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Research in the behavioural and social sciences to improve cancer control and care: a strategy for development

A report of an Expert Group*

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Abstract

The need for a better co-ordinated interdisciplinary approach to cancer is widely recognised. An analysis of strengths and weaknesses has emphasised the importance of a better understanding of the behavioural and social factors which determine the success of preventative and screening programmes and those which will enhace the quality of care and support available to patients and their families. The European Commission provided funds to establish a consultation to formulate a strategy for the development of research in the behavioural, social and related sciences relevant to cancer. The key objectives were to inform research organisations of the steps necessary to enhance research capacity in these areas and identify the most productive directions for research in the forseeable future. The expert group identified 11 areas in which research might be expected to improve cancer control and treatment.

Keywords: Cancer care; Cancer control; Europe; Interdisplinary approaches; Research; Behavioural and social aspects of cancer

1. Introduction

The need for a better co-ordinated interdisciplinary approach to cancer has been recognised at the European level. An analysis of strengths and weaknesses in current approaches to cancer research has highlighted a need to improve understanding of the behavioural and social factors which determine the success (or lack thereof) of preventive and screening programmes and enhance the quality of care and support available to patients and their families. This need has been emphasised at meetings held under the aegis of the European Union (EU), World Health Organization (WHO), International Union against Cancer (UICC), the European Cancer Leagues (ECL), the Organisation of European Cancer Institutes (OECI), the European Cancer Research Managers Forum and the International Agency for Research on Cancer (IARC).

An interactive consultation has been carried out with the support of the European Commission (DG Research) to develop a strategy through consensus on the approaches necessary to enhance European research capacity in the Behavioural and Social Sciences relevant to the prevention and management of cancer. This consultation brought together representatives of the major disciplines in the field. The specific objectives were to:

- identify research needs and opportunities on an interdisciplinary basis—highlighting the contributions which the research might make to the more effective control and care of cancer;
- encourage the development of constructive interdisciplinary links between those in the behavioural and social sciences and those in other disciplines;
- inform public health and research funding bodies of the health and social needs and research opportunities in the area.

The names of the participants are to be found in the appendix.

2. Background

Cancer is a major and a growing health problem worldwide. It causes untold distress to patients and their families. In the year 2000, 10 million people (5.3 million men and 4.7 million women) developed a malignant tumour and 6.2 million died from the disease. Within the EU 4.5 million people suffer from cancer, and there

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are 1.6 million new cases and 1 million deaths from the disease each year. In the light of current trends, the incidence rate is expected to grow by 50% in the next two decades to reach 15 million new cases worldwide annually by 2020. This poses an immense challenge for public health and healthcare delivery systems.

Despite advances in prevention, early diagnosis and treatment, the overall mortality from cancer in the EU has not been significantly reduced and is predicted to increase due to continued high levels of tobacco consumption (responsible for approximately 30% of all cancers), the adoption of unhealthy lifestyles and increased life expectancy.

3. The public health challenge

A century ago, the major challenges which faced public health systems were generally amenable to relatively simple solutions (e.g. the provision of clean water, ensuring better nutrition and childcare, improvement of housing conditions, immunisation programmes, etc.) and these were delivered to a largely passive and homogeneous population which had an ingrained respect for authority. The challenges facing public health authorities today are considerably more complex. There is a need to encourage major changes in health-related behaviour within the multi-ethnic, multicultural society of modern Europe. This society is further characterised by ever increasing expectations, consumerist attitudes, a growing need to exercise individual choice and a lack of automatic respect for authority and expert opinion. There is a strong need to learn more of the factors which lead to the adoption of healthy lifestyles and an understanding of these is essential for the development of appropriately designed and targeted health promotion and prevention programmes.

