

CANCER IN SCOTLAND ACTION FOR CHANGE



A GUIDE TO SECURING ACCESS TO INFORMATION



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FOREWORD

“Information is the greatest gift”

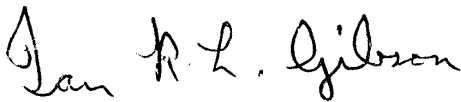
cancer patient

Information and communication are crucially important. People affected by cancer rightly expect to have access to relevant information that is clear, at a time and in a form appropriate to them, and to have the opportunity to talk. Accessible information can lead to a greater sense of being in control at a time when everything can seem out of control. Being given access to information has a beneficial effect on patients and reduces anxiety. Those working with people affected by cancer need to ask themselves “how would I feel – and what information would I want to have?”, and act accordingly.

We know that in Scotland people affected by cancer do not always get the information that they need and are often confused about what is happening to them. There can be a lack of clarity about who is responsible for communication at different points in the journey, what has been communicated and there can be problems with the quality of some of the information provided. Sometimes busy health professionals do not know of other sources of information outside the immediate clinical episode that could make a real difference to people affected by cancer.

This document poses relevant questions that the Cancer Networks and NHS Boards should seek to address. The challenge is to ensure that each Network has both a strategy for patient information and information policies so as to ensure easy access by patients and their carers to consistent and reliable information within the health system, as well as to sources of information and support outside.

As the working group heard from patients during the consultation process, finding and interpreting information can be a difficult and emotional area. It needs to be given priority.



IAN GIBSON

Chairman – Patient Information Sub-group of the Scottish Cancer Group

01.

IMPORTANCE OF INFORMATION TO PATIENTS AND CARERS

Cancer is one of the greatest health problems facing Scotland. In 1998 over 25,500 cases of cancer were diagnosed in Scotland, and in 2000 almost 15,000 people died of the disease. By the age of 74, approximately 1 in 4 people can expect to have been diagnosed with cancer. Survival from cancer in Scotland has improved significantly over the last 25 years resulting in more and more people living with cancer. And that is the key – living with cancer. More people will need palliative care and other support services, more people will need information individual to their needs.

Direct involvement of individuals in their own care requires relevant information that is both accessible and comprehensive to the individual user/patient (NHS Executive *et al* 1998). The NHS Centre for Reviews and Dissemination (1997) suggested that offering people affected by cancer full verbal and written information about their condition and its management would “*make a major contribution to improving quality of care*”. It is recognised that the desire/need, amount and timing of information provision varies among different patients and carers. Information on procedural, factual and practical support appears to be sought to help people manage the social, psychological and financial constraints that illness imposes. Patient information needs include – information on diagnosis, prognosis, risks, results of tests and investigations, therapeutic procedures, drug information, aetiology of cancer and care and treatment following discharge from hospital. This also includes information on feelings, examples of experiences and coping mechanisms. Local arrangements for providing support and further information should be available across cancer networks, including opportunities for discussion with relevant professionals.

The Nuffield Institute for Health and NHS Centre for Reviews and Dissemination (1996) in presenting studies of consultations found women with breast cancer were less anxious when given full verbal and written information, as well as opportunities to discuss options with clinical staff. Similarly, in 1998 they found that patients with lung cancer who were given sufficient information were less anxious and expressed higher satisfaction. Bell *et al* (1996) for the National Cancer Alliance found the provision of information to be a significant issue for people affected by cancer, and at times became a pressing need.

A high proportion of complaints received by the NHS result from inadequate information or poor communication. Feedback from the public repeatedly emphasises a need for better information about their health, their treatment, the options for care and the availability of health services. Without access to information it is impractical to expect patients to make informed choices or take more responsibility for their own health.

CANCER INFORMATION

SCOTTISH EXECUTIVE HEALTH DEPARTMENT POLICIES, NHSSCOTLAND PATIENT INFORMATION INITIATIVES AND THE VOLUNTARY SECTOR INTERFACE

A Patient Information Sub-group of the Scottish Cancer Group was established in January 2002 with a remit **'To prepare an action plan including milestones and targets to secure better access to information needed by people with cancer and their families throughout the cancer journey.'**

Since the sub-group first met in January 2002 a number of publications and initiatives have had significant impact on the scope of its work. So much is being taken forward as a result of subsequent Scottish Executive and other national strategies that it was felt, rather than produce a separate cancer information strategy, a distillation of work already published and underway will provide a useful tool. NHS Boards and Regional Cancer Advisory Groups can use this publication to determine whether local patient information strategies meet the needs of people affected by cancer. The wider strategic picture is described below.

