



# Delivering patient information in 2010 and beyond

Welcome



# Purpose of day

- Overview of context for patient information
- Inform you of regional work
- Discuss the implementation challenges and how to overcome these

‘More than just a leaflet...’

# Information Revolution

# Information Revolution

Media is the prime educator

Media has become the prime  
educator

Fragmented and confusing



# Information Revolution

Language is always evolving

What words mean to people

# Information Revolution

- A years worth of telephone calls made in 2000
- A years worth of e-mails sent in 2001
- A years worth of research made in the 1960's

# The changing face of cancer care

Doctor-patient partnership

How do jellyfish feed?

# How do jellyfish feed?

‘The jellyfish petrifies its pray by grabbing hold of its testicles’

Little Johnny, Class 7BX

# Computer Jargon

- **Search engine**
- **PDF file**
- **Track changes**
- **List serve**
- **Dialogue box**
- **Modem**
- **Router**
- **Software**
- **Application**
- **Menu**

# Medical Jargon

- **Metastasis**
- **Adjuvant therapy**
- **Ablation**
- **Prognosis**
- **Immunotherapy**
- **Lesion**
- **Malignancy**
- **Negative**
- **Progressed**
- **Digital examination**

# Information-experiences

‘They used a big word but because they hadn’t said ‘spread’, I thought I was ok’

# Information-experiences

“Now I know what ‘terminal’ means. I thought it was a kind of disease. Maybe it was better that way”

# Information-experiences

‘It was very confusing,  
sometimes the results were  
positive and so that was good  
but other times they were  
positive and they were bad’

# Information-experiences

‘My doctor told me I was going to be ‘managed’. I went home thinking it was so bad that there was no treatment for me. I did not know until much later that ‘managed’ was another word for treatment’

# Information-experiences

‘They all use big words and  
it made me feel scared’

# Information-experiences

‘It’s strange thinking back now  
but I hadn’t a clue what all the  
words they used meant. I just  
nodded’

# Information-experiences

‘They said I needed to go to the cancer centre. I didn’t know what it was or where it was’

# Information-experiences

'At school everything is marked out of ten and so it was hard when I found out that there's no stage 5'

# Information-experiences

‘It was only because [name] took time to explain things in layman’s language, otherwise I would have continued being so upset

# Information-experiences

‘I had imagined the worst and if it had not been for the nurse who explained it all to me and the words I had thought meant everything was bad, I would still be thinking this’

# Information-experiences

‘The nurse gave me a wee card..., my worries were helped a lot by calling her’

# Survey respondents

Whipple's cancer

TURP cancer

Metastasis cancer

Malignant cancer

Biopsy cancer

# The changing face of cancer care

- Re-organisation of cancer services
  - Multidisciplinary care
  - Central role of the CNS

# The changing face of cancer care

Better treatments/survivorship

The information needs of people  
affected by cancer

People need to understand or get a  
sense of what's going on...

# The information needs of people affected by cancer

Health and wellbeing

Choice

Informed consent

Understand their healthcare pathway

Self-care management

Access services

# The changing face of cancer care

Jim, a patient with bowel cancer (26 months)

- 22 doctors
- 63 sisters and nurses
- 10 allied health professionals
- 16 other healthcare staff
- 3 GPs and 12 practice/district nurses

# Whatever the approach...

## **Has to support Jim**

- Understand
- Personally relevant/tailored
- Navigate the healthcare system
- Access services
- Look after himself

## **Has to support health-professionals,**

- Re-enforce key messages
- Effective communicators
- Coordinate care

# How well are we doing?

74% of all patients received information  
(48% in 2003)

83% < 1 year ago (61% > 5 years ago)

# How well are we doing?

(variations in delivery)

The delivery of information varied between,

- One cancer type and another
- Different stages of the cancer pathway
- Clinical and non-clinical information

What gaps in information can  
mean...

“Nobody told me that I should be  
more careful with my teeth until  
it was too late”.

What gaps in information can mean...

“I had no information about side effects so I didn't know I was having a side effect when it happened”.

What gaps in information can  
mean...

‘It would have been good to have  
information on the sort of  
symptoms to look out for’.

# What gaps in information can mean

‘The first time I heard about help with money was when I was at the hospice’

# How well are we doing?

(% patients receiving information)

- 20% complementary therapies (35%)
- 40% counselling (23%)
- 21% sexuality issues (47%)
- 37% support groups/charities (40%)

What gaps in information can  
mean

“Finding information about other  
things I could take that might help  
was impossible. Nobody seemed to  
know”

# What gaps in information can mean

“Sometimes it is hard to say to someone that you need help because you are trying so hard to be strong. I would have loved for someone to have offered it to me”

# What gaps in information can mean

“I found out about a support group. They were all older than me and different but it was the only place I belonged’

# What gaps in information can mean for carers

‘When you start to look after someone it can be hard. You want to do your best for them because you love them, but how do you lift them without causing pain or help them eat well? It would be good to have practical advice’

