Prescriptions Event designed to raise awareness about the aims, ethos and advantages of information prescriptions and the pilot for all stakeholders. The event would provide an opportunity to invite practices to put themselves forward to become a pilot site. The Cancer Information and Support Services Steering Group would oversee the wider/generic aspects of the pilot. However, membership of this Group will be reviewed and expanded to include more of the key stakeholders outlined above. More detailed development work would be co-ordinated by a sub-group headed by the Project Worker and include: professionals representing G.P. practices, community nursing, and specialist palliative care team; the Cancer Information and Support Service Manager and volunteers; the Macmillan Cancer Information Centre's Adviser; representatives from P.A.L.S., Communications, I.T.; clinical governance staff and service users.

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| <p><b>Develop systems for delivering information prescriptions in your area</b></p> | <p>The Group would be responsible for:</p> <ul style="list-style-type: none"> <li>• Providing opportunities for joint working, sharing ideas and developing good practice</li> <li>• Agreeing joint working practices, protocols and systems across all pilot sites</li> <li>• Agreeing targets and to provide mutual support</li> <li>• Working with the Department of Health’s chosen evaluation team</li> <li>• Identifying training and development needs</li> <li>• Providing a forum for updates and feedback from the National Pilot Team.</li> </ul> <p>In addition, the Project Worker would convene regular meetings with each practice to provide support, review and evaluate how the project is developing within that particular practice. Similarly the Project Worker would attend Cancer Information Support Service (CISS) volunteer meetings to ensure appropriate support.</p> <p>In order to inform and raise awareness amongst patients and carers, a patient information leaflet will be developed. This leaflet will also clearly highlight that the proposed service is free and not subject to normal prescription charges. Opportunities for targeted information dissemination would be identified within the Steering Groups, as well as publicity via the local press. Existing localised patient and public involvement structures within the Primary Care Trust would be utilised to engage with patients and carers.</p> <p>It would be the responsibility of the CISS Steering Group/Sub-Group to establish agreed systems of delivery. That said, the group would be tasked to do the following:</p> <ul style="list-style-type: none"> <li>• Develop an information prescriptions template, which combines both a free form and tick – box format.</li> <li>• Explore the feasibility advantages/disadvantages of developing paper based and/or electronically generated information prescription in order for prescriptions to be issued within a surgery and the community.</li> </ul> |
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**Identify the content for information prescriptions**

- Agree clear guidelines about who completes prescriptions, when and why they are issued and how to instruct and advise patients about them.
- Agree protocols for working with and signposting service users to the Cancer Information and Support Centre and practice based outreach services in support of take-up of an information prescription.
- Develop a health professionals handbook to assist in the identification of information available (where it is available); which organisation can provide it; and who can assist in retrieving information and searching for information, as well as providing appropriate support to understand information.
- Review and develop appropriate patient consent issues to support signposting to the CISS.
- Review the need for and use of duplicate copies of prescriptions.
- Explore the need and feasibility of generating patient prompts to secure higher patient take-up rates.

Identification of content would be achieved in several ways:

- Practice-based evidence - a review of the most common types of information enquiries made within the area, based on usage statistics from the Macmillan Cancer Information and Support Centre. This evidence can also be cross-referenced with statistical information from across all Information Centres within the Northern Cancer Network and Cancer Care Alliance.
- The identification of the most appropriate information to be prescribed would be governed by cancer-specific Patient Information Pathways and Improving Outcomes Guidance. This work is currently being overseen by the Northern Cancer Network and Cancer Care Alliance.
- The local Cancer Information and Support Service is continually developing a directory of resources covering local, regional and national support for people with a diagnosis of cancer and their families. The directories cover topics such as transport, self-help support groups, emotional support and financial assistance/charities. These resources will also be used to shape information prescriptions.



**Information Prescriptions Pilot Proposal  
Macmillan Cancer Information and Support Centre  
County Durham PCT**

**Response to request for further information**

**1. Estimated Number of Dispensed Prescriptions**

It is extremely difficult at this stage to project an exact number, as we have no previous experience of this type of service delivery. It is hoped therefore that any stated figures could be reviewed if necessary during the duration of the pilot.

In order to establish an estimated number consideration has been given to the current number of monthly contacts made to the existing Cancer Information and Support Service as well as Cancer Review statistics provided by a local practice that may be interested in being part of the pilot. Hence we estimate 20 prescriptions dispensed per month per practice.