Our National Health: A plan for action, a plan for change, published in December 2000 recognised that, *"Better information and better communication can significantly reduce worry and anxiety but, patients and their families are often unable either to access information or receive the support they need to gain most benefit from it. This situation must be addressed – we will set up an Information Task Group to develop better access to the information that cancer patients and their families need."*

The publication of *Cancer in Scotland: Action for Change* (CIS) in July 2001 signalled a renewed drive to tackle cancer and its causes. Building on the pledges identified in *Towards a Healthier Scotland* and *Our National Health* the strategy identified a wide range of actions necessary in order to prevent cancers whenever possible, to detect tumours earlier and to improve treatment and care for people with cancer in Scotland.

Cancer in Scotland Chapter 5 states, *"Patients and their carers ... must be provided with the information they need when they need it ... there is ample evidence to support the need for healthcare professionals to communicate more effectively if we are to improve the patient's journey between and across different care settings."*

The *Patient Focus and Public Involvement (PFPI)* framework was published in December 2001 to help achieve many of the patient focus aims set out in *Our National Health* and help put the patient at the centre of service delivery.

Patient Information is one of the key themes of this policy. It deals with the generic issues surrounding the quality, accessibility and future developments of patient information. The provision of cancer information is therefore integral to this generic theme.

This Patient Information initiative aims to raise the quality and widen the range of patient information and improve access to it. This Initiative will:

- (1) Develop and implement a patient information quality assurance framework.

As part of the Information Strategy the Health Services Research Unit (HSRU) Aberdeen, has produced guidance to support the development of quality-assured patient information (methodology available at www.abdn.ac.uk/hsru/guide/hti).

To test the methodology the HSRU have developed three patient information leaflets prepared in a patient-friendly format based on the best research evidence available, in consultation with health professionals, consumer representatives and users of services.

- (2) Involve and engage with other sources of expertise such as expert patients.

- (3) Make information accessible and available in a variety of formats.
- (4) Link to ongoing and future developments (e.g. NHS24 on-line).

NHS24 (a Special Health Board) was established to provide a 24-hour direct telephone access advice service to the public (via one rate phone call) on health or healthcare services; assessment of symptoms by a trained nurse and, if appropriate, direct access to the service they need.

NHS24 services are currently available in Grampian and Greater Glasgow NHS Board areas, and roll-out across the whole of Scotland is planned throughout 2003.

Designed to Care (1997) tasked NHS Boards and Trusts with appointing an executive team member with responsibility for extending patient and public involvement in the NHS. Designated Directors are now co-ordinating work across their area on the development of local information policies and strategies.

They are also working with the Involving People Team to develop the performance indicators for Section 5 of the Performance Assessment Framework (PAF). Included in this will be indicators dealing with the design, development and evaluation of patient information.

The Scottish Executive *Fair for All* strategy draws out key themes and recommendations for improving the health and access to services of ethnic minority groups and the wider community in Scotland. The principles of the *Fair for All* strategy will be rolled out to ensure that other excluded groups are heard at all levels. An Inclusion Manager has been appointed to act as a focal point for the *Fair for All* agenda and explore how its principles can be applied to other equality issues.

A National Resource Centre for Ethnic Minority Health, supported by the Scottish Executive, has been operational since summer 2002. The Centre aims to help NHSScotland deliver a culturally competent service.

Patient Focus and Public Involvement Initiatives include:

- › A Patient Information Initiative and network of patient information specialist is being established throughout NHSScotland.
- › A Patient Information strategy is being developed to provide guidance and support in the development of quality assured patient information.
- › Designated Directors will ensure that PFPI principles are included within local information/communication strategies on an ongoing basis as part of the development of the local sustainable framework for PFPI.

NHS QUALITY IMPROVEMENT SCOTLAND (NHS QIS) INCORPORATING THE CLINICAL STANDARDS BOARD FOR SCOTLAND (CSBS)

The CSBS was established as a Special Health Board on 1 April 1999 with responsibility for developing and running a national system of quality assurance and accreditation of clinical services with the aim of promoting public confidence in NHSScotland. On 1 January 2003 CSBS became part of the new Special Health Board NHS Quality Improvement Scotland (NHS QIS) established to integrate Scotland's clinical effectiveness organisations and their work programmes.