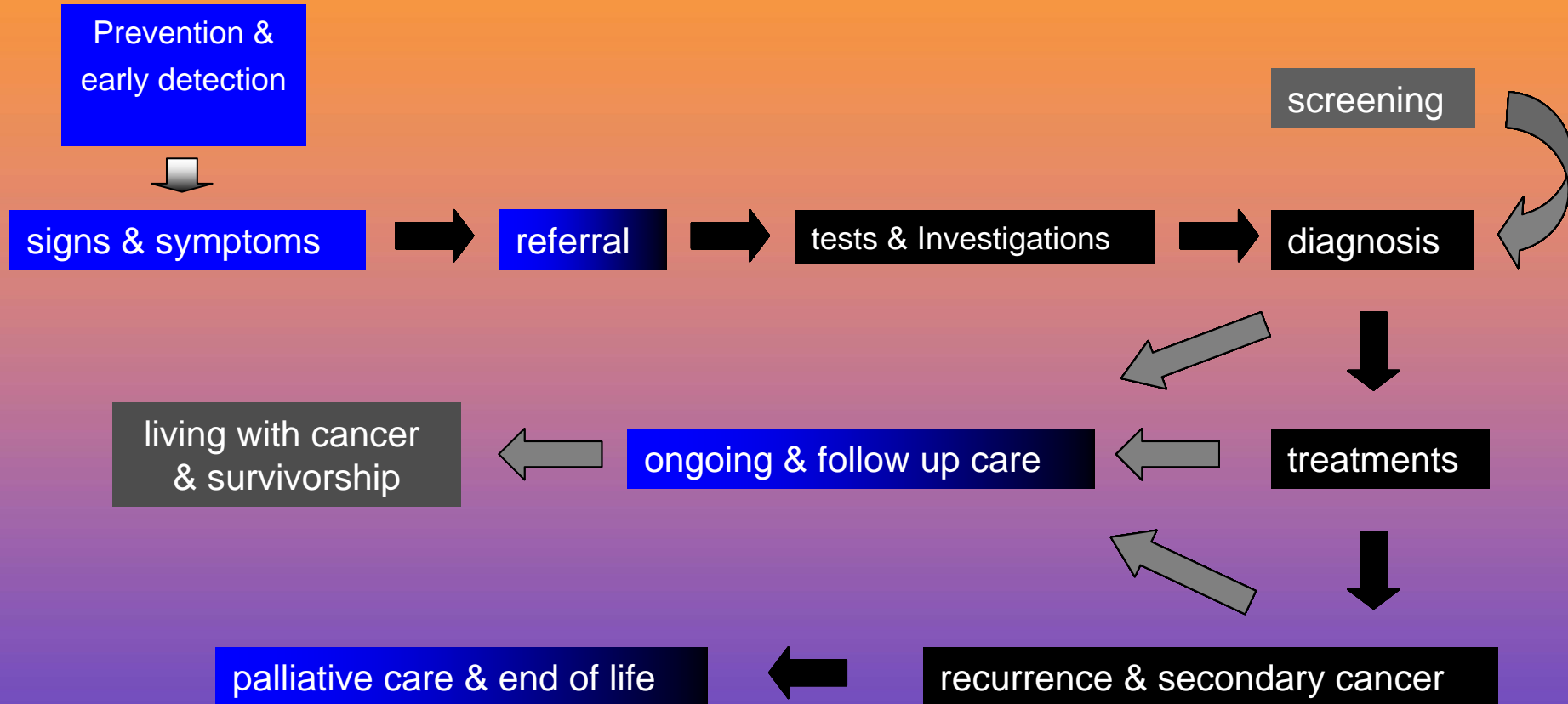
# What patients worry about

- Family
- What might happen next
- Finances
- Body Image
- Filling in forms
- Practicalities around the home

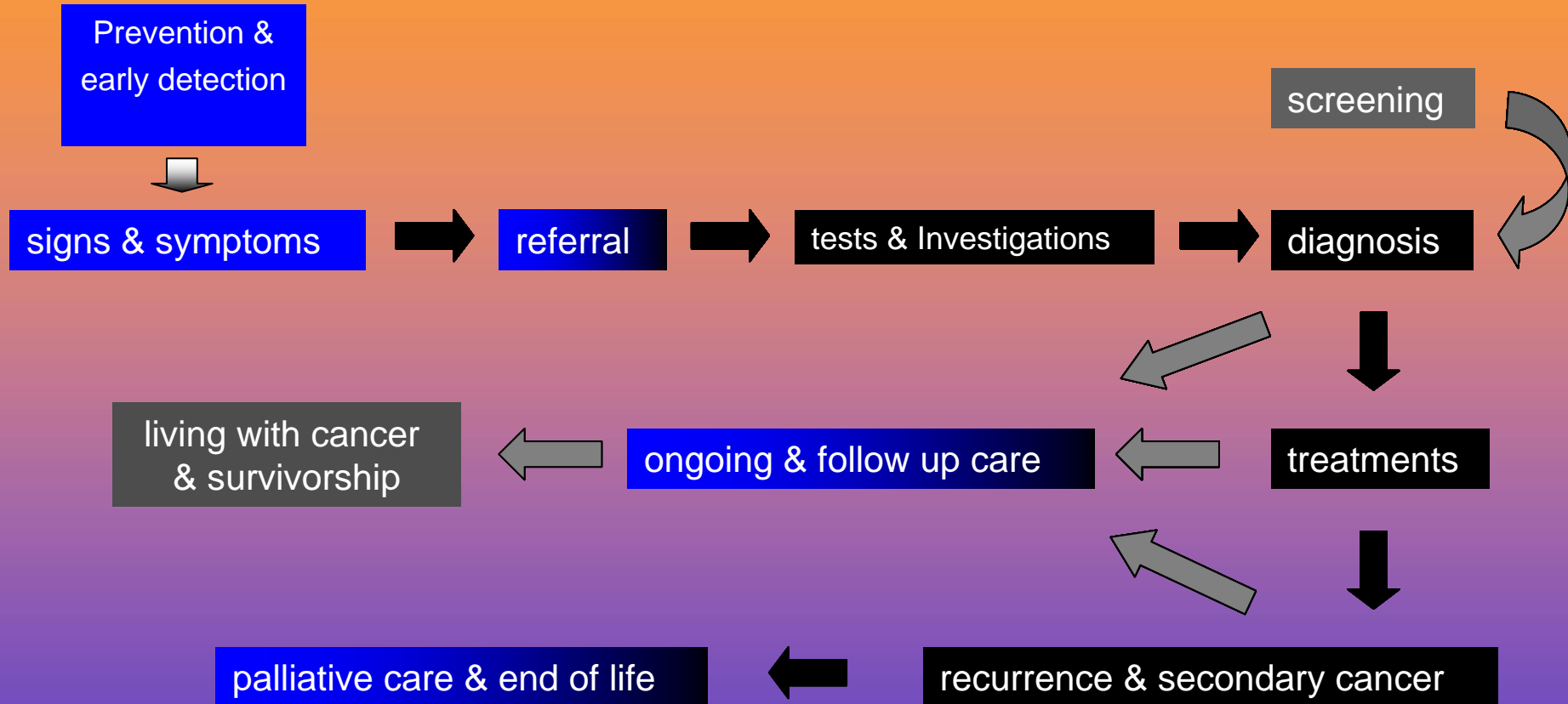
# How we can improve the flow of information

## Patient Information Pathways

# The Information Pathway



# The Information Pathway



## Welcome to the pilot National cancer patient information delivery system.

Help

This system is for you - health and social care professionals. This is a tool to help you meet the patient information requirement of the Cancer Reform Strategy. It makes it easy for you to provide personalised information to people affected by cancer during an appointment.

We want you to use this system to inform, engage and empower your patients.

Follow the simple step-by-step process to get information on specific cancer types that your patient needs. There are four quick steps to take before you will be able to print off the information it will take just a few minutes.

The system just includes specific information on the cancer types for which there are national cancer patient information pathways. If the cancer that's applicable to your patient is not listed, then use the information for all cancers section to find information that is relevant for people with any type of cancer.

The templates section provides national best-practice templates for topics related to appointment letters, directions and patient diaries.

The site has been developed in partnership by Cancer Research UK, Macmillan Cancer Support and the National Cancer Action Team.

[Find out more about the site here.](#)

### Step one: Cancer type

Select one cancer type by clicking on the circle to the left of the cancer name. The type of cancer you select will then be highlighted.

### Select cancer type

Select a cancer type from the menu below. You will be guided through information for the specified cancer and then information for all cancers.

- |   |                                       |
|---|---------------------------------------|
| <input checked="" type="radio"/> Ovarian cancer | <input type="radio"/> Cervical cancer |
| <input type="radio"/> Breast cancer             | <input type="radio"/> Vulval cancer   |
| <input type="radio"/> Prostate cancer           | <input type="radio"/> Bowel cancer    |
| <input type="radio"/> Vaginal cancer            | <input type="radio"/> Womb cancer     |

Can't find the cancer type you're looking for?

Next >>

### Information for all cancers

Select this option if you are looking for information applicable to all cancers or if the cancer type you're looking for is not listed above.

Here you can find:

- Clinical information
- Non-clinical information
- Palliative care and end of life information

Next >>

### Templates

Use these straightforward templates to create a number of different useful documents including letters, directions and patient diaries.

Next >>

You are currently at step 2 of 4

Help

## 2 Key information point: Ovarian cancer

Select preferred option(s)

- 1. Prevention and risk factors
- 2. Symptom awareness and early detection
- 3. Screening
- 4. Referral, tests and investigations
- 5. Diagnosis and staging
- 6. Treatments
- 7. Follow-up care and remission
- 8. Advanced and recurrence
- 9. General ovarian cancer information

Back

Next

The National cancer patient information delivery system is designed to be used as part of a consultation with a health professional. It is not a substitute for medical care, and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem then you should consult your Doctor

Brought to you by:

**WE ARE  
MACMILLAN.**  
CANCER SUPPORT

CANCER RESEARCH UK

### Step two: key information point

Select the key information points you require by clicking on the box to the left. The key information points you have selected will then be highlighted.