A strategy designed to identify public health research needs and opportunities must take account of the context within which public health policy and practice is developed. In formulating their recommendations, the consultation group reviewed and took account of the following factors:

- the development of effective prevention programmes requires a multisectoral approach to promote healthy lifestyles and develop healthy environments—the sectors involved include, but are not limited to, health, education, environment, employment, planning, etc.;
- effective communication is necessary to ensure that health promotion programmes are appropriately designed, targeted and delivered taking account of age, gender, educational attainment, socio-economic status and cultural background;
- the media have a significant influence on the public understanding (and misunderstanding) of the nature of cancer and its control;
- the increasing availability of information of variable quality and reliability on the internet accessible to an ever-increasing proportion of the population;
- the interactions between risk communication, motivation and behaviour change are complex and poorly understood;
- the achievement of equity in access to prevention and care (e.g. in terms of age, gender, socio-economic status, etc.) is an important goal of all EU member states.

4. The cancer care challenge

The predicted increase in the number of cases emphasises the need to provide appropriate treatment, care and support facilities. The diagnosis of cancer has a profound impact on patients and their families. This is, in part, shared by all patients with serious illnesses, but the diagnosis is accompanied by the particular fear which the condition engenders and the consequences of treatment which are frequently unpleasant and debilitating. There are well documented psychological, familial and social consequences of cancer which are frequently not satisfactorily addressed and these may also continue to exist amongst those who are judged to be ‘cured’ by conventional criteria (e.g. 5-year survival). The provision of adequate information and psychosocial support should be an established part of cancer care.

5. The need for research co-ordination in europe

There is a need for broadly-based interdisciplinary studies which will assess the impact of preventive interventions and a range of therapies for patients with cancer. There is a strong argument for developing these on a European basis. The multi-ethnic, multicultural environment of Europe provides unique opportunities to study the impact of social, environmental, cultural and behavioural factors on preventive, diagnostic and therapeutic interventions. An understanding of these factors is essential to ensure that interventions are appropriately designed to reduce cancer risk in specific groups and in the population at large.

6. Progress in the field

Significant advances in cancer prevention, diagnosis and treatment have been achieved in recent years. Progress is being made towards the prevention of a number of cancers by reducing occupational and environmental exposures to carcinogenic agents in the workplace and elsewhere (including reducing exposure to ultraviolet (UV) radiation). Further reductions are to be anticipated through immunisation against infectious agents such as hepatitis B virus (liver cancer) and, in the future, human papillomavirus (cervical cancer). Reductions in mortality have also been achieved by early detection through screening programmes. There have been major reductions in cervical cancer in Western Europe based on cervical cytology, although these results have not been matched in Eastern Europe where treatment outcomes are poorer. Advances have also been made in the early detection of breast cancer through mammography and colo-rectal cancer by faecal occult blood testing. However, the low response rates amongst certain groups in the community (often including those at greatest risk) have limited the impact of many screening programmes. These advances are important, but the gains in terms of reductions in incidence and mortality of certain cancers have been more than counterbalanced by increases which are largely attributable to the adoption of unhealthy lifestyles and the demographic changes which are occurring in Western society. There is an urgent need to improve understanding of the social, cultural and psychological factors which influence health-related behaviours, including the level of uptake of screening programmes, and to reduce the negative consequences of screening.

Significant advances in cancer treatment have also been achieved. Advances in surgical oncology have included more precise identification of the tumour margin leading to reduced local recurrence and less invasive surgery. Developments in radiotherapy have led to more accurate targeting and a higher dose to the tumour tissue and these have been complemented by improved management of the adverse effects of treatment. Progress has been made in chemotherapy and a wide range of agents is now available for use singly or in combination. Advances in the molecular sciences raise the prospect of the identification of new targets for drug design and effective gene and immunotherapy in the future. However, the diagnosis of cancer continues to have a profound psychological and social impact. The challenges to be faced include the need to maintain an acceptable quality of life for patients and develop appropriate mechanisms for delivering the necessary psychosocial support. In the absence of curative therapies for many cancers, there will continue to be a major role for palliative therapies for the relief of symptoms and in the provision of end-of-life care. Psychosocial support should be provided in a flexible and patient-centred manner, since the needs of patients and their carers change radically through the course of the disease.