In 2001 all NHSScotland Trusts, the three Island NHS Boards, the State Hospital Board and the Scottish Ambulance Service were visited by CSBS teams including healthcare professionals and members of the public, to assess performance against published cancer services and generic clinical governance standards (CSBS 2001). Reports were published in 2002 providing the first comprehensive national overview of work under way to improve the quality of clinical care in Scotland and report on performance against standards including examples of local initiatives.

CSBS reports feed into the NHSScotland Performance Assessment Framework (PAF) that forms the mandatory core of the Executive's annual review of NHSScotland's performance. The reports also provide a stimulus for continuous performance improvement.

CSBS Patient Information Criteria

1. The organisation has a strategy to meet the information needs of patients, relatives and carers.
2. Patients (and, with their consent, carers) are provided with appropriate information materials about their condition at diagnosis which are evidence-based, identify treatment options, possible outcomes, risks, possible side-effects, and sources of further information. Where an explanation is required one is given.
3. Information materials are jargon-free and easily understood, presented in a variety of formats and they are explained to patients as appropriate. Patients are involved in their preparation and they are subject to periodic review and updating.
4. Patients have access to their health records as allowed for in legislation.
5. The confidentiality and security of health records comply with relevant legislation and published guidance.

There are a number of local initiatives highlighted in Generic Clinical Governance Reports from first-round visits, some are listed below. Second-round visits have demonstrated further improvements in these initiatives.

Ayrshire & Arran Acute Hospitals Trust	<p>All patient information is reviewed as part of a two-year rolling programme and a review group has been set up to standardise the format of the information.</p> <p>The health promotion department produces a Patient Information Resource Index, which is available in all areas within the Trust. Link nurses, patients and their carer can easily access the department.</p>
Yorkhill NHS Trust	<p>The children's hospital has a Family Information Centre, which contains a wide range of patient information for people to access. The centre is staffed by three family support workers.</p>

EFFECTIVE COMMUNICATION

Communication with people affected by cancer is complex. All staff concerned with patient care should be aware of potential problems with communication and be aware that patients often find it difficult to take in information given during consultations, especially just after hearing a diagnosis of cancer or other “bad news”.

CSBS Patient/Staff Communication Criteria

1. All patients are informed of the names and designations of the key healthcare professionals responsible for managing their care and how to contact them.
2. There is effective two-way communication with patients, as well as with their carers, that is regularly monitored.
3. A written policy on patient advocacy is in place and its implementation monitored.

CSBS Cancer Specific Standards – Essential Criteria for Communication and Information Sharing

1. Patients with cancer receive information about their illness at all stages. The treatment options are discussed and decisions taken in partnership with the patient.
2. Written information leaflets (including information about local support groups) are available for all patients (including those with disabilities and those requiring translation services).
3. The breaking of bad news is handled in a sensitive manner.
4. Private areas are available in clinics and wards for communicating information.

Interdepartmental communication is also an important aspect of access to, and transfer of, information between the multidisciplinary team across the patient pathway. This should be addressed as evidence suggests that this type of communication is often not well understood and/or planned for.

Communication and Information Sharing

CSBS Breast Cancer Standard Statement

Patients are fully informed of the different options for treatment and involved in decision making to the extent they wish. Clear lines of communication are maintained between the staff in the breast unit and the primary care team.

CSBS standards for Breast, Ovarian, Lung and Colorectal cancer services also recognise that effective interdepartmental communication and between primary and acute care is essential at referral to ensure patients are referred to the right place without unnecessary delay.

CSBS identified a variety of strengths and challenges for NHSScotland as well as examples of local initiatives. Some local initiatives are listed below and are intended to be used as stimuli/contact point for action elsewhere and to avoid duplication of effort across NHSScotland.