### 3 Information for all cancers

Select preferred option(s)

#### Clinical Information

- Treatments
- Symptoms and side effects - lymphoedema
- Diagnostic and staging tests
- Clinical trials
- Advanced disease and recurrence
- Symptoms and side effects - general

#### Palliative care and end of life

- End of life - emotional and practical support
- Children and young people
- Palliative care

#### Step three (a): Information for all cancers

The information on this screen gives generic information for all cancers. Select as many categories to view as you wish.

#### Non clinical information

- Finance and employment
- Complementary therapy
- Lifestyle and diet
- Carers and partners - relationships and sexuality
- Living with cancer - feelings, emotions and communication
- Other information
- Living with cancer - general

Patient declined information

### Information for all cancers required documents

Tick the boxes to select the documents that you want.

Click on document icon to view in a new window (please note, some documents may take some time to open).

Patient given paper booklet(s)

#### Treatments

- The cancer guide-your treatment(MCS)(6 pages) [View document](#)
- Radiotherapy-side effects (CB)(7 pages) [View document](#)
- Radiotherapy-about radiotherapy (CB)(3 pages) [View document](#)

#### Step three (b): Information for all cancers

Click on the boxes to the left of the title of the documents you wish to select. There is no limit to the number of items you can select.

## Print your documents

Help

The documents you selected, with a summary for the patient and two summaries for your records, have been collated below for printing.

**To print**, please click on the print icon at the top left of the document window.

Thank you for using this pilot information pathways system.

[Return to the start](#)

**Step 4b: Print**  
To print the documents and summaries, click on the print icon at the top left of the document window.

**cancerbackup**  
improve understanding

### Which treatment

This information is a booklet, *Understanding your treatment*. To find the full booklet help from cancerbackup, visit [www.cancerbackup.org.uk](#) or you can order you a copy free - see page 4.

A number of different types of treatment are used to treat ovarian cancer. These include surgery, chemotherapy and possibly radiotherapy.

### Treatment planning

In most hospitals a team of specialists will work together to decide which treatment is best for you. This multidisciplinary team (MDT) will include:

- a surgeon who specialises in gynaecological cancers
- a clinical or medical oncologist (to advise on chemotherapy) and may include a number of other healthcare professionals such as:
- a gynaecological oncology nurse specialist
- dietitian
- physiotherapist
- occupational therapist
- psychologist or counsellor.

Your doctor will plan your treatment by taking into consideration

...the treatment to you. You may be asked to sign a form saying that you give your permission (consent) for the hospital staff to give it. No medical treatment can be given without your consent. Before you are asked to sign the form you should have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any possible other treatments that may be available
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain it again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations.

It is often a good idea to have a friend or relative with you when the treatment is explained. This can help you remember the discussion more fully. Patients often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you. The staff should be willing to make time for you to ask questions. You can talk to the specialist gynaecological nurse at the hospital or the nurses at Cancerbackup.

You are currently at step 4 of 4

Help

## 4 Confirm

Please uncheck the relevant tick boxes if you do not wish to print that information. Note that if you uncheck all tick boxes, the summaries for the patient record and audit file will state "patient declined information".

Please click on the "back" button to select alternative documents.

Click on document icon to view in a new window (please note, some documents may take some time to open).

### Key information point: Ovarian cancer

- |  |                               |
|--|-------------------------------|
| <input checked="" type="checkbox"/> Which treatment for ovarian cancer? (CB) (2 pages) | <a href="#">View document</a> |
| <input checked="" type="checkbox"/> Radiotherapy for ovarian cancer (CRUK) (3 pages)   | <a href="#">View document</a> |
| <input checked="" type="checkbox"/> Chemotherapy for ovarian cancer (CRUK) (4 pages)   | <a href="#">View document</a> |

### Information for all cancers

- |  |                               |
|--|-------------------------------|
| <input checked="" type="checkbox"/> The cancer guide-your treatment(MCS) (6 pages) | <a href="#">View document</a> |
| <input checked="" type="checkbox"/> Radiotherapy-side effects (CB) (7 pages)       | <a href="#">View document</a> |
| <input checked="" type="checkbox"/> Radiotherapy-about radiotherapy (CB) (9 pages) | <a href="#">View document</a> |

### Step 4a: Confirm

The confirm screen lists all of the items you have selected. If you are happy with these click the collate button and the collated documents will appear on the next screen as a PDF document in a separate window.

[Collate documents and summary](#)

(Depending on the documents you have chosen, this may take some time)

# Prostate Cancer B

## Patient Information Prescription

Patient Name	Date
Trust Name	Healthcare professional

I have discussed my information requirements with my healthcare professional and would like to receive the following information free of charge.

I consent to take part in a survey on patient information.

### Information Providers Key:

CB: CancerBackup

CRUK: Cancer Research UK

PCC: Prostate Cancer Charity

LOCAL: Locally available information

<b>1. RISK FACTORS &amp; PREVENTION</b>
<input type="checkbox"/> Risk factors and causes-CB
<b>2. SYMPTOM AWARENESS &amp; EARLY DETECTION</b>
<input type="checkbox"/> Are you worried about prostate cancer?-CB <span style="margin-left: 100px;"><input type="checkbox"/> Prostate cancer: spot the symptoms-CRUK</span>
<b>3. SCREENING</b>
<input type="checkbox"/> Screening for prostate cancer-CRUK
<b>4. REFERRAL, TESTS &amp; INVESTIGATIONS</b>
<input type="checkbox"/> How prostate cancer is diagnosed-CB <span style="margin-left: 100px;"><input type="checkbox"/> How prostate cancer is diagnosed-PCC</span> <input type="checkbox"/> Tests for prostate cancer-CB <span style="margin-left: 100px;"><input type="checkbox"/> Tests for prostate cancer-CRUK</span> <input type="checkbox"/> Understanding the PSA test-CB <span style="margin-left: 100px;"><input type="checkbox"/> Letter, details of clinic &amp; description of tests, key staff-LOCAL</span>
<b>5. DIAGNOSIS &amp; STAGING</b>
<input type="checkbox"/> Prostate cancer: A guide for newly diagnosed men-PCC
<b>STAGING TESTS</b>
<input type="checkbox"/> Individual staging tests & scans-LOCAL <span style="margin-left: 100px;"><input type="checkbox"/> Further tests for prostate cancer-CB</span> <input type="checkbox"/> Further tests for prostate cancer-CRUK <span style="margin-left: 100px;"><input type="checkbox"/> The stages of prostate cancer-CB</span> <input type="checkbox"/> The stages of prostate cancer-CRUK
<b>6. TREATMENTS</b>
<b>GENERAL INFORMATION</b>
<input type="checkbox"/> Benefits and disadvantages of treatment-CB <span style="margin-left: 100px;"><input type="checkbox"/> Choices of treatment for prostate cancer-CB</span> <input type="checkbox"/> Treatment options for prostate cancer-CRUK <span style="margin-left: 100px;"><input type="checkbox"/> Active surveillance-PCC</span>



# Delivering Patient Information in 2010 and Beyond

## Have we a mandate?

Liz Henderson  
NICaN Nurse Director

# What is a mandate?

- A document giving an official instruction or command
- Assigned authority to...



