



CONSTITUTION FOR NORTHERN IRELAND CANCER NETWORK (NICAN) PATIENT AND PUBLIC INVOLVEMENT FORUM

OCTOBER 2007

This paper sets out the constitution for the Northern Ireland Cancer Network (NICaN) Patient and Public Involvement Forum. This was discussed and endorsed by the NICaN Board at its meeting on 19th October 2007.

This document forms part of the Constitution of the Cancer Network. Other parts include: Constitution of Network Board, Constitution of Network Team and Constitution of Regional Groups.

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BACKGROUND CONTEXT

What is NICaN?

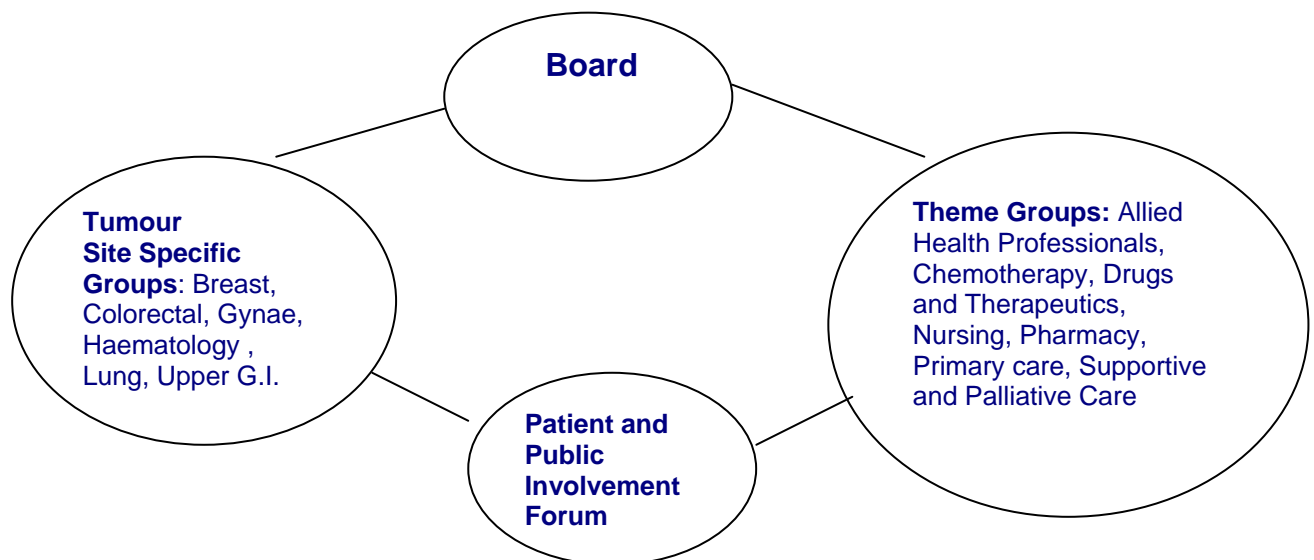
The Northern Ireland Cancer Network was established to ensure a regional approach to the planning and developing of cancer services. The Cancer Network is recognised as the way forward in which cancer services will best be co-ordinated across boundaries. The inaugural meeting of the Network Board was held in 2004.

The Cancer Network

'is working towards the continuous improvement in cancer care and cancer survival for the people of Northern Ireland. It aims to promote equitable provision of high quality, patient focused and clinically effective cancer services.'
(NICaN Report, 2004)

It is comprised of a Network Board, Network Team, Tumour Site Specific and Theme Groups. Patient and Public Involvement is interwoven throughout the Cancer Network. See Appendix 1 for details of Tumour Site Specific and Theme groups.

Figure 1 Organisational arrangements within NICaN



The Cancer Network recognises the valuable work currently undertaken by voluntary groups and charities throughout Northern Ireland. Patient and Public Involvement within the Cancer Network does not, therefore, intend in any way to replicate the work of charitable organisations and groups which provide advocacy and support to individuals affected by cancer throughout the Northern Ireland. **Consequently it is NOT another support group.** Rather, it seeks to be a way of bringing together many individuals who are involved in the different cancer related organisations. It also seeks to provide the opportunity for individuals not involved in any specific organisation to have their input into developing cancer services.