7. Cancer prevention—research needs and opportunities

7.1. Background

Cancer predominantly affects those in middle life and old age. The major carcinogenic hazards (particularly tobacco products) are now well known. However, many other environmental and lifestyle factors (often resulting from behavioural patterns established at a young age) increase the risk of cancer, particularly in certain cancers, in those with a genetic susceptibility to the disease. Improving understanding of the social, political, cultural, emotional and behavioural factors which lead to the adoption, or rejection, of appropriate lifestyles will play an important role in designing strategies for healthy ageing and cancer control. Experience in many countries in developing health promotion programmes designed to reduce smoking (and to discourage young people from adopting the habit) has demonstrated how difficult it is to modify lifestyles, even in situations where the health risks of a particular behaviour are substantial and well known. The difficulty in developing effective programmes to achieve lifestyle modifications in circumstances where the evidence is less dramatic and the health gains less substantial is all too clear. Little is known about the best mechanisms for communicating health-related information.

Important factors in the development of effective health promotion programmes include a better understanding of:

- risk, risk perception and risk-taking or avoidance behaviour at individual and population levels;
- the influence of a range of socialisation processes (family, neighbourhood and peer group influences) on the adoption of risk-taking or health-protective behaviours;
- the impact of formal and informal (e.g. through the media) education in determining risk-taking and risk-minimising behaviour in childhood and later life;
- the influence of cultural, psychological, social, political and economic factors in shaping behaviour and lifestyles;
- the factors which lead to effective communication by healthcare professionals at population and individual levels and how the impact and interpretation of such information is enhanced or diminished by cultural, emotional and social factors and levels of educational attainment.

7.2. The role of psychosocial factors as determinants of cancer

The role of psychosocial factors in the causation of cancer is controversial. Such evidence that exists is inconsistent and only provides very limited support for the view that stressful life events, chronic stress or personality traits are significant risk factors for cancer. Recent reviews have been critical of the methods used in earlier studies and have indicated that further larger scale studies based on sound methods are required. Many members of the research community and the general public continue to believe that such factors do play a role. More definitive studies are required to determine the importance, if any, of possible psychosocial determinants of cancer, with due consideration of possible interactions with known risk factors.

It is recommended that the significance of examining the possible role of psychosocial factors as determinants of cancer should be recognised in the strategies of research funding bodies.

7.3. Major determinants of cancer risk behaviour

The level of exposure to most exogenous cancer risk factors is related to behaviours which reflect the choices of individuals (e.g. smoking, levels of alcohol consumption, dietary choices, physical exercise, exposure to UV light, risky behaviour at the work place when handling recognised carcinogens, etc.). Research to date has had a strong emphasis on personal factors. Less emphasis has been placed on the study of the role of organisational factors or public policy relevant to cancer prevention, and how these might interact with personal factors to result in behaviour change.

Behaviour is the result of a person's intentions and abilities. Intentions can range from no intention to change to a high intention to change behaviour. A person's abilities, motivation and environmental barriers determine whether their intentions will be realised. The level of motivation to change will be determined by a range of proximal (e.g. attitude, education, perceptions and self-efficacy or control beliefs) and distal factors (e.g. involvement in other risk behaviours, psychological, biological, social and cultural factors). It is essential to distinguish between these and to understand the nature of the interactions between them. More research is required on social influence processes as well as cultural and structural (societal) determinants of cancer-related behaviour. There is a need to focus research on both changeable determinants and non- or less changeable determinants (such as gender, age or socio-economic status) of behaviour. The former is essential to inform the development of strategies for behavioural change at the individual level and the latter for planning interventions tailored for specific populations.

The notion of risk perception/risk avoidance is critical at the individual level. Many interventions have focused on increasing the perception of risk to attempt to influence behaviour towards avoidance, but the impact of such approaches has been limited. Enhancing risk perception increases the likelihood of behaviour change only if a specific way of avoiding risk is proposed which is seen as realistic and acceptable and the health gain is perceived as significant (and in some instances the benefits are realised on a short time scale). The understanding of risk and the benefits which may accrue from behavioural change are heavily influenced by social, cultural and emotional factors and these are shaped by personal interactions (including those with healthcare professionals), the media, family and peer pressure/opinion, and the level of educational attainment. Risk perception plays a role in initiating the process of change, it plays a much less prominent role during later stages—when factors such as outcome efficacy and self-efficacy, as well as the environment, may be more important.

