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Review article

A review of literature about involving people affected by cancer in research, policy and planning and practice☆

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Abstract

Objective: To systematically review the literature on involving people affected by cancer in healthcare research, policy and planning and practice.
Methods: Database searches, cited author, and grey literature searches were conducted.
Results: 131 documents were included. Rationales for the agenda of involvement represent two polar characteristics of modernity: individualism and collectivism. In research, people acted as advocates, strategists, advisors, reviewers and as participatory researchers. In policy and planning, people were involved in one-off involvement exercises and in longer-term partnerships. Men, those with rare cancers, children, and people who are socially deprived have been rarely involved. There is little research evidence about the impact of involvement. Training and information, resources and a change in attitudes and roles are required to implement an agenda of involvement.
Conclusion: The USA, the UK, followed by Canada and Australia have promoted an agenda of involvement.
Practice implications: A dissemination strategy to share good practice; involvement of all types of people; an individualised and flexible approach; training, resources and a shift in thinking from paternalism towards partnership working are required. More research is needed about the impact of involvement and relationships between rationales for involvement and implementation.

Keywords: Cancer; Community-based research and or services; Decision-making; Self care; Involvement

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Contents

☆ For more information on the Reflective Practice section please see: Hatem D, Rider EA. Sharing stories: narrative medicine in an evidence-based world. Patient Education and Counseling 2004;54:251–253.

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1. Introduction

The promotion of the involvement of people affected by cancer is part of a general turn towards patient and public involvement in healthcare where involvement is expected to make services more responsive to patients' needs, more acceptable, accountable, equitable and improve quality and outcomes of care [1]. Hence, it is anticipated that research will focus on issues that matter to patients and carers; healthcare policy and services will be developed on the basis of what patients and carers want; and decisions in the practice setting will be made by patients or in consultation with patients so that they have some control over what happens to them.

A range of government policy initiatives has encouraged the agenda of involvement in healthcare within the UK, and as such, has stimulated a growing interest in promoting and supporting public and patient involvement in many spheres of healthcare including, research, policy and planning, and healthcare practice. In England, an advisory organisation called *INVOLVE* has been funded by the Department of Health to support public involvement in NHS, public health and social care research, whilst the *Health and Social Care Act (2001)* [2] and the *NHS Reform and Health Care Professions Act (2002)* [3], have seen the introduction of a new statutory duty on Strategic Health Authorities, and NHS and primary care trusts to involve and consult patients and the public in local service planning, and the creation of patient forums (re-named Patient and Public Involvement Forums – PPI) in every NHS and primary care trust. In relation to healthcare practice, patients have also been encouraged to adopt a greater level of responsibility for, and participation in, their care. *The Expert Patient: A new approach to chronic disease management for the 21st Century* [4] highlighted the importance of enabling patients to have a much greater role in decisions about their own treatment and care, whilst recently, the Department of Health launched the report *Self Care – A Real Choice: self care support – a practical option* [5] as part of their initiative to improve support for people with long term conditions. Similar policy initiatives promoting an agenda of involvement have been introduced in Scotland [6,7], the United States of America [8,9], Canada [10], and Australia [11,12].

This paper presents a summary of the main findings of a review of literature about involving people affected by cancer in research, policy and planning and practice, and highlights the gaps in this area, for example, the absence of involvement by key groups including, older people, people living in deprived and rural communities, and men. Specifically, the review aimed to answer:

1. *Why* are people affected by cancer involved in research, policy and planning, and practice?
2. *How* are people involved?
3. What *influence* does their involvement have?

As reported in further detail later, this review identified that there is continuous debate over who should be involved in research, policy and planning, and practice, with some organisations suggesting that only patients or survivors of cancer should be involved, whereas others recommend the involvement of their family carers too. However, from the outset of this review, the phrase 'people affected by cancer' was used as an umbrella term to include, for example, patients, survivors, family/informal carers, patients' advocates, and members of the public. This term is used throughout this paper, unless authors, who are cited explicitly, use another term, for example consumer, patient, survivor.

2. Methods

2.1. Searching for literature

All database searches ran from 1994 to 2004 inclusive. No language, geographical or methodological limits, was imposed upon the results. Table 1 lists the keywords (grouped by concept) that were used in the searches and shows for example, the different terms that are used to describe 'people affected by cancer'. The majority of 'hits' were contained in the major and best-known health databases: AMED (Allied and Complementary Medicine), CINAHL, EMBASE, Evidence Based Medicine Reviews (Cochrane DSR, ACP Journal Club, DARE, and CCTR), HMIC (Health Management Information Consortium), Medline, and PsychINFO. A cited reference search and free text searches were also conducted.

We attempted to source most of the grey literature from the Internet, which included literature not controlled by commercial publishers, such as, government reports, proceedings and conference papers, discussion papers and unpublished studies. A web search using the similar free text combinations as the database searches strategies was limited to the UK and conducted via three main search engines, Google, All the Web and Visvismo, and was reinforced with searches across Copernic Agent.