Patient and Public Involvement should, therefore, be viewed as

- An opportunity for individuals affected by cancer to shape cancer services *as they are being developed*
- An opportunity where individuals affected by cancer i.e. those diagnosed with cancer, family carers, friends or those generally interested in contributing to services, meet to discuss aspects of cancer care which they consider to be important
- A conduit for the flow of information between a variety of organisations, statutory, voluntary, acute and community based throughout Northern Ireland
- An opportunity for individuals to become actively involved in developing innovative opportunities which will enhance patient care
- An opportunity to provide health professionals with a clear mechanism of accessing patient and public input and the opportunity to work together, enhancing outcomes of care for all.

Purpose of Patient and Public Involvement Forum

The purpose of the Patient and Public Involvement Forum is ultimately to provide a unique platform from which the voice of individuals affected by cancer throughout Northern Ireland can be heard and acted upon.

Purpose of Patient and Public Involvement Constitution

The purpose of this Constitution is to set out clearly and concisely what is meant by Patient and Public Involvement (referred to hereafter as PPI) within the Northern Ireland Cancer Network and the processes through which it will be enabled.

SECTION 1: The Seven Guiding Values

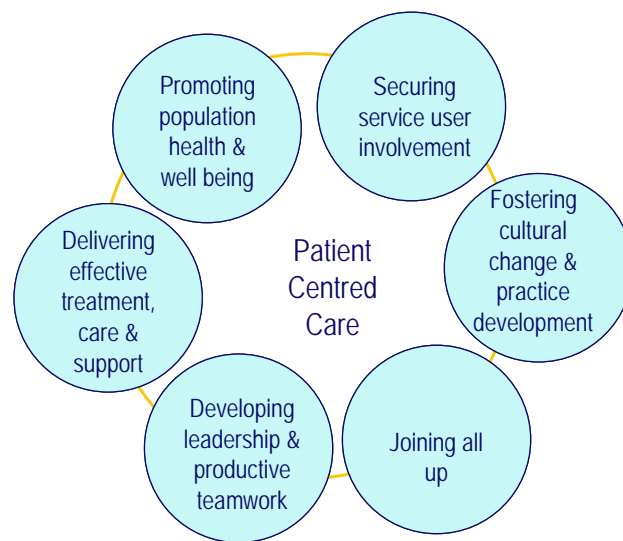
The overall work of the Cancer Network is guided by the seven values set out below. They are the binding principles which are mutually respected and endorsed by all involved with the work of the Cancer Network.

Central to these values is the aim of securing the involvement of individuals affected by cancer and those with an interest in cancer services.

1. Creating a person centred service
2. Securing involvement of individuals affected by cancer and those with an interest in cancer services
3. Fostering cultural change and development
4. Joining 'everything' up to provide seamless care
5. Promoting population health/well being
6. Providing clinically effective treatment, care and support
7. Developing clinical leadership and meaningful teamwork

Figure 2 The seven guiding values of the Cancer Network

Building the Network



SECTION 2: PATIENT AND PUBLIC INVOLVEMENT

The need to involve patients and the public generally within health care is acknowledged in the DHSSPSNI document 'A Healthier Future 2005 -2025'. Participation of individuals at all levels should, through open and transparent processes, be seen to make a difference.

Specifically within the area of cancer services the Department of Health now places a priority upon

'involving people affected by cancer in all aspects of care
(and) identifies the importance of engaging with communities and patients at the centre of service development, design and delivery.'
(Cancer Control Programme, 2006, 30)

The avoidance of tokenism as to *how* PPI is both initiated and developed is considered to be of paramount importance. This is in order that 'box ticking' exercises are avoided and that all involved understand what active and meaningful patient and public involvement actually looks like. Hence, PPI is more than giving out information and consulting with individuals, vital as these activities are. Active and meaningful patient and public involvement may be said to be happening when individuals are enabled to participate in developing services and ultimately are involved in processes that allow them to be able to affect change.

SECTION 2 (i) Composition of Patient and Public Involvement

PPI is being developed in a variety of ways within the Cancer Network and is aimed at including individuals who have had a diagnosis of cancer, relatives or friends of those diagnosed and other individuals who have an interest in cancer services. Following a series of regional meetings with individuals from a variety of cancer support groups and charities, as well as those with no specific link to any organisation, a framework for taking PPI has gradually developed.

