

## **Communications and involvement strategy to support the implementation of *Improving Outcomes Guidance* (IOG) for pancreatic cancer in the East of England**

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### **Introduction**

NHS organisations have a statutory duty to consult local people about the services that they commission and plan on behalf of their local population. They must involve people in annual commissioning plans and in any decisions that involve a substantial change in service.

The proposals for implementing the IOG for pancreatic cancer involve designating a specialised pancreatic cancer centre serving a population of around 3.2 million within the East of England. The aim is to improve survival and outcomes for pancreatic cancer patients, which could be around 200-300 people a year.

Most of these people (at least 80%) would not see a change in the way they access services, although they will still benefit. The majority of care for pancreatic cancer would continue at local hospitals, but under the leadership of the proposed specialised team. However, in line with the IOG, specialist surgery would only be available at the proposed specialised centre. There could be 40-80 patients who would need to travel further for surgery than they do now.

The proposed service change may be considered relatively small, affecting around 40-80 patients a year. However, it raises issues for those 40-80 patients and their families and has implications for the clinicians that are currently providing pancreatic cancer services and for the network of local hospital and community services.

It is therefore important to the success of this service change that people and their representatives are involved in the decisions to commission a pancreatic cancer centre, and have the opportunity to influence the way in which decisions are implemented.

This project is in line with the *Towards the best, together* principles to provide services that are clinically led, evidence based, patient centred – local where possible, centralised where necessary with the aim of improved clinical outcomes.

**This communications and involvement strategy provides the framework and plan for involving service users, carers, professionals, staff and local public. The strategy will ensure that people have access to good quality, up to date information and a range of opportunities to influence decisions and plans.**

## **Aims**

The purpose of this strategy is to support the implementation of the IOG for pancreatic cancer in the East of England. This involves changes that need the expert advice and collaboration of service users and their families and the professionals that are involved.

The main aim is therefore to ensure effective and productive two-way communications between these priority audiences and the decision-making process. Our strategy is in line with the national guidance on patient and public empowerment in order to ensure best practice.

Our aims are:

- To identify and engage all key stakeholders with timely and clear information and effective channels for discussion and feedback.
- To manage a robust process of public consultation that fulfils the requirements of legislation, makes the most of national guidance and is regarded by stakeholders as fair and meaningful. This includes consultation with the relevant Health Overview and Scrutiny Committees.
- To maintain a proactive and responsive communications and briefing system for local representatives and local media.
- To support the Project Steering Group and the East of England Specialised Commissioning Group in listening to and taking account of local views as part of the decision-making process.
- To support the Project Steering Group and East of England Specialised Commissioning Group in ensuring that all internal partners are kept informed and engaged with the project.

## **Roles and responsibilities of the Communications team for this project**

### **Project Manager – Pam Evans**

The Project Manager will be responsible for the consultation process as part of the overall project management plan. The Communications team will report to the Project Manager.

### **Communications Adviser – Wendy Smith**

The Communications Adviser is responsible for the design and overall implementation of the consultation process and is the specialist adviser on consultation with HOSCs and media handling.

### **Communications Manager – Ros Stevenson**

The Communications Manager is responsible for implementation on a day to day basis with the advice of the Communications Adviser and Project Manager.

### **Communications Assistant – Brenda Allen**

The Communications Assistant is responsible for all administrative aspects of the consultation process, handling enquiries and is the keeper of the records.

See further details below:

<b>Key element</b>	<b>Lead responsibility</b>
Consultation document and feedback form	WS
Reports to Project Steering Group/Directors Forum/EoESCG	WS
Briefing to PCTs and key stakeholders	WS
Briefing for HOSCs	WS
Stakeholder map and risk analysis	WS/PE
Promotional material and press information	RS
Enquiries and media enquiries	RS/BA
Consultation events	PE
Venue bookings, liaison and planning	BA
Consultation support materials	WS/RS
Liaison with Communications leads	RS
Outcome analysis and report	PE with independent evaluator (UEA)
Local briefing within PCTs	PCT Comms leads

(PE: Pam Evans [Project Manager], RS: Rosalind Stevenson [Communications Manager], WS: Wendy Smith [Communications Adviser], BA: Brenda Allen (Communications Assistant))

