

# Agenda of involvement and engagement

## Introduction

---

Across Europe, members of the public, whether as current, previous or future patients or as carers, have been encouraged to participate in healthcare research, policy and planning, and practice. This article is a module looking at the agenda of involvement and engagement with a particular focus on cancer care.

This module should take approximately 4 hours to complete, made up of up to 2 hours of activities and 2 hours of reading, thinking and reflection.

## Learning objectives

---

The activities and content of this module are built around the following learning objectives:

- Describing current policy, and in particular UK policy directives that promote the agenda of patient and public involvement and engagement;
- Identifying different models of involvement and engagement;
- Understanding the process of involvement and engagement and identifying barriers to involvement and engagement work;
- Identifying and developing involvement and engagement in your workplace;
- Identifying the outcomes of involvement and engagement activity.

## Current policy

---

Developing a patient and public focus to healthcare is not a new concept. Arnstein (1969) first described different levels of involvement for citizenship involvement in political/policy decision-making – moving from consultation (as the lowest level of involvement) through to participation (where there is more partnership and power sharing) and finally to user-led initiatives where power is explicitly held by service users.

Thus, since the late 1960s ideas of involvement have been developed and theorised. Throughout the UK National Health Service (NHS), health care providers have sought to involve users in service improvement initiatives to drive up standards of care and delivery. In recent years, a range of government policy has encouraged the agenda of involvement and engagement in healthcare in a number of different countries.

For example, the latest England and Wales legislation is the **Local Government and Public Involvement in Health Care Act 2007**. The Act introduces Local Involvement Networks (LINKs). LINKs are networks of local people and groups that will ensure local communities can monitor service provision, influence key decisions and have a stronger voice in the process of commissioning health and social care. LINKs will cover the geographical area of Local Authorities that have social services responsibilities. To enhance their independence, LINKs must be hosted by a body other than a Local Authority or an NHS body. Under the new Act, Strategic Health Authorities, Primary Care Trusts, NHS Trusts and NHS Foundation Trusts must make arrangements for people who receive or may receive services to be involved in:

- Planning of the provision of those services;
- Developing and considering proposals for changes in the way those services are provided;
- The decisions to be made affecting the operation of those services.

The Act says that people can be ‘involved’ either by being consulted or provided with information or in other ways. The Act also says that ‘involvement’ can be either direct or through representatives.

The promotion of an agenda of patient and public involvement and engagement in health care can also be seen in other countries, for example:

**Scotland** – *Patient Focus and Public Involvement*, Edinburgh: Scottish Executive Health Department, 2001. This Scottish Government document sets out the agenda of patient and public involvement in health care for the nation.

**United States** – United States Food and Drug Administration (FDA). The FDA is responsible for protecting the public health by assuring the safety, efficacy, and security of human and veterinary drugs, biological products, medical devices, our nation’s food supply, cosmetics, and products that emit radiation. The Patient Representative Program is responsible for providing FDA the unique perspective of patients and family members directly affected by a serious or life-threatening disease. The Drug Development Patient Consultant Program incorporates the perspective of patient advocates into the drug development process allowing them an opportunity to participate in the FDA drug review regulatory process.

**Canada** – Health Canada is the Federal department responsible for helping Canadians maintain and improve their health, while respecting individual choices and circumstances. Health Canada developed its departmental *Policy Toolkit for Public Involvement in Decision Making* in 2000. The policy provides direction for Health Canada employees on public involvement. It provides principles, guidelines and information for the effective involvement of the public in government decision-making on health issues.

Cancer specific policy reflects a general promotion of patient and public involvement. For example, *The Cancer Reform Strategy*, (Department of Health, 2007) for England and Wales recognises that user involvement should play a central role in improving the quality of patient care and in decisions about which services should be provided in the future.

**Thinking Point:**

How many patients and members of the public do you think are aware of policy promoting the agenda of involvement and engagement? Are you aware of the policy that exists about patient and public involvement and engagement in your country? Does it matter that members of the public are aware of it?

**Activity 1 (allow approximately 30-45 minutes)**

---

**Task 1:** You wish to become involved in the health services in your area in your capacity as a patient, carer and/or member of the public. Using the internet, research opportunities in your local general practice, health board, cancer network and/or hospital to identify ways in which you can become involved in developing and shaping local health services.

Keep a record of:

- How long it takes to obtain the information
- Whether the information was accessible
- Whether you feel encouraged to get involved
- What you can become involved in.