**2. Usage of Information Technology**

IT technology would be used to support information prescriptions in the following ways;

- Use of the internet to search and retrieve appropriate information for patients and their carers
- Development of a database of information/information directories to be installed within GP practices. To be monitored and updated by the development worker, a process that will be informed by work undertaken by both Cancer Networks.
- Service user will also be able to email requests for support and information, using a secure and dedicated email address.

**3. Types of Information Provided by the Pilot**

The information dispensed to carers and patients will predominantly be provided by staff and volunteers within the Cancer Information and Support Service, following consultation with a medical professional. The types of information delivered would cover both medical and social issues, securing a holistic approach and support to service users. Essentially the information we would provide would reflect care pathways for cancer patients.

Examples of information and sign posting categories, include

- Tests, diagnosis and treatment
- Social care services and support
- Health promotion
- Self Help and Support
- Benefits and financial advice
- Prescription charges and cancer care
- Services provided by the voluntary sector
- Support for Carers
- Transport and access.

**4. Contingency Plans – If Recruitment of Project Worker Fails**

Planned timeframes for the recruitment and engagement of the project worker are as follows;

January – preparation of job description, agenda for change banding, and advertisement

February – Selection, interview and appointment of post holder

March/ April - start date and staff induction.

The current reconfiguration within Primary Care will have an impact on the recruitment process as a clearing house system for regional vacancies has been established. The post will have to be advertised internally before it can be circulated externally, if necessary. However it may also be possible and desirable to attract an existing NHS employee to the post on a secondment basis.

Currently, there is only one member of staff supporting the operation of the existing Cancer Information and Support Service. There is at this point in time no capacity within the service to absorb all the extra work generated by the year long pilot. Recruiting another member of staff is crucial. A time delay in recruiting to the new post would be considered by the Service's Steering Group and members would endeavour to support the initial preparatory stages of the pilot's roll out. This is a high-risk area for our proposal, but without securing another member of staff the pilot could not be rolled out.

#### **5. Project Timescales**

April 2007 refers to the point at which the project worker would be appointed and information prescriptions would be dispensed. Members of the CISS and Steering Group would undertake some preparatory work prior to April. e.g. the development of the job description, raising health professional awareness about the pilot, recruiting practices onto the pilot, initial work around patient/carer awareness and publicity.

#### **6. Outreach Venues - Resources**

To date any outreach sessions developed within GP premises have been by invitation only, with no charges levied for use of premises and telephones etc. That said it is acknowledged that not every GP practice interested within the pilot would take this position.

Therefore the question posed has led to further considerations around the costs implications for room hire, telephone and internet charges, plus access to and usage of computers. It is unlikely that existing budgets could be used for these purposes. The PCT would therefore wish to revise our initial pilot budget proposal to reflect these costs.

#### **7. The Hub and Spoke Model**

It is envisaged that the existing Cancer Information and Support Centre, based in Peterlee would be the hub and the GP practices enlisted, the spokes. Therefore patients have the choice of receiving information and support on a face-to face basis at local venue or a more centralised location. Both paid staff and specially trained volunteers will supervise central and GP outreach services.

However information, support and contact with the service will also be achieved in other ways i.e.;

- Via access to existing Free phone Helpline
- Via access to designated email address
- Forwarding information by post
- Promotion of other Help lines and websites i.e. Cancer Backup, Macmillan and the Northern Cancer Network.

All of the above systems are currently operational within the Cancer Information and Support Service and can be easily incorporated into the proposed hub and spoke model.

## **8. Governance Arrangements**

Robust governance arrangements would be achieved as outlined below.

Clinical Governance – This would be achieved via close liaison with the PCT's Clinical Governance Officers, who would provide direction and advice regarding systems management, monitoring, training, and patient information. Previously this function would have been overseen by former PCT's Clinical Effectiveness Group. However due to the impact of organisational restructure this group is undergoing review and transition.

Information Governance - the PCT's Information Governance lead would be invited to contribute to the pilot's Steering Group. The Caldecott lead would also be engaged in this and the processes outlined above.

Research Governance – Robust governance arrangements would be met through registering the evaluation process with the Research Management and Governance Unit for County Durham PCT. This would ensure appropriate research governance processes are in place and monitored. Issues around patient involvement and data protection would be covered by local NHS ethics (LREC) approval.

The Trust's rights to benefit from any intellectual property arising from the evaluation should be addressed by issuing the external consultants/ researchers with an Honorary Contract, to enable them to work with an NHS organisation. The PCT would also liaise with / seek advice from NHS Innovations for legal advice to ensure the Honorary Contract was robust and in keeping with the evaluation process.