## Specific responsibilities for Communications and media handling

Lead responsibility for draft releases and lines to take	Wendy Smith <a href="mailto:wsmitty@btinternet.com">wsmitty@btinternet.com</a> 07748 116416
Spokespersons briefing / support	Wendy Smith
Press office / Enquiry handling / interview bids	Ros Stevenson / Brenda Allen EoE SCT <a href="mailto:pancreatic@eoescg.nhs.uk">pancreatic@eoescg.nhs.uk</a> 01371 877263
Liaison with SHA, PCT, Trust Comms leads	Ros Stevenson
Electronic distribution and web posting	Ros Stevenson / Brenda Allen
Steer and approval of drafts and plans	Project Steering Group members
Referral of major issues to:	Trevor Myers / Pam Evans
Receive and process correspondence Fast track MP, clinicians and key stakeholders	Ros Stevenson / Brenda Allen
Media spokespersons: (arrangements required for urgent contact 24 hrs)	Rory Harvey (main spokesperson) Trevor Myers (as required) Paul Morris (as required)

## **Audiences and key stakeholders**

The proposed service changes will potentially affect people living in Norfolk, Suffolk (including Great Yarmouth and Waveney), Cambridgeshire (including Peterborough) and the northern parts of Bedfordshire and Essex.

The main priority audiences are:

- Service users, carers and people who may have had experience of pancreatic cancer. There are relatively low numbers of such people; however, there is a strong voice for this group provided by the national charity Pancreatic Cancer UK. The charity's Chief Executive is keen to assist and we will reach some local people through this route as well as through other cancer support groups in the region, including the cancer network partnerships.
- Clinicians and staff at participating hospitals within the network, particularly the teams that have been providing specialist services in the interim at Cambridge University Hospitals, Ipswich Hospital and the Norfolk and Norwich University Hospital.
- The East of England Health Overview and Scrutiny Committees (HOSCs) represented by the East of England HOSC Chairs' Group.

The EoE SCG Communications team is maintaining a database of all contacts and is working with the primary care trusts and all contacts to ensure a far-reaching cascade system to anyone who has an interest in improving outcomes for pancreatic cancer patients.

The main stakeholders include:

- The general public
- Patients and families with experience or history of pancreatic cancer
- Patient representative groups, including links to patients that are "hard to reach"
- Partnership groups associated with the relevant cancer networks (Anglia, Essex and Mount Vernon)
- Professionals and staff in the three current specialist centres that are directly affected by the proposed change
- Professionals and staff in all local hospitals that would be part of the proposed network of services for pancreatic cancer patients
- GPs and primary, community, mental health and social care teams that have a role in the care of pancreatic cancer patients
- Patient transport services
- Staff representatives such as staffside groups and unions
- Voluntary sector bodies, such as hospices, Macmillan Cancer Support and patient and carer support groups
- Local voluntary sector representatives such as councils for voluntary services
- National voluntary sector bodies such as Pancreatic Cancer UK
- Local authority health overview and scrutiny committees (HOSCs)
- Local Involvement Networks (LINKs)
- Local authority members, including county councils and unitary authorities
- Public representatives such as district and borough councils and local MPs
- Local press and media

## **Overview of communications and involvement**

The communications and involvement plan runs from November 2008 in the following phases:

- |                   |   |
|-------------------|---|
| • Nov 08-Feb 09   | Preparations and introductory communications                                |
| • Mar 09-Jun 09   | Public consultation and progress reports                                    |
| • June 09         | Reports on outcomes of consultation   |
| • June 09 onwards | Updates on progress<br>Staff and service user involvement in implementation |

The process will be overseen by the Project Steering Group. This Group will consider an analysis of feedback from consultation and report to the East of England Specialised Commissioning Group, which will make the final recommendation for commissioning plans to the primary care trust boards for approval.

The Communications Adviser has the overall lead responsibility for implementing the communications and involvement strategy, with support from the Communications Manager.

## **Working partnerships**

The EoE SCG communications team will work in partnership with the SHA and PCT Communications Leads to ensure effective communications planning and implementation, including a rapid response to media issues throughout the project.

PCT Comms Leads are being kept up to date on the progression of the project and are being fully engaged. A summary of the Communications Strategy highlighting points of involvement of the PCTs has been distributed.

The distribution plan has been negotiated between the SCG and PCTs and will be recapped prior to launch of the consultation. The Communications Assistant will monitor progress and receive updates from the PCTs concerning actions completed.

PCT Comms Leads are also being encouraged to get involved with the events, many of which have expressed interest in working collaboratively in terms of the workshops.

## **Summary of the process**

### Face to face discussions

The project will set up a programme of meetings and discussion workshops with key groups from the audiences listed above. These will be organised by the EoE SCG Communications team and will require the participation of representative clinicians and commissioners.