## Resources required to complete this activity

### Useful websites

Involve:

<http://www.involve.org.uk/>

NHS Centre for Involvement:

<http://www.nhscentreforinvolvement.nhs.uk/>

Local Involvement Networks (LINKs)

[http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/dh\\_076366](http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/dh_076366)

Cancer Care Research Centre

<http://www.cancercare.stir.ac.uk>

The USA's National Coalition for Cancer Survivorship

<http://www.canceradvocacy.org/get-involved/cancer-advokit/>

Scottish Executive (2001) Patient Focus and Public Involvement, Scottish Executive, Edinburgh

<http://www.scotland.gov.uk/Publications/2001/12/10431/File-1>

Scottish Health Council

[http://www.scottishhealthcouncil.org/shcp/CCC\\_FirstPage.jsp](http://www.scottishhealthcouncil.org/shcp/CCC_FirstPage.jsp)

Health Canada

<http://www.hc-sc.gc.ca/ahc-asc/public-consult/index-eng.php>

US Department of Health and Human Services; National Institutes of Health

<http://getinvolved.nih.gov/>

### Background reading

Arnstein SR. (1969) A Ladder Of Citizen Participation. *Journal of the American Planning Association* 35: 216-224.

Department of Health (2007) Cancer Reform Strategy. Her Majesty's Stationery Office. London.

## Models of involvement and engagement

Involvement and engagement are often used as synonyms. But this belies the important differences that they imply about the level of power sharing and control that people using health services have with each. We understand involvement to be the lower level, and engagement to be more advanced where there is joint working and where service users have genuine power and ability to influence decisions.

## Hierarchy of involvement

Hanley et al (2005) distinguish between consultation, collaboration and user-controlled involvement in a hierarchy of involvement:

- *Consultation* – people are asked for their views that are used to inform decision-making. These views will not necessarily be adopted, although they may have an influence on decision making.
- *Collaboration* – involves active, on-going, partnership with members of the public/people who use services.
- *User-controlled* – power, initiative and subsequent decision-making lies with service users rather than with professionals.

Thus, using Hanley's typology of involvement, 'consultation' would be an example of involvement whereas 'user-controlled' would be an example of engagement.

Models of involvement and engagement can also be distinguished by what services users are involved in. The way involvement is articulated in policy and literature, positions patients as consumers, citizens, partners and co-researchers depending on context and ideological drivers. As consumers and citizens, patients are involved in developing policy and service planning; as consumers and partners, they are involved in their own care practice deciding upon where and how they are treated and as co-researchers they are involved in health research. Thus, four models of involvement are visible in the literature and policy. They are defined by *who* is involved and *what* they are involved in doing. These are laid out in table 1.

**Table 1: Four models of involvement**

Who	What	Ideological drivers
Patient as consumer	Purchase or choice of service	Free-market economics
Patient as citizen	Policy and service planning	Social-democratic
Patient/Partner as partner	Care practice	Experiential knowledge
Patient as researcher	Co-research	Emancipation and empowerment

The first is the involvement of *consumers* in purchasing or choosing services. The second is the involvement of *citizens* in developing public policy and service planning. The third is the involvement of *patients, service users and their carers* in care practice, and the fourth is the involvement of *patients, service users and their carers* as co-researchers.

### Model 1 – patient as consumer

Consumerism and marketisation position patients as consumers of healthcare services. In a private healthcare market consumers *buy* healthcare products or services for personal use whereas in a welfare state model they *choose* them. In both models, the Free-market economic doctrine (Needham, 2003) asserts that health services will be developed as a consequence of consumer preference. The underpinning ideology is that consumers form preferences for health services without reference to others, and make choices in a purely self-regarding and self-interested way. The aggregation of individual consumer actions ultimately decides what services are available because those that consumers choose thrive, whilst those that are not chosen cease to be offered. Accountability of services is thereby secured by competition and complaint, with the consumer playing the pivotal role. The extent to which consumers are 'free' to exert their influence via purchase and control is a marker for this model.

## Model 2 – patient as citizen

The second model is one where social democracy and civil society position patients and members of the public as a collective of citizens. A citizen forms preferences for services with reference to others and in the interests of the public good. Choices about services are made collectively and in the context of wider interests than that of the purely personal. Citizens can devolve decision-making about service organisation to professionals and politicians who are entrusted to use their expertise and judgement to plan and deliver services. Accountability of services is secured through democratic structures in which citizens participate. Ideological drivers for patients as citizens originate in a form of government known as social democracy.