# Where do we get our authority?

- Patients
- Public
- Professional Practice
- Policy

# Public expect... Patients want...

- Tailored Information
- Support
- Choice & flexibility
- Pleasant environment
- Appropriate referrals
- Timeliness
- Equality
- Aftercare

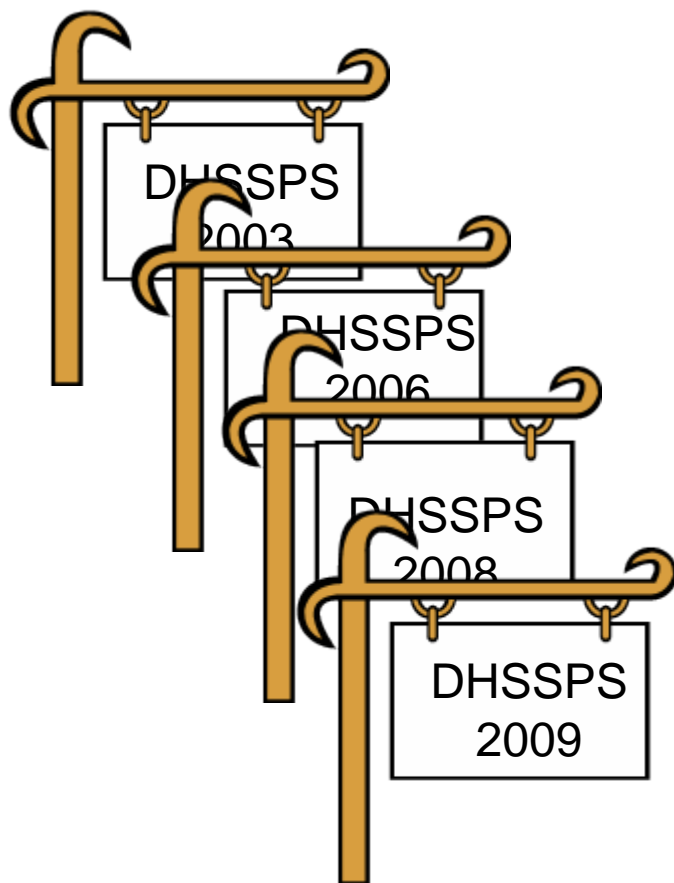


# Professional....codes

## Example: Nurse Midwifery Council

- You must act as an advocate for those in your care, helping them to access relevant health and social care, information and support
- You must make arrangements to meet people's language and communication needs
- You must share with people, in a way they can understand, the information they want or need to know about their health

# Policies and Guidance



# Plethora of Policy / Guidance

NICE Guidance 2004	Improving the Patient / Client Experience	NHS Toolkit for producing patient information
Regional consent HPSS Standards	Cancer Control Programme 2006 DHSSPS	NHS Litigation Authority
HSC Trust style guides	Regional audit of patient information	Regional scoping study of information and support services in NI
Improving Outcomes Guidance	Service Framework for Cancer 2010	Manual of cancer services & Peer Review

# NHS Litigation Authority

- ..handles negligence claims and works to improve risk management practices in the NHS
- It requires Trusts to have a systematic process in place for developing and reviewing patient information

# NICE SPC Guidance 2004

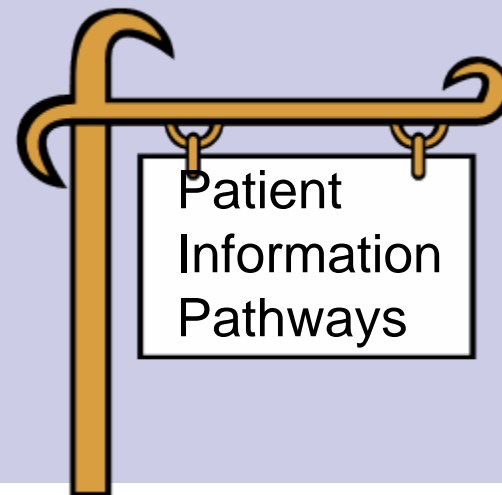
4.3 Patients and carers cannot express preferences about their care or make choices on whether to be involved in decision making unless they are given appropriate information. Many report, however, that they receive insufficient information from health and social care professionals, and that the information they do receive is inadequate and of variable quality. There can also be a tendency for professionals to make assumptions about the amount or nature of information patients seek, rather than asking them directly.

# NICE Guidance 2004

4.3 Patients and carers cannot express preferences about their care or make choices on whether to be involved in decision making unless they are given appropriate information. Many report, however, that they receive insufficient information from health and social care professionals, and that the information they do receive is inadequate and of variable quality. There can also be a tendency for professionals to make assumptions about the amount or nature of information patients seek, rather than asking them directly.

# NICE Guidance 2004

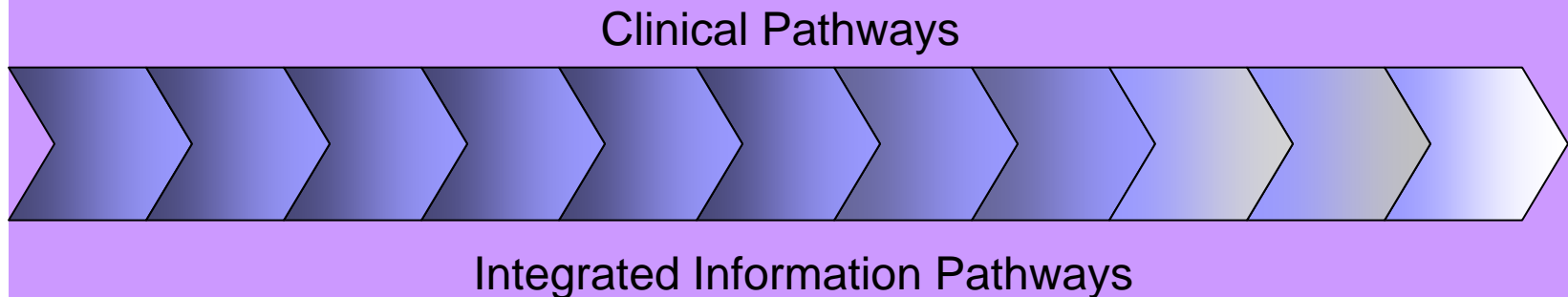
4.18 Policies should be developed at local (Cancer Network/provider organisation) level detailing which information materials should routinely be offered at various stages in the patient pathway to patients with particular cancers



Information for people affected by cancer

# Cancer Control Programme DHSSPS, 2006

5.14 Patients and carers need to be offered high quality information, tailored to their individual needs at appropriate points across the care pathway - clinical and patient information pathways should be integrated.