PPI will be developed in a variety of ways;

- i)* through development of the role of **Forum Leads**. The role of Forum Lead will involve individuals having direct access to the Cancer Network Board, representatives in the Tumour and Theme groups and the Northern Ireland Regional Forum. Forum Leads will be closely involved in developing PPI within the Cancer Network through working with the Regional Co-Ordinator for Patient and Public Involvement.
- ii)* through the development of patient and public representatives in the **Tumour and Theme Groups**
- iii)* through a **Core group** which will be made up of Forum Leads, the Regional Co-Ordinator and the PPI Representatives who sit on the Tumour and Theme groups
- iv)* through the **N.I. Regional PPI Forum** which will be the means of providing information to patients and the public as well as being a means of receiving information from them and affording them the opportunity to become involved in work projects within the Cancer Network

The diagram below sets out the components which will make up PPI within the Cancer Network. Each component has a unique role which is set out later in this document.

Northern Ireland Cancer Network

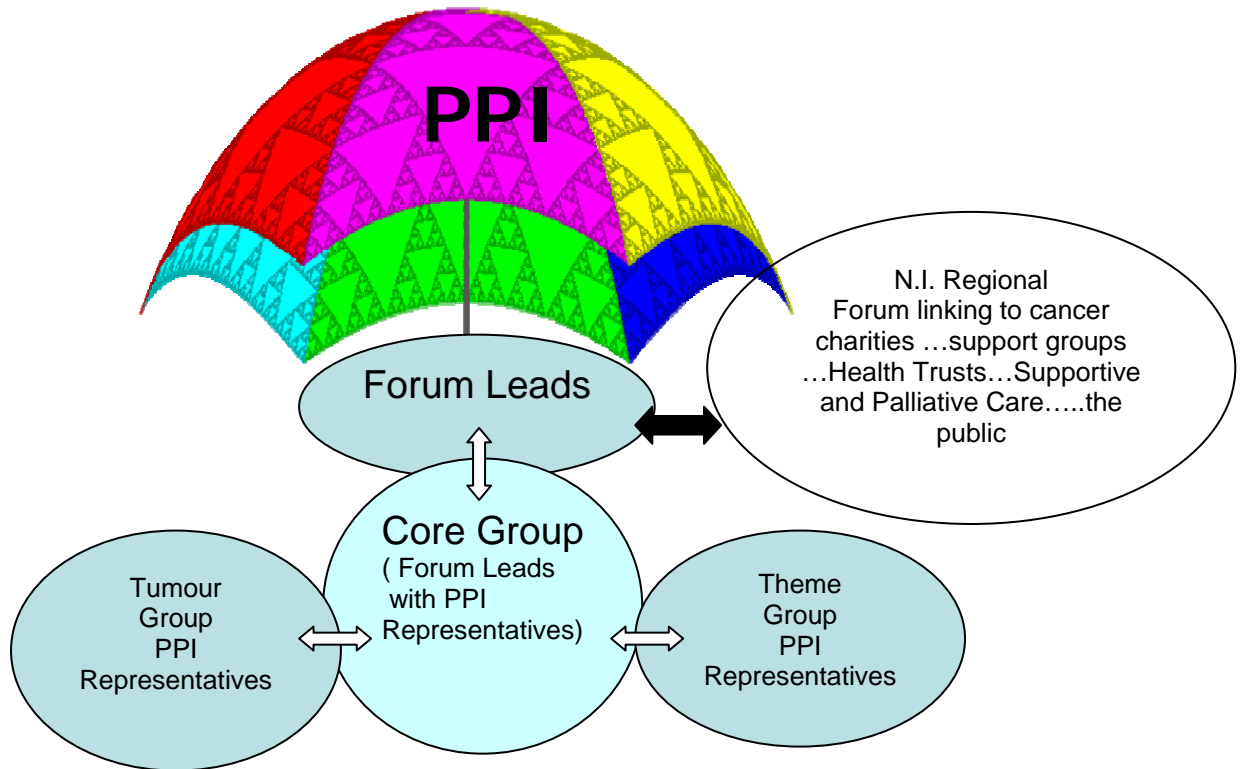


Figure 3: Overview of Patient and Public Involvement within the Cancer Network

SECTION 2 (ii) Vision & Purpose of Patient and Public Involvement

The overall vision of Patient and Public Involvement within the Cancer Network is to enable individuals to be actively and meaningfully involved in the planning and development of cancer services within Northern Ireland.