### Activity 2 (allow approximately 30 minutes)

---

#### **An example of involvement service planning (patient as citizen)**

The Cancer Care Research Centre (CCRC) at the University of Stirling worked collaboratively with cancer services and cancer patients to drive forward service change (Knighting et al. 2007). This work occurred over a six month period, with the first month dedicated to developing collaborative teams of people working in cancer care and people using lung cancer services, alongside researchers from CCRC. Together they looked at the research evidence regarding people's experiences of cancer within the first year of diagnosis and then identified areas of potential service improvement. Together, these collaborative teams developed ideas for small changes to the service which would improve people's experiences of the service. For example, a patient-held record (with details of the diagnosis, treatment plan and tests/results) was developed with the hope that this would address an identified gap in information provision. The patient held record was developed and then tested out with a small number of patients and modified based on patient feedback. It was tested again with several more patients until it was felt to be satisfactory and when no new further feedback is gained, the change was fully implemented.

**Task 1:** Referring to this example, please answer the following questions:

- What considerations were needed when working with people who use lung cancer services?
- Which part of this process could be considered involvement and/or engagement?

## Model 3 – patient/partner as partner

In the third model, involvement in care practice is distinguished from the above types of involvement because it is about an individual's involvement in his or her own personal health care. Examples include involvement in treatment decision-making and self care. These two loci of involvement in practice are distinct, with one focusing on making *decisions* about care, particularly treatment, and the other focusing on *actively performing* their own care.

However, they share common ground as they both concern the involvement of patients as partners alongside professionals in care practice.

#### **Examples of involvement in research**

Roles people affected by cancer have played in research include:

- *Research advocates* – for example, lobbying the government for money for cancer research
- *Research advisors* – for example, members of study advisory committees
- *Research reviewers* – for example, members of research commissioning bodies deciding which research projects to fund
- *Researchers* – for example, gathering data and presenting research findings at conferences.

The ideology underpinning this model is experiential knowledge, which is a conception that patients have a unique perspective on, and knowledge about, their illness because they are the one's most affected by it.

#### **Model 4 – patient as researcher**

The fourth model shows involvement in research as a distinct conceptualisation. Involvement in research (Hanley, 2005) has been driven by agendas underpinned by ideologies of emancipation through recognition of differential experiences of truth, stemming from both disability and feminist lobbies. The ideological driver is one of epistemology. That is, an acknowledgement that a health care event could be interpreted, understood and knowledged into being in a number of different ways. Traditionally illness research has prioritised clinicians' concerns, thereby disadvantaging patient perspectives and reinforcing hegemonic knowledge. By attending to patient views and experiences by involving them in driving and contributing collaboratively to the research agenda the power imbalance is challenged and historical hierarchies of erudition can begin to be dislodged.

#### **Thinking Point:**

Can the consumer and citizenship model exist side by side? Do individual and collective interests always coincide? Are there any groups in the community that may lose out or gain using a consumer or citizenship model?

### **Activity 3 (allow approximately 30-45 minutes)**

---

**Task 1:** Hanley et al (2005) distinguishes between consultation, collaboration and user-controlled involvement in a hierarchy of involvement:

- *Consultation* – people are asked for their views that are used to inform decision-making. These views will not necessarily be adopted, although they may have an influence on decision making.
- *Collaboration* – involves active, on-going, partnership with members of the public/people who use services.
- *User-controlled* – power, initiative and subsequent decision-making lies with service users rather than with professionals.

In your own work environment, which level of involvement/engagement has occurred?

**Task 2:** Provide examples where it would be appropriate to:

- Consult
- Collaborate
- Have user-controlled initiatives in your work environment.

### **Resources required to complete this activity**

#### **Useful websites**

Patient and Public Involvement Exchange Network  
<http://www.ppix.nhs.uk/>

## Background reading

Hanley B. (2005) Research as empowerment? Report of a series of seminars organised by the Toronto Group. Joseph Rowntree Foundation.

<http://www.jrf.org.uk/bookshop/eBooks/1859353185.pdf>

Knighting K., Forbat L., Cayless S., Kearney N. (2007) Enabling Change: Patient experience as a driver for service improvement. CCRC. University of Stirling.

Needham C. (2003) Citizen-consumers: New Labour's marketplace democracy. Catalyst. London.