Research into factors which may effect behavioural change must be accompanied by studies to evaluate the effectiveness of intervention programmes (e.g. through education, social marketing, etc.). These should be evidence-based and comprehensible to the recipients. It must be remembered that strong conflicts of opinions amongst experts may diminish or negate the impact of health promotion programmes.

Research is needed to improve the evidence base and provide the framework for more focused and effective health education and promotion programmes aimed at achieving long-term behavioural change. Research is particularly needed in the following areas:

- *the proximal and distal determinants of health-related behaviours and their interactions;*
- *the nature and impact of peer, parental, neighbourhood and other influences (positive and negative) on the effectiveness of cancer prevention programmes and the implications of these for the design of programmes targeted at populations or specific groups;*
- *the influence and significance of socio-economic, cultural and educational factors in shaping health related behaviours and the response to cancer prevention programmes;*
- *evaluation of the impact of social marketing approaches designed to achieve behaviour change at the population and group level;*
- *analysis of the political and economic factors which influence the development of health promotion programmes.*

7.4. Evidence-based best practice in cancer prevention interventions and future research needs to improve intervention strategies

There are many examples of interventions with limited impact in the cancer field. There are also examples of well planned, research-based interventions that have been effective. Nevertheless, despite the limited impact of many interventions, there have been considerable changes in health-related behaviours in some countries and populations. There is a need for research to identify the processes which have led to such changes. This will involve the analysis of the interplay between social, behavioural, economic, educational and cultural factors. Studies should focus on the influence of approaches initiated at the political level and those developed through the public health and healthcare systems, education and the media. It will be important to analyse the impact of specific cancer control programmes within the context of more general health education programmes (i.e. those which promote healthy eating and physical activity). Further work is also required to determine how best to translate interventions which have been shown to be effective in experimental settings, into public health measures and evaluate their cost-effectiveness. Insights are needed into why interventions may (or may not) work in different social and cultural settings.

The effective evaluation of cancer control programmes can be carried out in part using established techniques (e.g. randomised controlled trials (RCTs)) and these are useful for interventions targeting well defined populations and with straightforward interventions. For more complex interventions, and particularly for interventions which are consistent with the principles for health promotion (involvement and empowerment), RCTs are less useful. It is, therefore, necessary to develop a broader range of tools for evaluation.

Specific areas in which research initiatives are required include:

- *the processes of change at population level as well as in specific sub-groups through prospective and retrospective studies;*
- *the development of data- and theory-based interventions in schools, workplaces, and communities utilising modern strategies (e.g. intervention mapping) with strong research designs and appropriate approaches to data analysis;*
- *the development of new methodologies, in addition to RCTs, to evaluate complex interventions which are consistent with the principles of health promotion;*
- *the mechanisms by which orchestrated multi-sectoral action can best be developed at the policy-making level;*
- *the impact of communication through the mass media, including interactions between the research and public health communities, and the media and the impact on the public.*

7.5. The development of interdisciplinary links and collaborations

There is a need for the greater involvement of researchers from a wider range of behavioural and social science disciplines such as economics, political science, law, environmental sciences, communications and media studies. Multidisciplinary research teams are required at the European and member state levels. There is a need to address many cancer control issues at a European level in the light of the growing importance of the Union in providing a framework for the regulation of many aspects of human activity (e.g. employment, environment, trading standards, food quality and public health). In addition, the cultural and ethnic diversity of Europe provides unique opportunities for comparative studies of the effectiveness of cancer control programmes. These programmes should be developed in partnership with those who have responsibility for the formulation and implementation of policy (e.g. policy-makers at all levels, public health authorities, healthcare professionals, educators, etc.). It is also essential, in certain areas, to work in collaboration with industry. It is recognised that this is neither practicable nor acceptable with the tobacco industry, but there are opportunities for constructive engagement with other sectors such as some parts of the food industry.