It is recognised that: -

- PPI may occur in a variety of ways i.e. through individuals working alongside health care professionals within the regional Tumour and Theme groups or individual projects undertaken by individuals or sub groups within a Regional Forum
- there must be clear guidance as to how individuals can become members of the various Tumour or Theme groups
- links must be established to cancer charities and clear lines of communication developed with same (please see Appendix 2 for a list of all support groups /organisations associated with the Forum)
- *all* individuals connected to PPI are aware of the purpose of the Cancer Network and their role within same

SECTION 2 (iii)

Code of Conduct

Effective working relationships will be based upon mutual respect, trust and support. Members will be required to sign a Constitution in which

- attitudes adopted by members will be respectful, acknowledging that differences of opinion should be dealt with respectfully and gently without causing offence to others
- each member will be committed to the purpose of the PPI Forum and the work which it seeks to undertake within the Cancer Network
- each member will seek to create a democratic environment in which all participants feel that they can have their voice heard and where differences are recognised and accepted
- an atmosphere of trust is generated through a setting in which all individuals are recognised as being of equal standing
- all individuals are afforded the opportunity to be listened to and in turn give others their chance to be heard in a positive and facilitated way
- members have a sense of accountability to the PPI Forum recognising the importance of attending Forum meetings as well as those relating to any sub group projects of which they may be part. Where attendance at a meeting is not possible, apologies should be forwarded in advance
- use of jargon is kept to a minimum
- confidentiality is respected
- See Appendix 2– Code of Conduct Agreement

SECTION 2 (iv)

Forum Leads

Composition

The roles of Forum Leads will be undertaken by

- individuals who have had their own experience of receiving a diagnosis of cancer
- OR**
- Individuals who have cared closely for a family member who has received a diagnosis of cancer
 - Three individuals will hold the role of Forum Leads simultaneously

Role

- To understand and maintain the vision and purpose of the Cancer Network and be guided by the seven core values
- To work with the Regional Co-Ordinator in shaping and directing PPI in cancer services throughout Northern Ireland
- To represent patients and the public on the NICaN Board
- To ensure that the PPI Forum maintains links to the appropriate individuals, groups and organisations throughout N. Ireland
- To liaise regularly with the Regional Co-Ordinator in planning the dates, venues and agenda of N.I. Regional Forum meetings

- To work with the Regional Co-Ordinator in planning ,developing and maintaining a process through which effective, meaningful and sustainable involvement of PPI in the Tumour and Theme groups can take place
- To work with the Regional Co-Ordinator and other Forum members in developing evaluation and audit tools which will measure the effectiveness of Patient and Public Representatives within the Network groups
- To lead in proposed projects within the N.I. Regional Forum
- To be an advocate for patients and the public throughout Northern Ireland in the area of cancer services
- To liaise with appropriate individuals/agencies throughout the various care sectors within Northern Ireland i.e. statutory, voluntary, independent in order to:
 - 1) raise awareness of the benefits of co-ordinated PPI
 - 2) guide policy makers as cancer services are developed based upon the experiences of individuals affected by cancer
 - 3) influence policy development

From the date of adoption of the Constitution the Forum Leads will serve for a minimum of two years. One Lead will remain for a further twelve month period for the purposes of ensuring continuity, supporting and guiding Forum Leads newly elected to the role. Future election to the role of Forum Lead will take place through a process of electing nominees from within the membership of the N.I. Regional Forum.

SECTION 2 (v) Core Group

Composition

- Forum Leads, Regional Co-Ordinator, representatives sitting on Tumour and Theme Groups

Role

- To meet with Forum Leads in order to
 - provide direction and guidance to the Forum Leads and PPI within the Forum in general
 - receive support and guidance in the role of PPI Representatives

SECTION 2 (vi) Tumour Site Specific and Theme Groups

Composition

- PPI in the form of a minimum of two representatives thereby ensuring that the voice of those affected by cancer is heard throughout all discussions and developments
- Professionals from all areas of health care i.e. nursing, medical, physiotherapy, occupational therapy, pharmacy etc.