Wright D., Corner J., Hopkinson J., & Foster C. (2006) Listening to the views of people affected by cancer about cancer research: an example of participatory research in setting the cancer research agenda. Health Expectations. 1(9): 3-12.

Carter T., Beresford P. (2000) Age and change: models for involvement for older people. Joseph Rowntree Foundation. York.

Involve (2007) Public involvement pack. How to get actively involved in NHS, public health and social care research. Eastleigh. Hampshire.

## Process of involvement and engagement

A recent review of international literature about involving people affected by cancer in research, policy and planning and practice (Hubbard et al. 2007) describes factors that are needed for successful involvement including:

**Training** – training and information for people affected by cancer, researchers and healthcare professionals was identified as an essential requirement for the successful implementation of the agenda of involvement in research, policy and planning and practice. For example, patients involved in practice were found to need an awareness of the aetiology of cancer and the skills to manage treatment-related symptoms. Whilst several examples of training programmes were provided for those involved in research and practice, there were fewer training opportunities for those involved in policy and planning. In the UK, more examples of training for involvement in research were found than for involvement in policy and planning.

### Example of research training programme

Project LEAD is a 4-day programme organised by the United State National Breast Cancer Coalition. Attendees are selected through a competitive application process based on their personal connection to breast cancer, commitment to breast cancer activism and motivation to learn scientific concepts.

**Resources** – finance, dedicated personnel and sufficient time were found to be needed to involve people affected by cancer in research and policy and planning. For example, time, which costs money, was required to build trust, negotiate and consult with all partners involved.

**Culture** – a change in attitudes and roles was also found to be a requisite for the successful implementation of the agenda of involvement. In particular, it was suggested that there needed to be a shift away from paternalism towards partnership where power and control is shared equally.

A further impediment is lack of trust. Healthcare professionals may not welcome patient and carer involvement because they regard criticisms of the service as a 'name and shame' exercise

and may take any criticism as a personal insult. Likewise, patients and carers may be wary of complaining about a service in case it impacts on their treatment. However, many healthcare professionals and patients and carers through actually working together learn to trust one another. For example, Langton et al. (2003) found that students on a work-based learning module for people involved in cancer care who were expected to collaborate with service users on a work-based service development project were initially reluctant to collaborate because of fear of the unknown, fear of loss of power and inexperience; however, through the process of collaboration students found real benefits and changed their attitude. Langton et al. (2003) conclude:

*'Therefore, this project concluded that some of the barriers are more related to fear of the unknown and inexperience of working collaboratively with users and that these barriers can be moved through support and encouragement and positive experience'* (Langton et al, 2003:249).

#### **Thinking Point:**

Debates about who should be involved have taken place. Should new patients or more experienced patient advocates be involved? Should the carer's voice also be heard? Can carers represent patient views? Should the carer experience carry equal weight to that of the patient? Should patients be representatives of a wider community or be there as individuals? Are so-called hard to reach groups of people and marginalised voices be heard?

### **Activity 3 (allow approximately 30 minutes)**

---

**Task 1:** Select a model of involvement/engagement that you think most applies to your work (e.g. if you are a nurse you may wish to focus on the third model which is about involvement of patients in their own health care or if you are a manager of a service you may wish to focus on the second model – patient as citizen – involving citizens in developing and managing your service. Once you have decided on the model, answer the following questions:

- Who are you wishing to involve?
- What are you going to involve them in?
- What is the expected outcome of their involvement i.e. what is the added value of involving them?
- What are the procedures for involving them?
- What are the perceived barriers to involving them?

#### **Resources required to complete this activity**

##### **Useful websites**

National Breast Cancer Coalition

[http://www.stopbreastcancer.org/index.php?option=com\\_content&task=view&id=395&Itemid=138](http://www.stopbreastcancer.org/index.php?option=com_content&task=view&id=395&Itemid=138)

Involve:

<http://www.involve.org.uk/>

Patient and Public Involvement Exchange Network

<http://www.ppix.nhs.uk/>

### **Background reading**

Hubbard G, Kidd L, Donaghy E, McDonald C, Kearney N, (2007) A review about involving people affected by cancer in research, policy and planning and practice. *Patient Education and Counseling*. 65: 21-33.

Langton H, Barnes M, Haslehurst S, Rimmer J, & Turton P (2003) Collaboration, user involvement and education: a systematic review of the literature and report of an educational initiative. *European Journal of Oncology Nursing*. 7(4): 242-252.