Some local initiatives highlighted in National Overview Cancer Services CSBS Reports in 2002	
Dumfries & Galloway	Dumfries & Galloway Royal Infirmary is in the process of developing a colorectal cancer website to provide patients with online access to information about colorectal cancer and details of the Dumfries & Galloway Royal Infirmary colorectal cancer service. For more information contact the Colorectal Nurse Specialist on 01387 241380.
Forth Valley	The Trust makes use of the National Interpreting Service which is accessible on a 24-hour basis. Communication in 140 languages is readily available at www.languageline.co.uk The local council also produces a guide on barrier free communication with regard to language and disability
Glasgow (North)	A comprehensive protocol for the breaking of bad news has been developed in North Glasgow University Hospitals NHS Trust. This includes practical advice on preparing patients to receive bad news, assessment of patient knowledge, finding out how much a patient wants to know, sharing information and how to respond to patients' statements and emotions.
Glasgow (North)	Stobhill Hospital Glasgow runs a dedicated clinic for breaking bad news, which is attended by both the Consultant and Clinical Nurse Specialist. Stobhill Hospital also gives all patients who are receiving radiotherapy an information folder. This contains information about patient regimes, contact telephone numbers and what to do with each drug. For more information contact Nurse Specialist on 0141 201 3625.
Glasgow (South)	The Southern General Hospital, Glasgow has a staff database which provides details of those members of staff who are able to provide a translation service should the need arise.
Grampian	Aberdeen Royal Infirmary also has a walk-in information centre within the surgical breast unit. For more information contact 01224 552211.
Lothian	Patients in and around Edinburgh have access to 'Maggie's Centre' at the Western General Hospital. This provides a walk-in information centre as well as support services. More such centres are planned. More information available at www.maggies.ed.ac.uk
Lothian	There is a Trust standard, <i>Sharing Difficult Information with Patients and Relatives</i> and a guideline to accompany the standard is available. A nurse is always present during the breaking of bad news and this is an important link which assists the ongoing support the nurses provide to patients. For more information contact the Co-ordinator, Palliative Care Service, Royal Infirmary of Edinburgh on 0131 536 1735.
South East Scotland Cancer Network (SCAN)	The SCAN Cancer Information Network project is designed to improve access to quality-assured, locally relevant information for people affected by cancer in Lothian, Borders, Fife and Dumfries & Galloway. For more information contact the Project Manager on 0131 536 9308.
Tayside	There are high quality, locally-produced, patient information leaflets on a range of topics relevant to colorectal cancer patients such as diet, investigations, high dependency unit and chemotherapy in use. These have been produced according to a Trust policy and are evaluated by patients before final production. Leaflets are reviewed annually to ensure that the information they contain is up-to-date.

VOLUNTARY SECTOR

The voluntary sector has a broad and diverse membership with well over 1,000 organisations active in improving health, tackling health inequalities and providing health and social care. Many thousands of paid staff and volunteers work with cancer charities and hospices to improve the care of people affected by cancer.

Information provision has been a major driver for some sections of the voluntary sector. Most people with cancer and their carers want full information about their condition and its effect on their lives. When patients understand their illness, they are more likely to be able to act as partners in the decision making about their care. Health services should fully involve the voluntary sector as partners in providing information and support to people affected by cancer, building on the expertise already in place.

Many patients prefer to get information in their own time, and at their own pace. This is happening already:

CancerBACUP provides high quality and up-to-date information, practical advice and support through its UK information service. In the last year, the cancer information specialist nurses answered more than 53,000 enquiries by telephone, e-mail and face to face from people across the UK affected by cancer; over 250,000 booklets and factsheets were distributed free, and the CancerBACUP website was visited by up to 120,000 people a month. CancerBACUP's 60 booklets and over 130 factsheets are regularly reviewed and updated by some of the country's top cancer specialists, with input from nurses, patients and carers.

DIPEX is a website that allows patients, their carers, family and friends as well as health professionals to access both written narrative and video clips of patient experiences of coping with cancer. Supporters include NHS Direct, Macmillan and CancerBACUP.

Macmillan Cancer Relief operates a helpline to signpost callers to the most appropriate sources of help. Macmillan can, through their Information Consultancy Programme, help NHS Boards, Trusts and health professionals with their information needs analysis, strategy, and options for development. This could include a Macmillan Information Resource. Good practice documents on information materials management produced by Macmillan are listed in Annex 4.

Other organisations including Maggie's Centres are involved in several local initiatives and it is important that their provision is fully integrated with the local strategy and planned appropriately to provide the maximum benefit for patients.

03.

INFORMATION NEEDS ACROSS
THE PATIENT PATHWAY

Local Patient Focus Group discussions have highlighted frequently asked questions by people affected by cancer as they progress through the patient pathway. The diagram overleaf highlights many questions and areas where patients feel there is a lack of information.

However, it is recognised that everyone has individual needs and that this list is not exhaustive. It is therefore important that sufficient, accurate and appropriate information is provided in the right format at the right time throughout the cancer pathway.

Because of these individual needs presenting the pathway in a format that everyone readily recognises and understands is difficult. A second model, prepared by a patient in a matrix format, is therefore also set out overleaf.