Role of Tumour and Theme Group PPI members

- To represent the views of patients and the public in the Tumour and Theme groups within the Cancer Network
- To have specific links throughout Northern Ireland with a variety of individuals /groups relevant to the specific Tumour group
- To provide patient perspective/ information *to* the health care professionals in the groups from patients and the public as well as providing information *from* the group out to patients and the public, thereby creating a network for the flow of relevant, up-to-date information to all parties concerned
- To take part in projects within the Tumour and Theme groups
- To be part of the Core Group which will exist to provide guidance to the Forum Leads as well as support to group members

SECTION 2 (vii) Northern Ireland Regional Forum

Composition

- The N.I.Regional Forum will provide a setting in which patients and the public can meet to discuss issues relevant to cancer services within Northern Ireland. It will include representation from
 - the various cancer support groups and charities within Northern Ireland
 - each of the five individual Trusts which will, in turn, liaise with the cancer related groups within its boundaries
 - Health Councils
 - interested parties not connected to specific groups or organisations
- Members will meet at intervals (to be agreed)- the agenda will be set by the Forum Leads in liaison with the Regional Co-Ordinator
- The N.I.Regional Forum will be open to individuals unconnected to specific cancer related groups thereby providing wider access to PPI regionally, openly and transparently

Role

The N.I.Regional Forum will provide

- a venue for a variety of individuals to meet, be informed of and discuss regional issues as well as those specific to their own local areas
- a direct means of linking individuals affected by cancer throughout Northern Ireland i.e. those connected with specific cancer support or advocacy groups, charities or the general public, thereby ensuring that the Cancer Network keeps its finger upon the pulse of the relevant, holistic needs of such individuals
- understanding of the vision and purpose of the Northern Ireland Cancer Network and be guided by the seven values upon which the Cancer Network is built
- the opportunity for individuals to participate in appropriate projects within the Cancer Network

See Appendix 3 for details of cancer support groups/organisations linked to the N.I. Regional Forum

SECTION 3: SUPPORT FOR MEMBERS

Support will be provided as follows:

- Through creating an open, friendly atmosphere where the input of all members is acknowledged to be of equal value
- Through facilitation of training, education and life skills for *all* involved
- Separate meetings will be held between Forum Leads , the Regional Co-Ordinator and representatives of the Tumour and Theme groups to facilitate open and honest discussion on the roles of PPI Representatives
- Through providing individuals with an awareness of, or access to, professional help if such is requested or considered necessary

SECTION 4: EVALUATION AND AUDIT TOOLS

A variety of evaluation /audit tools will be devised in order to ensure that the process of PPI is facilitated e.g. questionnaires, focus groups etc. and the effectiveness of PPI *throughout* the Cancer Network is assessed.

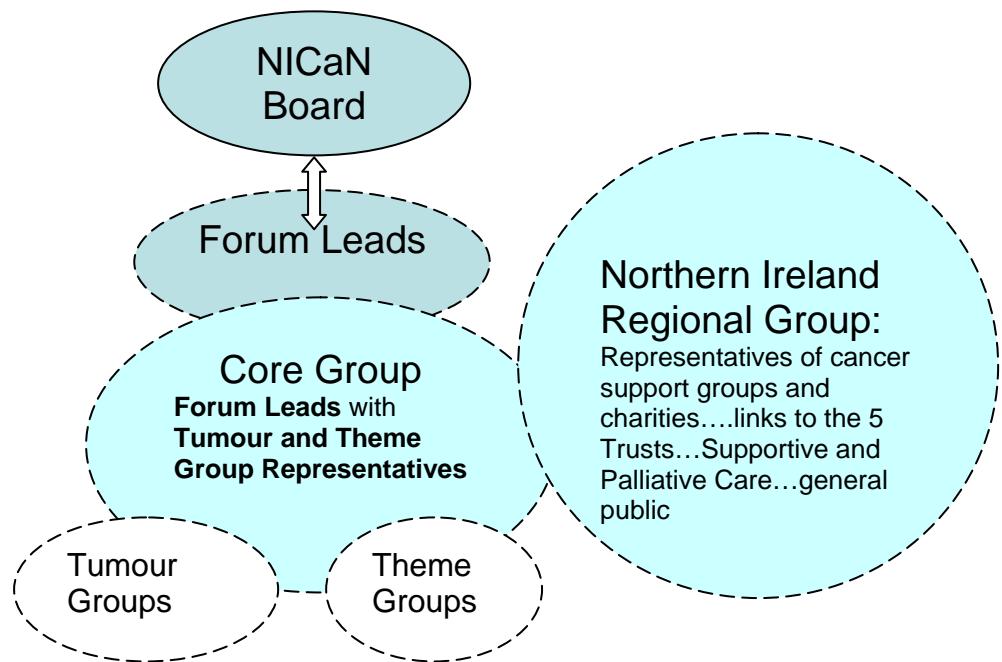
SECTION 5: LINES OF COMMUNICATION

Processes are in place to ensure that information is disseminated freely and that the voices of those affected by cancer are heard. Developing the PPI Forum in each of the ways set out will enable active and meaningful PPI within the Cancer Network.