Pancreatic Cancer UK is helping to identify service users in the region, from a database of contacts. We have constructed a contacts list of cancer support groups through which we will be able to meet people and, on this, we will seek the help and advice of local clinicians.

We propose to meet people at venues and times where they already meet, such as support group meetings, hospices and advice centres.

It is proposed that a half-day or longer is set up with managers and clinicians at the three trusts currently providing specialist services.

Other audiences as listed above will be contacted prior to the start of the consultation process to arrange discussion meetings. We have already had discussions with the East of England HOSCs to set the arrangements for consultation with them.

#### Written materials and feedback channels

The process will be supported as a minimum by a consultation document and a feedback form. It is recommended that the consultation document should be designed and typeset in the form of a simple PDF document for ease of electronic distribution. This will enable the inclusion of some information in pictorial and diagrammatic format to improve its readability and effectiveness.

People will be able to submit their views in discussion meetings or in writing by email and by post using the feedback form, if they wish.

Other supporting materials will include:

- Summary leaflet
- Website page on the EoE SCG website
- Press releases, background Q & As and lines to take
- PowerPoint presentations to support discussions
- Short summaries for use in newsletters etc.
- Agreed roles and briefings for Communications Leads and key communicators (e.g. identified clinical spokespersons, discussion leaders)

#### **Key dates:**

Initial contact with HOSCs Officer	30 October 08
Introduction and plan update for stakeholders (including HOSCs)	03 November 08
Formal letter to HOSCs	11 November 08
First meeting of Project Steering Group	17 November 08
Confidential draft communications materials	18 November 08
Update for EoE SCG Directors' Forum	20 November 08
Office of Government Commerce Gateway Review	26-28 November 08
Second meeting of Project Steering Group	15 December 08
Meeting with HOSC Eastern Chairs	17 December 08
First distribution of stakeholder bulletin	19 December 08
Meeting with independent evaluator to determine draft criteria for feedback analysis	12 January 09
Consultation stakeholder mapping and risk analysis	13 January 09
Redraft consultation document	13 January 09
Third meeting of Project Steering Group	19 January 09
Update for EoE SCG Directors Forum	20 February 09
Fourth meeting of Project Steering Group	02 March 09
Sign off of consultation by SHA	03 March 09
Start of consultation	09 March 09
End of consultation/deadline for feedback	01 June 09
Delivery of outcome report	12 June 09
Fifth meeting of Project Steering Group	15 June 09
EoE SCG recommendation	19 June 09

## **Project Steering Group meetings**

The Project Manager will liaise with, support and service the Project Steering Group. This Group will steer the consultation process and eventual implementation plans, ensuring all parties involved are represented.

The Project Manager will ensure that all papers are distributed before the meetings followed by timely distribution of minutes and action points.

## **Promotional material and press information**

Core messages have been developed in the form of a Q&A document, which is on stand-by ready for the start of consultation.

The Communications Manger will draft and produce:

- Public summary document
- Background Q&A
- Press releases
- Website page
- Other promotional materials (fliers and posters)

The Communications Manager will ensure, together with PCT Communications leads, that there is relevant media coverage at the following times:

- Before the start of consultation
- Mid-way through the consultation with an update on progress
- Towards the end of consultation with a final reminder
- In the week just before each consultation event (local newsdesk deadlines will be checked and met)

The PCT Communications Leads are fully engaged in the project.

The Communications Manager will also liaise with the cancer networks, support groups and hospices to ensure consultation events are made known to staff and patients.

## **Hard to reach groups**

All PCT Comms teams have contacts and liaison points with representatives of diverse groups. The PCT Comms leads will ensure that all consultation materials are distributed to these groups. They will also receive invitations to discussion meetings and we will meet with groups at their request.

Copies of the consultation documentation will be available in different languages, large print or other formats on request.

During the consultation process we will take specific action to reach minority and diverse groups in our communications. For example, there are strong networks with the black and Asian communities in Ipswich. We know there are other groups that PCTs have established links with. We will draw feedback from these groups on their specific issues relating to the proposed service change. This work will inform the Equalities Impact Assessment (EqIA) for the final decision.

## **Stakeholder Map and Risk Analysis**

The Communications team has produced a detailed stakeholder map showing each stakeholder for this project and specific actions for consultation. This is also part of a risk analysis for the consultation process.

The stakeholder map contains a compilation of all the key stakeholder groups for this project and the proposed methods of communications and involvement for each group. The document indicates where action is the responsibility of the EoE SCG and Project Steering Group, and where communications are best handled by the PCTs.