Department of  
**Health, Social Services  
and Public Safety**

[www.dhspsni.gov.uk](http://www.dhspsni.gov.uk)

AS SONA  
Sláinte, Seirbhísí Sóisialta  
agus Sábháilteachta Poiblí

HEALTH AND  
Public, Residential Health  
and Public Safety

**DRAFT SERVICE FRAMEWORK FOR CANCER  
PREVENTION, TREATMENT AND CARE**

Consultation Document

Working for a Healthier People



# Service Frameworks

Cardiovascular Health and Wellbeing

Respiratory Health and Wellbeing

Cancer Prevention, Treatment and Care

Mental Health

Learning Disability

Children's Health and Wellbeing

Older People's Health and Wellbeing

# Cancer Service Framework Draft 2010

- All people affected by cancer should be offered good information to support them throughout their cancer journey this information should be tailored to the needs of the person both in content and the way in which it is given

# Cancer Service Framework Draft 2010

- Three Performance Indicators
  - Regionally agreed information pathways developed
  - Number of trusts with identified person(s) with responsibility to support delivery of cancer information pathways
  - Percentage of patients offered 'core' information around the time of diagnosis

# Manual of Cancer Standards (DH)

- The MDT should provide patients and carers with written material which includes:
  - MDT local provision of treatment services
  - Patient involvement and patient self-help groups information
  - Information about the services offering psychological, social, spiritual/cultural support available
  - Information about the cancer type and treatment options
  
- Included in current NI Peer Review of MDT



Department of  
**Health, Social Services  
and Public Safety**

[www.dhssps.gov.uk](http://www.dhssps.gov.uk)

en tithes  
**Sláinte, Seirbhíis Sóisialta  
agus Sábháilteachta Poiblí**

departhamint  
**Ponstic, Resydénter Heisin  
an Fowk Siccar**

**IMPROVING the  
Patient & Client  
experience**

5 standards

**respect  
attitude  
behaviour  
communication  
privacy & dignity**

 **NIPEC**

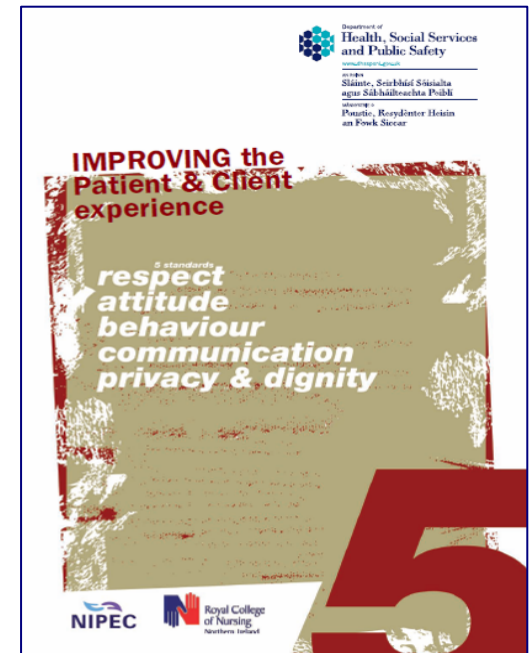
 **Royal College  
of Nursing**  
Northern Ireland

# Patient Experience Standards

## DHSSPS 2008

# Patient Experience Standards

- Patients and clients report that
  - communication has been sensitive to their needs and respectful of their preferences
  - that they have been provided with clear, correct information, using language they understand
- Documentation demonstrates
  - that the important elements of communication exchange have been recorded appropriately
- Staff members report
  - that respectful and sensitive communications are part of the organisational values



# Delivering Patient Information in 2010 and Beyond

Have we a mandate?

YES.....but....

# Challenge: Implementation!

## \* PHASES OF IMPLEMENTATION





# HSC Trust Patient Information Style Guides

- Clear writing style essential
- Consistent writing style helps to reinforce corporate identity
- Offers guidance on writing for publication and typographical principles that are to be adopted for HSC in NI



Guidance to crack the information  
barrier in Health, Social Services and  
Public Safety

## The 5 C's of Information Provision

2003

## Good Practice

- **Consider** Why are you doing it?  
Information should only be produced or provided when there is a reason and an identified target audience
- **Content** What is in it?  
Information in any medium needs to contain certain key items.
- **Composition** How is it presented?  
Information must be accessible, easy to understand, relevant and acceptable to target audiences.
- **Circulate** Where should it go?  
Information should be circulated to the target audience through channels which people use the most.
- **Check** Does it work?  
There will be a way to measure if it worked.

How well  
are we  
doing?





# Conclusion

- Patients: the right amount of information at the right time and in the right format to meet their needs
- Professions: skilled in provision of tailored information giving and checking for understanding
- Policy/Guidance/Standards: systematic processes, developing, implementing, auditing, reviewing, recording



# the website for the Northern Ireland Cancer Network

Cancer in NI

Information & support

Network & Services

Learning & Sharing

Teens

Kids

## Welcome to www.cancerni.net

You can use these three sections, the Quick Links on the right or the search box on the left to find what you are looking for.

### Information & Support



Information and support includes information about the cancer journey:

You can search for local services and telephone helplines here.

There are also links to other cancer websites.

### Network & Services



Information on NICaN's work including:

- tumour networks
- service networks
- the patient & public involvement forum
- Modernising Endoscopy
- Patient Information
- Peer Review
- Chemotherapy review
- Other regional projects

### Learning & Sharing



Information about education and training courses and events.

There are also presentations and other resources available.

## Quick links

[Helplines](#)

[Services Directory](#)

[Events Calendar](#)

[Resources](#)

[Useful Websites](#)

## Latest news

Macmillan's response to NICE decision on liver cancer drug

## Cancer in NI

[Your Cancer Network](#)

[Overview of Cancer Services in Northern Ireland](#)

[Cancer Policy & Targets](#)

[Patients and the public - how to be involved](#)

[Role of Cancer Charities](#)

[Role of the NI Cancer Registry](#)

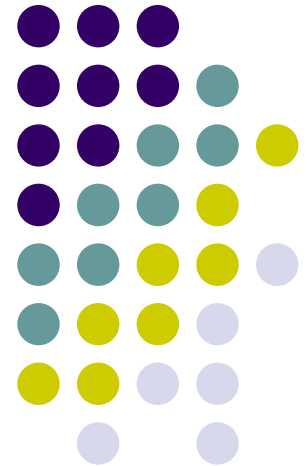
[Cancer in NI - Aims and Objectives](#)

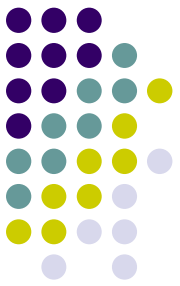
# Delivering Patient Information in 2010 and beyond

## Regional Patient Information Projects

Danny Sinclair

Regional Coordinator for Patient Information





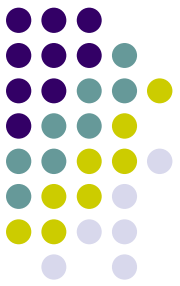
# Aims of presentation

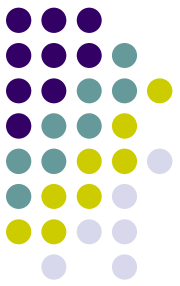
- Tell you about NICaN Patient Information Pathways
- Tell you about some of the work to support their implementation including
  - Regional audit of patient information
  - Policy for HSC staff
  - Options for recording information provision
  - Signposting
  - Empowering people to become partners in the information interaction

# Cancer Services Framework standard for patient information

The latest  
draft is in  
your pack  
(yellow)

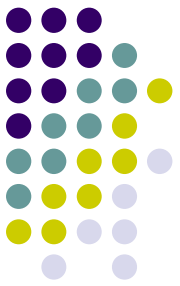
- Rationale, evidence and quality dimensions
- Responsible for delivery / implementation
- Performance indicators and expected performance level
- Date to be achieved by





# Performance indicators

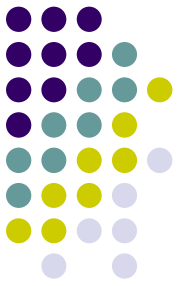
- All trusts identify person(s) with responsibility to support delivery of cancer information pathways
- 7 (tumour specific) information pathways developed by 2011
- Percentage of patients offered agreed 'core information' around time of their diagnosis (85% by 2012 and 95% by 2013)




# Performance indicators

- All trusts identify person(s) with responsibility to support delivery of cancer information pathway  
“in hand”
- 7 (tumour specific) information pathways developed by 2011  
“in hand”
- Percentage of patients offered agreed ‘core information’ around time of their diagnosis (85% by 2012 and 95% by 2013)  
“our challenge today”!