Forbat, L (2008) Patient involvement: Making it work. *Health Service Journal*. January 11th. [http://www.hsj.co.uk/goodmanagement/2008/01/patient\\_involvement\\_making\\_it\\_work.html;jsessionid=25D6180D07E3D9F47569DDC6F9C6ABF5?tmcsTrackingInfo=\\$OHle0PAn6b4ozPm\\_2ug1uuy41oihGZb\\_yMWk3ZRjeBsltCdYZC89h1kwlbsmt4t-vOpxukqLypt\\$](http://www.hsj.co.uk/goodmanagement/2008/01/patient_involvement_making_it_work.html;jsessionid=25D6180D07E3D9F47569DDC6F9C6ABF5?tmcsTrackingInfo=$OHle0PAn6b4ozPm_2ug1uuy41oihGZb_yMWk3ZRjeBsltCdYZC89h1kwlbsmt4t-vOpxukqLypt$)

## **Outcomes of involvement**

---

Evaluation of the impact of involving people affected by cancer is scarce. There is increasing evidence of organisations and networks developing ways of involving people affected by cancer but a paucity of information about the influence that involvement has. One of the reasons why evidence is thin is because structures and systems to evaluate impact are absent.

People ought to know the outcome of the initiative that they were involved in. This is because information about the outcomes of involvement is important to those that are involved. Macmillan Cancer Relief (2004) guidelines for involving people affected by cancer in policy and planning point out that 'users get involved to make a difference' and therefore recommend that the differences that their involvement has made should be fed back to them.

However, we also ought to know the impact that involving patients, carers and members of the public has on the actual initiative. What is the added value of involving them? The answer to this question is difficult because very few studies have been carried out to assess the influence and impact of their involvement. Below we provide documentation of the impact that patients, carers and members of the public have had.

### **Impact on research**

One study suggests that the involvement of people affected by cancer on research review panels is unlikely to alter which research projects get approved. Andejaski et al. (2002) evaluated the impact of including 'consumers' in the scientific review of breast cancer research proposals in America. They found that because there were only two consumers on each panel, and their proposal scores were similar to those of the scientists, consumers' votes had a minimal effect on final proposal scores. They point out that the evaluation was not able to show whether or not consumers' presentations or comments during discussion had any effect on scientist voting but they did report that scientists felt that consumers added an important perspective to the review process. According to Andejaski et al. (2002) these findings should allay fears of involving consumers on review panels.

### **Impact on services**

A randomised controlled study (Klein, 1999) was carried out with third year undergraduate medical students on an interview methods course; one group of students was taught with patients with cancer and the control group was taught with patients with other diagnoses

participating. Klein (1999) found that the involvement of patients with cancer enhanced students' ability to elicit psycho-social information and to relate more effectively to patients with cancer. Two years after the course, Klein (1999) found that those students taught by patients with cancer compared to those taught by patients with other diagnoses had a better rating in terms of:

*'... responding empathically, showing regard and concern for the patient, and assessing the impact of the symptoms on the patient's life'* (Klein, 1999:1455).

### **Impact on those involved**

Anecdotal evidence suggests that those involved in research and policy and service planning welcome the opportunity to discuss their care in a supportive environment, feel personally empowered, and find the experience therapeutic.

There is also evidence showing that patients with cancer involved in self care manage their side effects better and report reductions in severity of distress associated with side effects (Hubbard et al. 2007).

#### **Thinking Point:**

'Undertaking a specific user involvement activity (e.g. a carer satisfaction questionnaire about a cancer information centre) is likely to tell you something about how the carers who completed the survey felt about the information provision at the time. It might suggest things that you could do to improve it. However, you need to go round the cycle again to repeat the survey in order to check that the changes that have been put in place bring real improvements. Thus repetition holds the key to ensuring that changes inspired by users' views actually make the service better. Without repetition there is no way to be certain that user involvement is being successfully used for service development.' (Tritter et al. 2004:8).

#### **A case example from the Cancer Care Research Centre (CCRC)**

The CCRC has 14 Advisory Groups of people affected by cancer and dozens of individuals who help guide the direction of the research conducted. The following list a few of the ways in which people affected by cancer have been involved in the Centre in 2006.

Three advisory groups co-wrote bids with researchers. One bid was sent to the Prostate Cancer Charity (a non-statutory organisation) for a new project looking at how to encourage men with worrying symptoms to go to the GP. A second proposal went to Macmillan Cancer Support (another non-statutory organisation) for a research project looking at cancer's impact on the family.