All stakeholders will receive a consultation document and/or summary from a core distribution plus other information during the consultation period, such as Stakeholder Bulletins and press releases. All stakeholders will have access to information that is downloadable from the [www.escg.nhs.uk](http://www.escg.nhs.uk) website.

The Project Steering Group is also monitoring and managing a risk register that includes communications matters as part of the overall project risk management.

## **Enquiries and media enquiries**

All enquiries, including media enquiries will be coordinated and recorded by the Communications Manager with the support of the Communications Assistant.

Some journalists may contact the NHS East of England Press Office, or communications teams in Trusts and PCTs. Colleagues are being asked to refer all press enquiries to the SCG Communications team, but they will have copies of press releases and lines to take, which may be used if considered appropriate and efficient.

Actions to respond to media enquiries will require team work with assistance and approvals from the Senior Responsible Owner for the Project and the Project Manager. Where possible there should be a clinical media spokesperson e.g. Chair of the Project Steering Group, supported by the Senior Responsible Owner, and in some instances the Project Manager. The spokespersons will be supported by briefings from the Communications team.

All general enquiries should receive an acknowledgement, if not a response, immediately where possible and within a maximum of 2 working days.

The Communications Manager will ensure that all communications leads are kept informed and involved in handling enquiries.

It is likely that we will start to get enquiries from media newsdesks and community representatives as we approach the start of the consultation period. It is agreed that we should be proactive in our start to the release of public information and that this should be before the actual start of consultation.

We have already released an introductory press release explaining the background to the project and that we are preparing for consultation and respond to further enquires as required.

We have had enquiries from a journalist covering both the Ipswich Evening Star and the East Anglian Daily Times. This journalist has demonstrated a key interest in the consultation and will be invited for a briefing with senior representatives to ensure accurate and balanced reporting from the leading press.

## **Pre-consultation and launch management**

- Agree plan, draft press release and stakeholder briefing
- Issue confidential short briefing and draft press release to SHA, PCT and Trust comms leads (ensure DH informed)
- Issue press release and copies to SHA, PCT and Trust comms leads
- Post copies of press release and stakeholder briefing on EoE SCG website
- Distribute stakeholder briefing and press release to key stakeholders
- Spokespersons to be on standby for possibility of radio/TV interviews, supported by the Communications Manager and documentation (background Q&As etc). Project Steering Group members to be on standby for help with enquiries
- Continue on stand by for possibility of early morning radio and follow-up news enquiries
- Stand down except for ongoing enquiries
- Be ready to receive and record details of patients and families who would like to be involved in the consultation
- Continue preparations for consultation launch

## **Briefing to Project Steering Group, PCTs, Comms leads and SCG**

The Communications team will ensure that all key contacts will be kept briefed and updated on progress and developments. This includes formal reports to Group meetings and regular updates / alerts.

## **Briefing for HOSCs**

The HOSCs have been contacted and we are in discussion concerning how they wish to proceed. The Senior Responsible Owner and Communications Adviser attended a meeting to discuss the matter with the East of England HOSC Chairs Group on 17 December 2008. The HOSCs agreed to establish a joint HOSC for this project and are happy to receive the consultation document when ready. We will send the consultation document along with other supporting documents on launch of the consultation.

Our attendance at a future meeting may be requested, together with other "witnesses".

A copy of the outcome report will be sent to the HOSCs for a final view on the consultation process, prior to submission of the report to the SCG.

## **Consultation events**

Dates and venues have been provisionally booked as follows:

16 April 09	St John's Hospice, Bedford
21 April 09	Cobholm and Lichfield Resource Centre, Great Yarmouth
22 April 09	Hellesdon Park Road, Norwich
28 April 09	Cromer Parish Hall, Cromer
29 April 09	St Nicholas Hospice, Bury St Edmunds
08 May 09	Davison House, Cambridge
11 May 09	St Helena Hospice, Colchester
20 May 09	The Norfolk Hospice, Kings Lynn
22 May 09	St Elizabeth Hospice, Ipswich
28 May 09	Longthorpe Memorial Hall, Peterborough

The venues have been selected to ensure a reasonable spread of relevant locations and, where possible, we have sought venues where service users and carers already meet in order to reach our priority audience. However, the events are not exclusive to service users and carers. They will be advertised in the local media as open sessions.

The venues are booked for a whole day in each location. This is in order to run a programme designed to accommodate varying levels of interest. In one part of the day, there will be an informal style drop-in session for those who prefer to talk informally with professionals and give their views. In the other part of the day, there will be a discussion workshop for those who are interested in participating in a more detailed, structured discussion.