There are different ways of accessing/giving information either singly and/or in combination according to patients needs/preferences, e.g.

- › Staff explanation and communication
- › Information booklets, both general and specific
- › Electronic/websites

There are also other innovative ways emerging of delivering information including the use of video and menu driven digital information resources available electronically. Some examples are noted below:

StartHere is a small not for profit organisation that has a mission to provide high quality public information free at the point of access, for as wide as possible an audience. Public sited Kiosks are used as the main means of information delivery and their own simple to use touch screen 'button-net' technology is the interface.

Patientline provides integrated services via bedside units incorporating TV, radio, telephone, internet access and e-mail facilities for the patient as well as healthcare information for professional staff.

SCAN Cancer Information Network is creating an Internet-based information resource to provide a 'single point of entry' to access information about cancer and cancer services in Lothian, Borders, Fife and Dumfries & Galloway. The network will initially cover breast, lung, gynaecological and colorectal cancers.

Patient Pathway Model 1

TREATMENT

- Surgery
- Radiotherapy
- Chemotherapy
- Other supportive care
- Treatment side-effects
- Named Clinician, i.e. radiographer/physiotherapist/dietitian/ occupational therapist/speech & language therapist, nurse, doctor
- What to expect?
- What does it involve?

PRE-ACCESS/DIAGNOSIS

- Help & information
- Sources of information
- Screening
- Access
- Pre-referral
- Referral
- Signs + symptoms
- General information
- Supportive care

TESTS

- What do they mean?
- What to expect?
- Side effects?
- Getting results?
- Where do results go?
- Timescale for reports?
- What are the reporting arrangements?
- What do you do next?

where?

how?

TYPES OF INFORMATION:

- General/generic information
- Terminology – acronyms
- Clinical
- Practical, emotional, psychological, dietary
- Patient pathway information

Patient Pathway Model 2

Explanations: Clinical	Practical	Financial/Social	Psychological	Stage
Pre-clinical Signs + symptoms Investigations (Tests) Diagnosis Treatment options or none Time frames Patient pathway Side-effects Follow-up Relapse End-of-life care	Getting there What to expect Next appointment Who to contact Quality of life Equipment/aids Home nursing Child care Diet/Dietary supplementation Complementary therapies Accompanied Recorded	Benefits Transport Work Housing Debt	Supportive care Coping Distress Anxiety	Concern Enquiry Referral Diagnosis Treatment Side-effects Monitoring Home care

why?

DIAGNOSIS

- Out-patient appointment – what will happen?
- In-patient
- Investigations
- Diagnosis + time frames
- Treatment: No treatment
- Preliminary information
- Preparatory (pre-test) information
- Supportive care

HOSPITAL INFORMATION

- General, e.g. travel/parking
- What to expect
- Can someone be with you?
- Can I record the consultation?
- Can I telephone? – Who can I telephone?

ON-GOING CARE/SUPPORT

- Rehabilitation
- How do you feel?
- Follow-up – when/by whom?
- Out/In-patient
- Contact information
- End-of-life – Best supportive care/palliative care/hospice
- Equipment/aids in the home
- Isolation at end of treatment – point of contact

when?

OTHER VALUED INFORMATION:

- Financial information
- Support groups
- Complementary therapies
- Clinical trials
- Opening times/days of clinics and services
- Regular updates, e.g. if clinics are closed

who?

what?

From Whom?	
General Practitioner Consultant Specialist Nurse Nurse Allied Health Professional	Hospital Administration Local Authority Voluntary Sector Designated Care Co-ordinator Hospice

DOES YOUR LOCAL PATIENT INFORMATION STRATEGY MEET THE NEEDS OF PEOPLE AFFECTED BY CANCER?

Questions to consider

Rather than seek to set out a list of prescriptive recommendations/actions the sub-group felt it would be helpful instead to set out some important generic and cancer specific questions which should be considered locally by NHS Boards and cancer networks BEFORE looking at plans/proposed actions/solutions. This will also help to focus effort and facilitate the production of a regional cancer network reporting template for patient information.

- › What arrangements are in place to identify and promote the availability of cancer patient information/support locally and/or regionally?
- › Who co-ordinates that information?
- › Is there a process for reviewing patient information in your area?
- › Who is responsible?
- › How is that information disseminated?
- › Is there/what is the communication training strategy for all relevant staff?
- › Is there a record made of the information given to patients? – What does the patient know and understand about their illness?