One patient interviewed five Chief Executives of Scottish Health Boards about patient involvement for one of our research projects.

Three people affected by cancer conducted informal interviews with candidates who had applied for a new job at CCRC.

Three people affected by cancer helped present posters at conferences (e.g. the Cancer Open Forum in Dunblane and the Scottish Association of Support Groups Conference in Perth.)

Members of two advisory groups helped plan the Centre's first conference.

Advisory groups and individuals have reviewed and contributed to our reports on "Finding out you have breast, lung, prostate, gynaecological and bowel cancer". Their responses to the reports, including their thoughts about the key messages for patients and practitioners, are on the CCRC website.

One advisory group commented on the Research Centre's Strategic Plan, for 2007-2011, helping us think about our priorities for the coming years and the role of people affected by cancer in the next 5 years.

## Useful resources

### Background reading

Andejaski Y., & Bisceglia I. (2002) Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *Journal of Womens Health and Gender Related Based Medicine*. 11(4): 379-388.

Arnstein SR. (1969) A Ladder Of Citizen Participation. *Journal of the American Planning Association* 35: 216-224.

Hanley B. (2005) Research as empowerment? Report of a series of seminars organised by the Toronto Group. Joseph Rowntree Foundation.  
<http://www.jrf.org.uk/bookshop/eBooks/1859353185.pdf>

Hubbard G., Kidd L., Donaghy E. (2008) Preferences for involvement in treatment decision-making of patients with cancer: a review of the literature. *European Journal of Oncology Nursing*. 12(4): 281-408.

Hubbard G. Kidd L. Donaghy E. (2008) Involving people in research: a review of literature, *European Journal of Cancer Care*. 17(3): 233-244.

Hubbard G., Kidd L., Donaghy E., McDonald C., Kearney N. (2007) A review about involving people affected by cancer in research, policy and planning and practice. *Patient Education and Counseling*. 65: 21-33.

Klein S., Tracy D., Kitchener HC., & Walker LG. (1999) The effects of the participation of patients with cancer in teaching communication skills to medical undergraduates: a randomised study with follow-up after 2 years. *European Journal of Cancer*. 36(2): 273-281.

Knighting K. Forbat L. Cayless S. Kearney N. (2007) Enabling Change: Patient experience as a driver for service improvement. CCRC. University of Stirling.

Langton H., Barnes M., Haslehurst S., Rimmer J., & Turton P. (2003) Collaboration, user involvement and education: a systematic review of the literature and report of an educational initiative. *European Journal of Oncology Nursing*. 7(4): 242-252.

Macmillan Cancer Relief (2004) User support and involvement guidelines. The full guide to involving people affected by cancer in all Macmillan's work. Macmillan Cancer Relief. London.

Needham C. (2003) Citizen-consumers: New Labour's marketplace democracy. Catalyst. London.

Tritter J., Daykin N., Evans S., & Sanidas M. (2004) Improving cancer services through patient involvement. Radcliffe Medical Press. Oxford.

## Discussion Board

The discussion board is a forum in which you can exchange ideas with other participants. This activity relates to the work you will have completed in earlier tasks and provides an opportunity for you to explore the difference in perspectives between the participants.

### Discussion Board

#### When will it take place

For a 3 month period from date of publication of this article.

#### Which discussion thread

Agenda of involvement and engagement

#### What is expected of you as a participant

This module has only touched on some of the issues affecting patient and public involvement and engagement. By sharing your experiences of the issues that affect your practice, we can build on the current body of knowledge.

## Summary of this module

---

By completing this module you should have a general overview of policy promoting the agenda of patient and public involvement, the different models of involvement.

### On completion of this module you will have had the opportunity to:

- Gained insight into some of the complexities relating to the different models of involvement.
- Reflect on the barriers to successful involvement.
- Understand the outcomes of involving patients and members of the public.

#### Gill Hubbard

Department of Nursing and Midwifery  
Cancer Care Research Centre  
University of Stirling  
Stirling FK9 4LA UK  
email: [gill.hubbard@stir.ac.uk](mailto:gill.hubbard@stir.ac.uk)

#### Liz Forbat

Department of Nursing and Midwifery  
Cancer Care Research Centre  
University of Stirling  
Stirling FK9 4LA UK  
email: [Elizabeth.forbat@stir.ac.uk](mailto:Elizabeth.forbat@stir.ac.uk)