The diagram below sets out the lines of communication relating to PPI within the Cancer Network in keeping with the roles of the Forum Leads, Tumour and Theme Group representatives and individuals involved in the N.I. Regional Forum.

Figure 4

Enabling a strong voice for Patient and Public Involvement across the Cancer Network



SECTION 6: TRAVELLING EXPENSES

Reimbursement will be provided for individuals with whom there is a *prior agreement* to attend Patient and Public Involvement meetings either as a Forum Lead, member of a Tumour group or Theme group.

It is the aim of the Cancer Network that no PPI representative will be out of pocket as a result of attending *any* Network meeting- Lead, Core, Tumour, Theme, Regional or Board.

All individuals involved in Patient and Public Involvement *must* claim the expenses to which they are entitled

SECTION 7: ADMINISTRATION

(i) Agreed Times/ Venues for Meetings

Where possible, the dates, times and venues for all meetings will be agreed 3 months in advance. Tumour and Theme group meetings may be established for the year ahead.

(ii) Work Projects

Where individual projects are established within the Regional Forum, there will be a consistency in the process undertaken i.e. all projects will have a lead contact person who will liaise directly with a named Forum Lead. Times lines will be set for all projects.

(iii) **Contact Details**

For contact details of Forum Leads and Regional Co-Ordinator please see Appendix 4

SECTION 8 REVIEW OF CONSTITUTION

This Constitution will be periodically reviewed by the Forum Leads, Regional Co-Ordinator and NICaN Board. Any suggested amendments will be forwarded to all relevant parties for their perusal in advance of final changes being made to the document.

APPENDICES

APPENDIX 1

Tumour Site Specific and Theme Groups within the Cancer Network

These are groups made up of individuals who meet to address

- i) a particular type of cancer e.g. bowel
- ii) work evolving across specific areas of care

The Tumour Site Specific and Theme groups are the nucleus of the Cancer Network and are responsible for the development of work within the Cancer Network. They provide the opportunity for health care professionals and individuals affected by cancer to meet, discuss and plan both current and future developments which will affect the care of patients. The work undertaken through these groups is critical in shaping cancer services within Northern Ireland. Hence, the active participation by those individuals who have used such services is of utmost importance.

SITE SPECIFIC GROUPS

Breast

Colorectal (bowel, rectum)

Haematology (blood malignancies, such as leukaemia or lymphoma)

Gynaecology

Lung

Skin

Urology

Upper G.I (gullet and stomach)

THEME GROUPS

Allied Health Professionals

Chemotherapy

Drugs and Therapeutics

Nursing

Pharmacy

Primary Care

Supportive and Palliative Care

APPENDIX 2

Cancer Support Groups linked to the Patient and Public Involvement within the Cancer Network

Action Cancer

Angels of Hope

Brain Waves

Cancer Choices

Cancer Lifeline

Family Life Foundation

Leukaemia Care

Lilac

Macmillan Cancer Support

Mid Ulster Support Group

Northern Ireland Laryngeal Association

Northern Ireland Lymphoedema Support Group

Northern Ireland Oesophageal Association

Ulster Cancer Foundation

APPENDIX 3

Code of Conduct Agreement

I have read the Constitution for Patient and Public Involvement within the Northern Ireland Cancer Network and am willing to comply with the terms set out within this document.

Signed:

Date:

APPENDIX 4

Forum Leads

Mr Alex McGuiggan , Ulster Cancer Foundation Laryngectomy Support Group
Mrs Bernie Montgomery; Cancer Lifeline, Alliance Avenue, Belfast
Mrs Madeline Mulgrew; Cancer Choices, Dungannon

Regional Co-Ordinator for Patient and Public Involvement

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REFERENCES

Campbell Report (1996) Investing for the Future

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