- › Is there a library or list of patient information available across all Cancer Networks?
- › Who has it?
- › How can it be accessed by staff (for patients) and by patients and carers?
- › Can this information be accessed by patients in their own time, when they want it, tailored to their needs?
- › Who updates it?

IT'S HAPPENING ALREADY ...

The South East Scotland Cancer Information project, will provide a baseline of available patient information across the Network area.

- › Who is responsible for tumour specific patient information for each regional cancer network area? The local NHS Board? A specific service or hospital in the area?

IT'S HAPPENING ALREADY ...

Forth Valley – The patient-held guide to chemotherapy in colon and rectal cancer was commended by CSBS. All colorectal cancer patients who receive chemotherapy are given a copy of this guide. A patient satisfaction survey of this guide has been carried out, and revision of the guide is planned in response to the survey.

- › Is patient information included in investment planning for cancer services?
- › Is there a mechanism in place for measuring patient satisfaction with the information provided?
- › Are there processes in place to measure improvements as a result of local, regional and national patient information initiatives?

IT'S HAPPENING ALREADY ...

Ayrshire & Arran Acute Hospitals NHS Trust has developed a Cancer Nurse Steering Group to facilitate the dissemination of best practice amongst cancer nursing services across the Trust and consult with the Lung Cancer Multidisciplinary Team on issues relevant to communication and information provision for lung cancer patients.

- › Is there a process to share and benefit from others' experiences using leaflets or websites adapted as required?
- › Will a new patient information leaflet duplicate what is already there? Can existing information leaflets be built on?
- › Are there formal and/or informal processes in place to facilitate intra- and inter-departmental communication?
- › Are there formal and/or informal processes in place to facilitate communication between different members of the multidisciplinary teams and across different healthcare settings?

IT'S HAPPENING ALREADY ...

Argyll & Clyde, Ayrshire & Arran – The Royal Alexandra Hospital Paisley and Crosshouse Hospital Kilmarnock are planning to take part in the Electronic Clinical Communications Implementation (ECCI) pilot project which will help to improve the communication between primary and secondary care.

MONITORING PROGRESS

There are two strands to monitoring local and regional progress towards improving access to information for people affected by cancer – via the *Cancer in Scotland* (CIS) Implementation Framework and the NHSScotland Performance Assessment Framework.

Cancer in Scotland Implementation Monitoring Framework

An Implementation Framework has been developed to routinely monitor progress towards achieving the various objectives set out in *CIS*. RCAGs currently provide 6-monthly monitoring reports on their cancer investment plans to the Scottish Cancer Group which feed into the *CIS* Implementation Framework. These reports are published and can be accessed on the *Cancer in Scotland* website available at www.show.scot.nhs.uk/sehd/cancerinscotland

- ▶ RCAGs will require to report and monitor progress on securing better access to information for people affected by cancer via the *CIS* Implementation Monitoring Framework.
- ▶ The development of a regional reporting template for cancer information will help with both PAF and *CIS* monitoring and reporting and Regional Cancer Networks may find it helpful to use the *Questions to consider* in Chapter 4 as a basis for developing a regional reporting template. This will also help secure consistency in reporting across Scotland.
- ▶ A report providing baseline information should be included in October 2003 Monitoring Reports. Improvements will be tracked in subsequent Monitoring Reports.

Performance Assessment Framework (PAF)

The PAF forms the mandatory core framework for assessing the performance of NHSScotland and provides the stimulus for continuous performance improvement. The PAF draws together the targets that exist under various policies and will be used as the basis for reviewing NHS Boards' performance for 2002/03.

Patient Information is an integral part of the PAF and is included in two sections –

- (1) The Involving People Team – A Programme for Change

A successful local health system will: Provide high quality, appropriate information to the public.

- (2) NHS Quality Improvement Scotland incorporating the Clinical Standards Board for Scotland .

Patient Information and Patient/Staff communication are an integral part of CSBS Generic standards.

Performance against standards will be monitored within NHSScotland self-assessment reports and reported in the PAF.