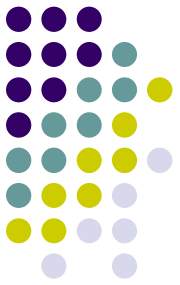
# Developing information pathways



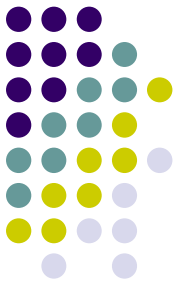
HSC professionals and patients/reps working together to...

- Identify possible information needs
- Identify existing information materials 
- Appraise their quality\*
- Select good quality materials\*
- Plug remaining gaps by designing new materials\*

# Quality



- NHS Toolkit for Patient Information
- Plain English principles
- 5 C's of written communication
- Trust Styleguides
- Supporting informed consent

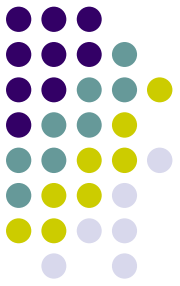


What are information pathways?

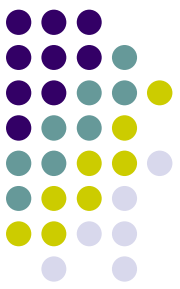




# Core items around time of diagnosis



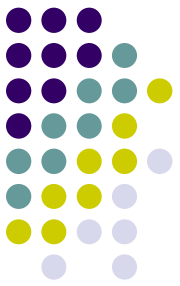
- About the cancer type
- HSC staff (roles, services, contact details)
- Signposting
- Spiritual support
- Financial and practical issues
- Fatigue
- About clinical trials



# Core items around time of diagnosis

- About the cancer type
- HSC staff (roles, services, contact details)
- Signposting
- Spiritual support
- Financial and practical issues
- Fatigue
- About clinical trials
- ‘Ask about’ (more about this later)

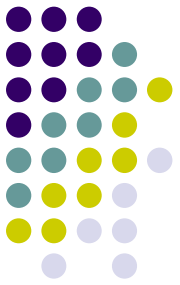




# Core items around time of diagnosis

- About the cancer type
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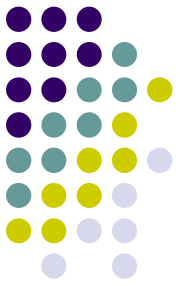




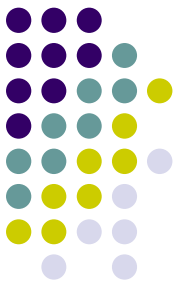
# As needed (examples only)

- Wigs and wig fitting
  - Talking to children about cancer
  - Work
  - Driving
  - Getting a wheelchair (temporary)
  - Travel insurance
- ... and many more, reflecting the range of information needs that cancer can raise

# Summary- Information pathways:



- Remind you of information **topics**
- List **core** items that all patients should be offered
- Feature ‘**as needed**’ items that can be offered if they are relevant for your patient
- Suggest **when** information might be relevant
- Let you **see** information before you order it
- Give you contacts for placing **orders**



# Which information pathway to use?

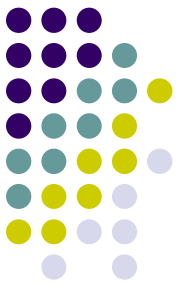
Tumour-specific information pathway

or

Generic information pathway (including advanced cancer and end-of-life)

Tumour-specific information pathways:

- Breast, Lung, Bowel (colon, rectal, anal cancers)
- Prostate, Ovarian
- Oesophageal, Myeloma, Lymphoma



# Guidance for HSC staff

- Basically...
  - use the tumour-specific information pathway if it is in place
  - use the generic information pathway if not
- Highlights the steps in a basic information interaction
- Highlights existing skills development resources (both in your pack)

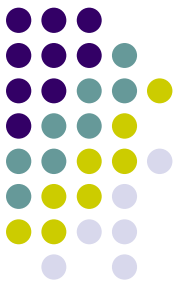
# Something to think about...



There are a range of people and organisations who provide information. Consider who could potentially use information pathways...

Nationally, **information prescribers** help patients work out their information needs

**Information dispensers** provide information materials and can often offer support to understand it



# Evidencing information provision

## Performance indicators

- 7 (tumour specific) information pathways developed by 2011
- All trusts identify person(s) with responsibility to support delivery of cancer information pathways
- Percentage of patients offered agreed 'core information' around time of their diagnosis (85% by 2012 and 95% by 2013)

# Evidencing information provision

## Aims

- Provide a baseline
- Develop a model for audit to support CSF monitoring



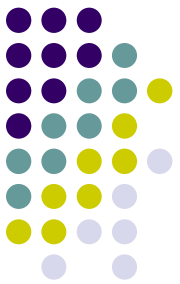
## Patient Information

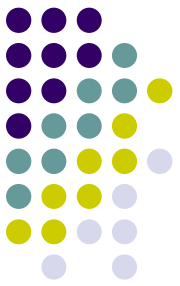
Regional audit

Report and recommendations



[www.cancemi.net/audit/patientinformation](http://www.cancemi.net/audit/patientinformation)





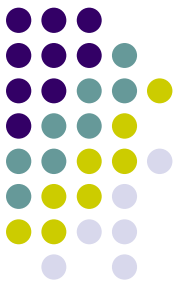
# Introduction

Multidisciplinary steering group including charities

Funded by GAIN

Staffing hosted by SHSCT

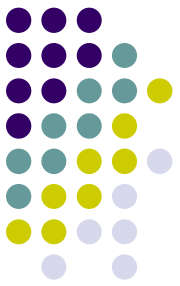
- Strand 1: information experiences of people with breast cancer and colorectal cancers
- Strand 2: patient audit panel audited and rated information using a pre-agreed set of quality criteria.



# Findings: information provision

- Patients primarily reported receiving *verbal information* rather than written information.
- Patients often reported a better ‘information experience’ than was recorded in their case notes.
- Where information provision was recorded, this was often in numerous sets of notes, likely making information coordination for an individual patient very difficult.

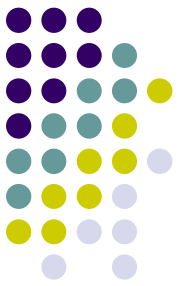
**8 recommendations made**



# Findings: information quality

- The main areas for improvement were the availability of alternative formats and clarity about how current each leaflet is.
- Measuring the subjective aspects of quality (e.g. suitability of language) confirmed the need to involve patients during design.