It is recommended that:

- *the EU and national research funding bodies should establish mechanisms for the development of multidisciplinary research programmes focused on cancer prevention which are designed to meet the needs of the end-users (public health authorities, healthcare professionals, educators, etc.) based on Networks of Excellence;*
- *efforts should be focused on research to develop cancer prevention programmes and research on the efficacy and effectiveness of such programmes;*
- *a European platform for cancer control should be created building on existing programmes to ensure effective implementation of the programmes at the European level.*

8. Cancer screening—research needs and opportunities

8.1. Background

Cancer screening involves the provision of a service which is offered to a non-selected group with the aim of identifying those at increased risk who will benefit from an appropriate intervention. An exception is genetic testing among certain cancer families. The availability of techniques for screening for certain common cancers (e.g. breast, cervix, prostate, colo-rectum, lung, etc.) poses major research challenges. There have been substantial efforts to increase accessibility in a number of countries, but uptake has often been variable with wide differences between ethnic and socio-economic groups. Little is known of the behavioural and social factors which lead to a limited uptake of such programmes. By contrast, certain studies have highlighted a paradox in that the overall level of concern in some members of the population about exposure to hazards throughout life has grown even though, in general, the environments in which we live and work have become progressively safer. This has led in some instances to demands for more frequent screening than is justified by the available evidence. Both over-screening and a reduction of screening frequency may be associated with morbidity. The availability of an increasing range of predictive (genetic) tests which will identify susceptibility to cancer in certain members of the population may offer opportunities for cancer prevention through the avoidance of exposure to environmental risk factors, the modification of lifestyles or appropriate screening. However, these raise issues relating to the acquisition, transmission and use of genetic information which may have profound implications for those tested and for members of their families. The ways in which such tests are made available demands careful evaluation taking due account of the medical, psychological and social implications of testing (and the considerable ethical issues which are raised).

8.2. Understanding non-participation in screening programmes

Certain key questions remain unanswered relating to the development and conduct of cancer screening programmes. These include:

- to what extent does non-participation reflect an informed choice or the operation of social or physical barriers or issues related to the organisation of screening programmes?
- why are those who are most socially disadvantaged least likely to participate—and what are the policy challenges and implications of this?
- is controversial media coverage or scientific disagreement (e.g. about benefits of mammography screening) harmful or beneficial?

The uptake rates of cancer screening programmes vary widely between and within countries, and also from one form of cancer screening to another. The objective of all screening programmes is to achieve high rates of uptake through informed choice. This should be based on relevant information which must be presented in a form which takes account of the social and cultural norms, values and attitudes of the communities concerned. An informed choice to undergo screening is taken when an individual has relevant knowledge and a positive attitude towards undergoing the test, and undergoes it. An informed choice to decline a screening test occurs when an individual has relevant knowledge, a negative attitude towards the test and does not have it.

Information should be delivered generally at the population level and also in a more targeted manner to the populations which will be offered screening. It is essential that the preconceptions of some in the community who are inclined to overestimate the benefits should not be reinforced.

An association between low socio-economic status and low screening uptakes has been observed In some (e.g. the United Kingdom (UK)), but not all (e.g. Denmark and Finland) countries. The reasons for these differences are unknown, but the possibilities include structural factors (e.g. organisation of screening programmes, format and contents of screening invitation letters), cultural and ethnic group attitudes to cancer and screening and general attitudes towards health (e.g. fatalism). There are also problems associated with language difficulties and literacy amongst some target groups.

The media are often blamed for uncritical and sensation-seeking reporting on cancer and it is possible that this might have a negative impact on screening uptake. However, scientists competing for funding also seek to sell messages to media: these are sometimes overly optimistic. There is a need for better informed and trained journalists to report on health issues, and also a better understanding by scientists of the culture and practices of the media.