ANNEX 1

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ANNEX 2

SCOTTISH CANCER GROUP – PATIENT INFORMATION SUB-GROUP MEMBERSHIP

Mr I Gibson	Director for Scotland Macmillan Cancer Relief and Member of the Scottish Cancer Group	Chair
Ms L Adams	Macmillan Lead Cancer Nurse	NHS Grampian
Ms C Campbell	Breast Care Liaison Nurse	Stobhill Hospital, North Glasgow University Hospitals NHS Trust
Dr S Devereux	Macmillan General Practitioner	Tayside
Mr I Dickson	Lay Member	
Mrs B Elliot	Lay Member	
Mrs D Hamilton	Project Manager, SCAN Cancer Information Network	South East Scotland Cancer Network
Mrs C Horne	Tak Tent Cancer Support	Glasgow
Ms J Inglis (to December 2002)	Patient Involvement Worker	South East Scotland Cancer Network
Ms L Webster	Macmillan Information Radiographer and Counsellor	Beatson Oncology Centre Glasgow
Ms J Whelan	Head of CancerBACUP Scotland	Glasgow
Dr S Williams	Mary Thomson Research Fellow	NHS Greater Glasgow

SCOTTISH EXECUTIVE HEALTH DEPARTMENT

Mrs J Birrell	Programme Manager, Cancer Services
Ms G Campbell	NHS Adviser, Patient Focus and Public Involvement Team
Mrs J Davies	Patient Focus and Public Involvement Team
Mrs S Dunn (from October 2002)	Patient Information Project Manager

ANNEX 3

WEBSITES: The undernoted list is not exhaustive but covers a wide range of cancer patient information related and generic patient information sites.

DISCLAIMER: The Scottish Executive Health Department is in no way responsible for these sites and cannot guarantee the accuracy or currency of any of the material you may find there.

<p>Cancer Research UK www.cancerresearchuk.org</p>	<p>CancerHelp UK is a free information service about cancer and cancer care, written especially for patients and their families developed by Cancer Research UK. There is information on specific cancers, treatment information, advice on living with cancer and a link to a clinical trials database.</p>
<p>CancerBACUP www.cancerbacup.org.uk</p>	<p>CancerBACUP aims to help people live with cancer by providing information and emotional support for patients, their families and health professionals. It is recognised as the foremost provider of cancer information in the United Kingdom. The website includes over 2000 pages of information.</p>
<p><i>Cancer in Scotland</i> website www.show.scot.nhs.uk/sehd/cancerinscotland</p>	<p>The <i>Cancer in Scotland</i> website was launched as a result of publication of Scotland's Cancer Plan – <i>Cancer in Scotland: Action for change</i> to provide detail of the work ongoing to implement the cancer plan.</p>
<p>Centre for Health Information Quality www.chiq.org</p>	<p>This site is dedicated to ensuring that all patient information is clear and evidence-based.</p>
<p>DIPEX www.dipex.org</p>	<p>For patients who wish to learn about their disease through seeing/listening to the experiences of other patients.</p>
<p>DISCERN www.discern.org.uk</p>	<p>The DISCERN website is an experimental site consisting of an online version of the DISCERN instrument and handbook. The handbook is designed to help readers understand and use DISCERN effectively.</p>
<p>Health Services Research Unit www.abdn.ac.uk/public_health/hsru</p>	<p>The national remit of the Health Services Research Unit (HSRU) is to research the best ways to provide health care, and to train those working in the health services in research methods. They have produced three evidence-based patient information leaflets.</p>
<p>HEBS www.hebs.scot.nhs.uk</p>	<p>The Health Education Board for Scotland is Scotland's national agency for health education, health promotion, health advice and health information.</p>
<p>Macmillan Cancer Relief www.macmillan.org.uk</p>	<p>Provides an online service for people living with cancer who need access to information and support. It has information about each stage of the cancer journey through diagnosis to treatment and care. The site also offers access to local support groups, helpful organisations and links to other reliable sources of information [Information Materials Directory www.hfht.org/macmillan]</p>