**7 recommendations made**



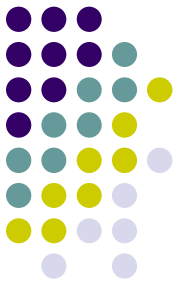
# Key areas for improvement:

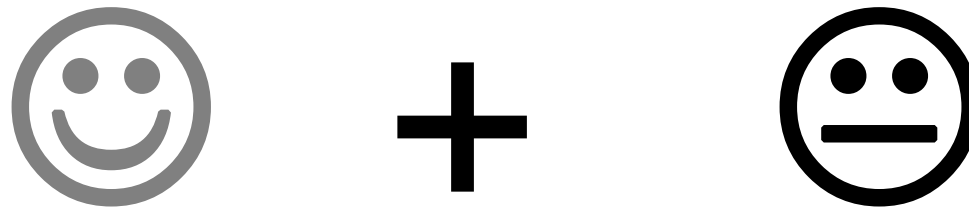
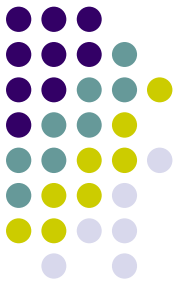
- **meeting patients' 'written' information needs,**
- **appropriately documenting such provision, and**
- **the availability of good quality information materials in formats to meet individual needs.**

The full report is available at

[www.cancerinfo.net/patientinformation](http://www.cancerinfo.net/patientinformation)

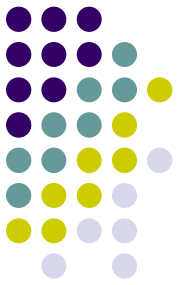
(a reference copy is on each table today)





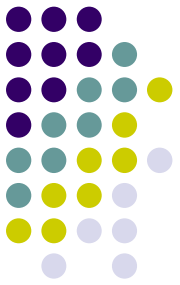
**Studies have shown that some patients only remember one tenth of what they were told during a consultation.** Face to face communication needs to be backed up with high quality, accurate information that the patient can return to in their own time.

NHS Cancer Plan, 2000



# Collection of audit data

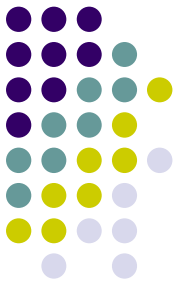
- Case note reviews
- Patient questionnaires
- Patient focus groups
- Staff focus groups



# Collection of audit data

- Case note reviews
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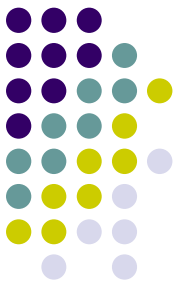
£ £ £ £ £ £ £ £ £



# Collection of audit data

- Case note reviews
- Patient questionnaires
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£ £ £ £ £ £ £ £ ...



# Evidencing information provision

## Performance indicators

- 7 (tumour specific) information pathways developed by 2011
- All trusts identify person(s) with responsibility to support delivery of cancer information pathways
- Percentage of patients offered agreed 'core information' around time of their diagnosis (85% by 2012 and 95% by 2013)



Place addressograph here

Accessment and provision code:

P	Patient accepted paper copy	D	Patient declined information
BC	Patient declined, carer accepted	NA	Information not relevant
S	Patient was signposted and assisted to seek own copy	O	Other; you may wish to write and/or

	Core Code	Date	Completed by:	
Clinic appointment details: date, time, appointment duration etc				For tests and investigations
Tests and investigations: list as appropriate (list below)				
Map(s) and/or directions				For tests and investigations
Parking information				
Consent - Ifs up to you - (DHSSPS)				
Health and Social Care in Northern Ireland RBSO (CSA)				
Glossary of terms				
Booklet / leaflet(s) about the cancer type diagnosed	X			
How a cancer spreads (Cancer Research UK)				
Where a cancer spreads (Cancer Research UK)				
Cancers sometimes come back (Cancer Research UK)				
Clinical Nurse Specialist and/or Keyworker contact details	X			
Who will be looking after me? (NIOak) Or MDT information leaflet both if available	X		-	
Our view of treatment options (record again here even if part of cancer-specific booklet / leaflet about)	X			All and from diagnosis (may also relate to advanced cancer and recurrence)
Coping with advanced cancer (Cancerbackup)				
Ask about your cancer medicines (Cancerbackup)				
Clinical Trials (Cancer Research UK)	X			
Understanding cancer research trials (Cancerbackup)				
Clinical trials opportunities in NI / UK (ORUK)				
Consent - Ifs up to you - (DHSSPS)				
* Signposting Handbook (NIOak PPO)	X			
National support organisations by cancer type (ORUK HSD)	X			
Hospital-specific emotional support services (HOF/Trust)	X			
* The emotional effects of cancer (Cancerbackup)				Care and support (continues overleaf)
How to help yourself - (ORUK)				
Depression - (ORUK)				
Counselling services - (Action Cancer)				

Core information given

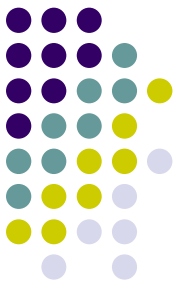
Permanent record given

Key worker details given

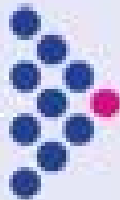
# Signposting

Information and support services  
Statutory and voluntary sectors  
Northern Ireland and national

Also specialist services  
Ethnic minorities support



CANCER RESEARCH UK



Freephone NI Cancer Helpline  
0800 783 3339



Service provided

Cancer type or condition

<All>

<All>

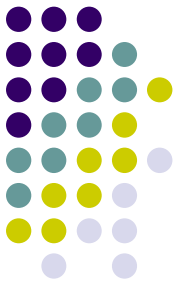
Submit

Organisation ▲	Contact number	Area
Action Cancer	02890 803344	All of Northern Ireland
Altnagelvin Breast Care Team	02871 611443	Derry, Tyrone, Fermanagh Area - Derry, Enniskillen, Limavady, Omagh, Strabane
Altnagelvin Cancer Services	02871 345171	Derry, Tyrone, Fermanagh Area - Derry, Enniskillen, Limavady, Omagh, Strabane
Altnagelvin Cancer Unit (Gynaecology)	02871 345171	Derry, Tyrone, Fermanagh Area - Derry, Enniskillen, Limavady, Omagh, Strabane
Altnagelvin Palliative Care Team	02871 345171	Derry, Tyrone, Fermanagh Area - Derry, Enniskillen, Limavady, Omagh, Strabane
Angels of Hope (Ovarian Cancer)	02838 339903	All of Northern Ireland
Antrim Area Hospital - Breastcare Nurse Specialist	02894 424000	Antrim Area - Ballymena, Carrickfergus, Coleraine, Cookstown, Larne
Antrim Area Hospital, Cancer Unit	02894 424000	Antrim Area - Ballymena, Carrickfergus, Coleraine, Cookstown, Larne
Bangor Cancer Support Group	028 9127 1800	Bangor and North Down
Belfast Carers Centre	02890 434700	
Belfast City Hospital - Lung Cancer Specialist Nurses	02890 329241 ext 3453	
Belfast City Hospital - Occupational Therapy	028 90 263519	Belfast area
Belfast City Hospital Oncology Speech and Language Therapy Department	028 9069 9286	All of Northern Ireland
Belfast City Hospital Palliative Care Team	028 90263934	Belfast Area

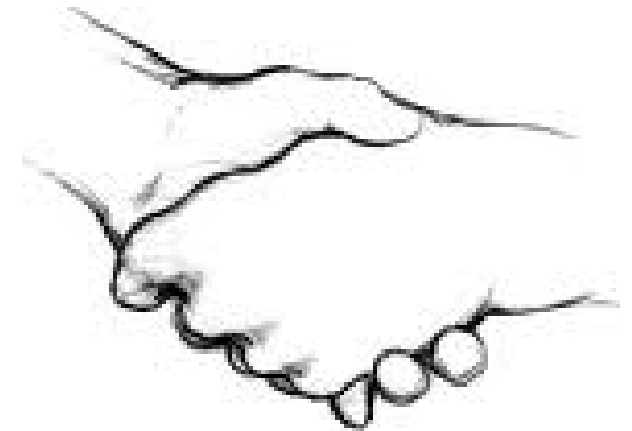


[www.cancerni.net/services](http://www.cancerni.net/services)

# Empowering patients



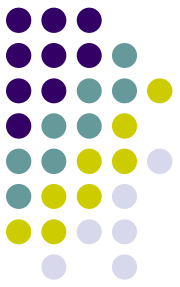
How can we help patients  
become partners in  
information provision?