There is a need to promote research to:

- *assess the impact of informed choices (using relevant theoretical models) on the level of screening uptake and the emotional and psychological responses to screening;*
- *determine the most cost-effective ways of ensuring informed choice in the context of screening programmes, where face-to-face time and resources are often more limited than in clinical settings;*
- *establish the most cost-effective means of providing adequate information at the population and individual levels;*
- *determine how best to meet the needs of groups for whom informed choice might pose a particular challenge (e.g. those with learning disabilities, ethnic minority groups, etc.);*
- *investigate the structural and cultural issues which influence screening uptake at a European level to*

ensure that the opportunity to participate is offered to all groups, including the socially disadvantaged;
- *study the impact and relative roles of the media and other channels of communication on the public understanding of health- and screening-related issues.*

8.3. Communicating uncertainty and risk information in screening programmes

Important questions remain unanswered regarding the management of uncertainty and risk information in screening programmes. Key ones include:

- how can one avoid high levels of anxiety, as well as false reassurance?
- how should the public health approach to screening programmes be developed when the benefits are uncertain and the subsequent therapeutic options controversial?

There is a widely-held view that, in general, levels of anxiety amongst participants have declined and that screening may generate a degree of reassurance which is not wholly justified. This contrasts with the increase in anxiety generated amongst those recalled for further investigation. It is argued that a certain (optimal) level of concern is necessary to motivate individuals to take due care of their health. It is important to determine the most effective means of encouraging appropriate concern without generating unnecessary fear and anxiety. These issues are particularly important in relation to screening for cancer. Both false-positive and false-negative findings have psychological implications and in the latter case these may delay the commencement of treatment. Little is known about the effectiveness of different approaches in preventing or reducing anxiety in the course of screening.

The optimum frequency for certain screening procedures has been well established. Over-frequent opportunistic screening is not only a poor use of scarce resources, but it may also lead to unnecessary treatment and psychological and physical morbidity. Clear examples have been described in relation to cervical, breast and prostate cancer screening.

Certain screening programmes, in which the benefits are uncertain and the therapeutic options controversial, need careful evaluation. This also applies to the detection of some specific lesions in established screening programmes when it is known that only a proportion of these will progress to invasive cancer (examples include ductal carcinoma *in situ* of the breast, cervical intraepithelial neoplasia and early tumours of the prostate). It is essential that all screening programmes should meet recognised standards for acceptability, follow-up and quality assurance.

There is clear need for the systematic study of:

- *the psychological consequences associated with the screening process (whether carried out systematically or opportunistically) taking account of the ways in which these are modulated by social, cultural and educational factors;*
- *the psychological and quality of life consequences in situations where there is therapeutic uncertainty and a course of 'watchful waiting' is followed.*

8.4. Is screening a useful opportunity to provide effective health education on reducing or maintaining low risks of cancer?

It has been proposed that screening provides opportunities for health education which are often not exploited. These include enhancing breast awareness in breast cancer screening or providing dietary advice in colo-rectal cancer screening programmes. This proposition could be extended further to the provision of general lifestyle and health advice. It is also argued that advice on what people can do themselves to avoid serious disease, would also be of benefit in enhancing perceived control—an important element of health behaviour change. However, there are concerns that the combination of 'messages' may have negative effects, particularly in the context of screening where negative findings might be assumed to provide a 'clean bill of health' and thus remove the incentives to adopt a healthy lifestyle—and positive findings might encourage a degree of fatalism.

There is a need for systematic study of the feasibility of combining routine screening with detailed health education, its impact on health and lifestyle and its behavioural and emotional consequences.