<p>NHS Quality Improvement Scotland (NHS QIS)</p> <p>www.nhshealthquality.org</p>	<p>As of 1 January 2003, the Clinical Resource and Audit Group (CRAG), Clinical Standards Board for Scotland (CSBS), the Health Technology Board for Scotland (HTBS), Nursing & Midwifery Practice Development Unit (NMPDU) and the Scottish Health Advisory Service have joined together to form NHS Quality Improvement Scotland (NHS QIS). The website for NHS QIS is currently under development.</p>
<p>Patient Focus and Public Involvement</p> <p>www.show.scot.nhs.uk/involvingpeople</p>	<p>This website has been developed following the publication of Patient Focus and Public Involvement in December 2001. The site contains information on work taking place throughout Scotland, information on forthcoming training events and online access to the Building Strong Foundations toolkit.</p>
<p>Scottish Accessible Information Forum</p> <p>www.saifscotland.org.uk</p>	<p>SAIF aims to make information more accessible to everyone who needs it. SAIF supports the rights of disabled people and carers in having access to timely and accurate information about a wide range of services.</p>
<p>Scottish Health on the Web</p> <p>www.show.scot.nhs.uk/indexhelp.htm</p>	<p>SHOW acts as the main access point for a range of NHS Scotland services and resources. The site is structured into four different categories, these being:</p> <p>For NHS Staff – this section provides links to resources to assist those employed in health care in the operation of their duties. Although accessible by the public, its intended audience means that technical language and jargon is much more frequent in this section.</p> <p>Organisations – this section provides links to NHSScotland and related organisations through a map of Scotland divided by health board area.</p> <p>Publications – the publications section can be used to search for NHSScotland publications produced by the Scottish Executive and a variety of other NHS organisations.</p> <p>For the public – this section is for the collection of resources that are intended for direct access by the general public. Topics include health promotion, patient information, and topical health issues.</p>

ANNEX 4

USEFUL READING

- › Macmillan Information Materials Guide; managing, selecting and producing information materials in cancer information and support services
- › Macmillan Cancer Relief – A Directory of Information Materials for people with cancer 2002/2003; a selected guide to nationally published leaflets, booklets, books, audio-visual materials and websites; 3rd edition (produced in partnership with the Centre for Health Information Quality)
- › Macmillan Black and Ethnic Minority Toolkit; Effective Communication with South Asian people affected by cancer 2002
- › The POPPi Guide. Practicalities of producing patient information Duman M Farrell C. Kings Fund 2000
- › Sharing Decisions with patients: Is the information Good enough Coulter A Entwistle V Gilbert D BMJ 99; 318: 318 – 322
- › Towards a global definition of patient centred care Stewart M BMJ 2001 322: 444 – 445
- › After Bristol: putting patients at the centre. Commentary: patient centred care; timely, but is it practical Coulter A Dunn N BMJ 2002; 324: 648-651
- › Informing Patients: an assessment of the quality of patients information materials. Coulter A, Entwistle V, Gilbert D, King's Fund 1998
- › Information needs of cancer patients in West Scotland: cross sectional survey of patients' views. Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, Fallowfield L. BMJ 2000 1996; 313: 724-726
- › Cancer patients' information needs and information seeking behaviour; in depth interview study. Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, McPherson K, BMJ 2000; 320: 909 – 913
- › NHS Modernisation Agency Cancer Services Collaborative 'Patients Issues' and 'Possible Solutions for Change' October 2001
- › How to provide information well to Bangladeshi, Chinese, Indian and Pakistani People: a good practice guide (1998) Published by National Information Forum
- › Royal National Institute for the Blind: See it Right! (2001) Published by the Royal National Institute for the Blind, London
- › Scottish Accessible Information Forum: Standards for Disability Information and Advice Provision in Scotland (1999) Published by Scottish Consumer Council, Glasgow

GLOSSARY

BMJ – British Medical Journal

CSBS – Clinical Standards Board for Scotland

CIS – *Cancer in Scotland: Action for change*

ECCI – Electronic Clinical Communications
Implementation

HEBS – Health Education Board for Scotland

HSRU – Health Service Research Unit

MCN – Managed Clinical Network

NHS – National Health Service

NHS QIS – National Health Service Quality
Improvement Scotland

PAF – Performance Assessment Framework

PFPI – Patient Focus and Public Involvement

POPPI – Practicalities of producing patient information

RCAG – Regional Cancer Advisory Group

SAIF – Scottish Accessible Information Forum

SCAN – South East of Scotland Cancer Network

SEHD – Scottish Executive Health Department

SHOW – Scottish Health On the Web

If you want to comment on any of the issues in *Cancer in Scotland: Action for Change* and associated documents or make suggestions about how these can be taken forward, you can contact a member of the Cancer Team at:

Scottish Executive Health Department
St Andrew's House
Regent Road
Edinburgh
EH1 3DG
e-mail: cancer@scotland.gsi.gov.uk

Useful web addresses:

Cancer in Scotland:

www.show.scot.nhs.uk/sehd/cancerinscotland

Scottish Executive Health Department:

www.scotland.gov.uk

Scottish Health on the Web

www.show.scot.nhs.uk

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