# Empowering patients

How can we help patients become partners in information provision?

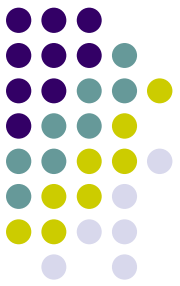
- Help them understand the **‘information role’** in various roles and services



Cancer services for  
patients, carers,  
families and friends  
2nd edition



# Empowering patients



How can we help patients become partners in information provision?

- Help them **understand** the range of information that is available



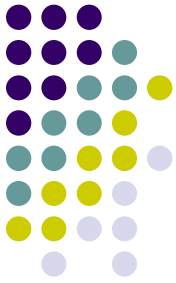
## Information for you


Helping you understand the wide range of information available for people affected by cancer

# Empowering patients

How can we help patients become partners in information provision?

- Help them **choose** from the range of information that is available



**General Information**   
Patient Information Pad

Name

**Part A**  
I have looked at the information catalogue and would like to receive the following titles free of charge.  
I give consent to take part in a survey on patient information.

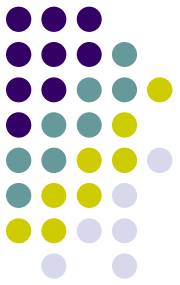
**Part B**  
From the list of titles tick the leaflets that you would like to receive. Then take the completed form along to your local information dispenser who will provide you with the information free of charge.

Key:  
CB: Cancer Backup      CRUK: Cancer Research UK  
LSC: Lymphoedema Support Network      MISC: Macmillan Cancer Support

**T. LIVING WITH CANCER - GENERAL**

<input type="checkbox"/> The cancer guide after the treatment ends MISC	<input type="checkbox"/> The cancer guide caring for someone with cancer MISC
<input type="checkbox"/> The cancer guide from symptoms to diagnosis MISC	<input type="checkbox"/> The cancer guide living with cancer MISC
<input type="checkbox"/> The cancer guide talking to your healthcare team MISC	<input type="checkbox"/> The cancer guide what is cancer? MISC
<input type="checkbox"/> The cancer guide your feeling MISC	<input type="checkbox"/> The cancer guide your healthcare team MISC
<input type="checkbox"/> Cancer survivors guide another cancer happens MISC	<input type="checkbox"/> Cancer survivors guide bowel & bladder problems MISC
<input type="checkbox"/> Cancer survivors guide anaemia MISC	<input type="checkbox"/> Cancer survivors guide fatigue MISC
<input type="checkbox"/> Cancer survivors guide lymphoedema MISC	<input type="checkbox"/> Cancer survivors guide follow up plan MISC
<input type="checkbox"/> Cancer survivors guide heart & lung MISC	<input type="checkbox"/> Cancer survivors guide joint & bone problems MISC
<input type="checkbox"/> Cancer survivors guide practical issues MISC	<input type="checkbox"/> Cancer survivors guide memory, concentration & behaviour MISC
<input type="checkbox"/> Cancer survivors guide non-painful problems MISC	<input type="checkbox"/> Cancer survivors guide peripheral neuropathy MISC
<input type="checkbox"/> Cancer survivors guide oral health MISC	<input type="checkbox"/> Cancer survivors guide sources of support MISC
<input type="checkbox"/> Cancer survivors guide teeth & mouth problems MISC	<input type="checkbox"/> Cancer survivors guide useful organisations MISC
<input type="checkbox"/> Cancer survivors guide complementary therapies MISC	<input type="checkbox"/> Adjusting to life after cancer? CB
<input type="checkbox"/> Adjusting to life after cancer - practical matters CB	<input type="checkbox"/> Spiritual support LOCAL
<input type="checkbox"/> Coping with advanced cancer - CRUK	<input type="checkbox"/> Coping with advanced cancer when cancer returns - CB
<input type="checkbox"/> Coping with advanced cancer - everyday life - CB	<input type="checkbox"/> Coping with advanced cancer - practical issues - CB

# Cancer Service Framework patient information standard

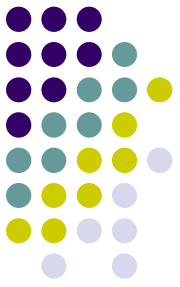


## Performance indicators

- 7 (tumour specific) information pathways developed by 2011
- All trusts identify person(s) with responsibility to support delivery of cancer information pathways
- Percentage of patients offered agreed 'core information' around time of their diagnosis (85% by 2012 and 95% by 2013)

# Conclusion

Much development work – thanks to you!



NICaN Patient Information Pathways

Policy for HSC staff

Regional audit

Recording information provision

Signposting

Empowering people to become partners in the  
information interaction

... How to take it forward..?

# Workshop



Discuss and complete your template by 4:40pm

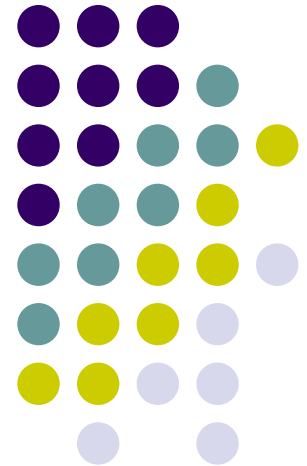
Feedback from each group                      4:40 - 4:50pm

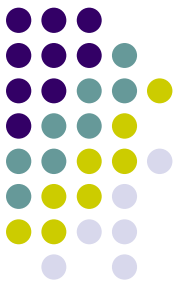
Closing remarks                                      4:50 - 5pm

Evaluation forms

# Delivering Patient Information in 2010 and beyond

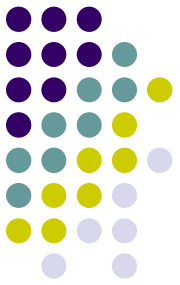
## Closing remarks



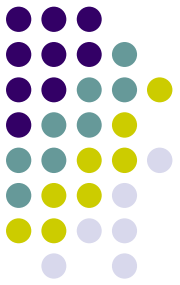


Materials will be available on our  
website by the end of the month

[www.cancer.net/patientinformation](http://www.cancer.net/patientinformation)



Those who make things happen



Those who make things happen

Those who watch things happen, and

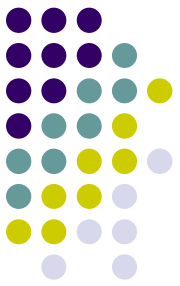


Those who make things happen

Those who watch things happen, and

Those who ask “What happened?!”





Those who make things happen

Those who watch things happen, and

Those who ask “What happened?!”

**Thank you**