The discussion workshop will keep presentations to a minimum and will focus on time and a workshop-style process to encourage written feedback from participants, along similar lines to the feedback form that goes with the consultation document.

A programme for the events will be submitted for approval at the next Project Steering Group meeting. Events materials will include:

- Programme for the discussion
- PowerPoint presentation for the lead spokesperson
- Facilitator and speaker support notes
- Confidential Q&A to support answers to questions

The proposed process is intensive and will require a division of human resources. Each event has:

- A clinician as lead spokesperson for the structured discussion session
- A facilitator
- A senior commissioner
- SCG or PCT comms support for set up, stage management and note-taking
- Specialist nurse from the local area (hospital or community based, but with no bias) to help with the "drop-in" session

We also have an independent patient representative who is keen to attend as many meetings as possible.

## **Distribution, database and feedback**

The initial distribution will have a specific plan agreed with SHA and PCT Comms leads. Most distribution will be by email.

The responsibility for distribution will be along the following lines, subject to further discussion with PCT Communications leads:

Cancer Network Directors - EoESCG

Pancreatic Cancer UK and local support groups - EoESCG

Hospices - EoESCG

Family Carers – PCTs

Councils for voluntary services – PCTs

LINKS – EoESCG

Patient and public involvement groups – PCTs

Racial Equality Councils – EoESCG

Cancer Back Up/Macmillan Cancer Support – Peggy Meredith and Jamie Spencer

HOSCs - Graham Redgwell

County Councils & Unitary Authorities – EoESCG

District Councils- PCTs

Local MPs – EoESCG (letter from Trevor Myers and Rory Harvey)

NHS hospitals and cancer networks – EoESCG

Primary Care Trusts – EoESCG

GP practices – PCTs

Local Medical Committees – PCTs

Local Pharmaceutical Committees - PCTs

Staffside and unions – EoESCG

Pancreatic Society of GB and Ireland – Richard Charnley

Primary Care Society for Gastroenterology - EoESCG

Cancer Action Team / DH – Theresa Moss

It is important that there is meticulous attention to keeping records of where all documents have been sent and all feedback received, whether written or oral. The aim is to ensure that every detail of the process is kept and easily retrievable. Most of the material will need to be reviewed in the writing of the outcome report and clear records may be called upon should there be a challenge to the process at any time.

The following folder system will be maintained in accordance with the Data Protection Act and NHS policies on confidentiality:

- Project planning (to include all project documents and briefing documents)
- Consultation document and feedback form drafts and related notes
- Promotional material drafts and related notes
- Publicity and media enquiries and responses
- General enquiries and responses
- All HOSC correspondence and related documents
- Planned meetings correspondence, documents and notes (with sub-folders for each venue)
- Meetings on request as above
- Project Steering Group meetings plans and notes
- Communications sub-group meetings plans and notes
- Distribution database (record of who has had what document from the initial distribution and ongoing ad hoc requests)

- Feedback database (record of all feedback with details of who has sent it and what they said)
  - Secure confidential equality monitoring database
- Outcome analysis and reports

All feedback should receive a standard acknowledgement, immediately if possible and within a maximum of two working days.

A specialist team at the University of East Anglia has been contacted to agree an independent analysis of feedback and report on process compliance. UEA uses the Cabinet Office Code of Conduct for Consultation criteria as the measure of compliance. Details of feedback analysis and proposed criteria are in discussion.

### **Local briefing**

PCT Comms leads will take responsibility for ensuring that all relevant contacts in their locality are briefed as necessary, including, for example:

- Executive team
- Board
- Commissioning team
- Provider services and staff
- GPs, PbCs and primary care teams
- PPI forums
- Local voluntary organisations and user groups
- Hospices
- Local MPs and other community representatives

## **References & Abbreviations**

This document should be read in conjunction with the consultation document (when available). All other documentation will be made available as the project plan progresses.

Other sources of information:

- Guidance on Commissioning Cancer Services: Improving Outcomes in upper Gastro-Intestinal Cancers  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4010025](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4010025)
- The East of England Specialised Commissioning Group website  
<http://www.escg.nhs.uk>

**EoE SCG** – East of England Specialised Commissioning Group

**HOSC** – Health Overview and Scrutiny Committee

**IOG** – Improving Outcomes Guidance

**PCT** – Primary Care Trust

**PPI** – Patient and Public Involvement

**SCG** – Specialised Commissioning Group

**SHA** – Strategic Health Authority