8.5. Developing genetic testing and counselling

Population-based genetic screening for cancer is not feasible at present since few mutations are known and these have a limited predictive value. Only a small percentage (5–10%) of the major cancers are genetically determined and for these only limited intervention options are available. However, there is experience with cascade screening, testing in cancer families for colon cancer, and for breast-ovarian cancer susceptibility. A systematic review has concluded that there appears to be no or only a negligible negative psychological impact of this form of family-based testing. However, the evidence is extremely limited, the samples studied were self-selected, the follow-up short, mainly global indicators of distress were used and the impact of the counselling provided was not studied. Experience so far has mostly been gained in organised research programmes with detailed protocols for testing and counselling. These circumstances are unlikely to apply in the less rigorously controlled environment of routine clinical practice. However, there are questions which need to be considered in light of the advances in genetics. The key questions are:

- what are the main challenges in terms of coping with test results, their implications, and intervention options?
- what are the implications for the follow-up of family members?
- are responses to predictive genetic testing for cancer different from responses to other biomarkers of disease (e.g. HPV testing)?
- what are the short and long-term ethical, cultural, and social aspects of genetic cancer risk notification?

The main challenges in developing genetic testing and counselling for cancer relate to the delivery of risk information and its short- and long-term implications. Genetic information on an individual also gives information about family members, whether this is wanted or not. The possession and sharing (or not sharing) this information can create major family tensions. It is not clear, at present, how realistic and balanced information about the limited, complicated, and often controversial, intervention options can best be provided. Genetic information often calls for detailed lifestyle advice, and there is little information on how best to combine genetic risk information and lifestyle advice in a way which assists people to make and maintain behavioural change. There are few data available on the long-term implications of genetic testing and counselling on people's responses, understanding and perceptions, and only incidental information regarding the larger societal implications of using genetic information in occupational settings and in insurance.

There is a need for research on:

- *the role, impact and levels of genetic counselling in controlled studies;*
- *how best to translate population-based predictive information to individuals;*
- *people's understanding of synergistic risks;*
- *the advantages and disadvantages associated with combining predictive genetic information with lifestyle advice;*
- *the behavioural implications of risk perception;*
- *the role and level of understanding of genetic issues amongst healthcare professionals;*
- *attitudes to determine public views on screening for nicotine (and other) addiction.*

9. Cancer care—research needs and opportunities

9.1. Background

A central challenge in cancer care is to maintain an acceptable quality of life for patients and to provide the necessary psychosocial support. The development of cancer has considerable social and familial consequences for patients. The diagnosis and subsequent treatment impacts on domestic relationships, affects employment prospects and limits access to facilities and services. The need to understand the nature and extent of these and provide practical and psychosocial support to facilitate coping by patients and their families has often been ignored. The requirements may change during the course of treatment. Additional and complex issues arise in the care of children and young people with cancer. There are few evidence-based guidelines to 'best practice'.

In the absence of curative therapies for many cancers, there will continue to be a major role for palliative therapies for the relief of symptoms and in the provision of end-of-life care. The development of appropriate social and behavioural forms of support is essential for patients and their families. Much of this is best provided in the home to allow independence for as long as possible and the opportunity for patients to die with dignity in their own homes. Psychosocial support should be provided in a flexible and patient-centred manner since the needs of patients and their carers change radically as the disease progresses.

9.2. Psychological and social factors relevant to cancer care

An important development in many countries has been the establishment of specialised multimodality cancer centres bringing together expertise and facilities for the diagnosis, treatment and care of patients. An important component of that care is the provision of psychosocial support at all stages from the time at which the possibility of a diagnosis of cancer is raised through treatment, supportive therapy, rehabilitation and, if necessary, palliation and end-of-life care.

9.3. Defining patient needs

The pervasive psychosocial effects of cancer are well documented. These include depression, emotional distress, familial and social disruption and long-term consequences in terms of employability and the availability of financial and other services. The development of a research strategy to improve the psychosocial support available to cancer patients and their families must be based upon an assessment of needs. The key needs are:

- accessible and reliable information for patients and their families;
- psychosocial support and interventions—including rehabilitation;
- continuing support for patients living with or without disease following treatment;
- access to self-help groups and other support facilities to permit patients to self-manage problems associated with cancer;
- psychosocial support for families—particularly for spouses and children;
- access to specialised care and support for specific groups of patients—e.g. children, minority groups, the socially disadvantaged, etc.;
- availability of palliative care and end-of-life support (ideally within the domestic environment).

9.4. The identification of specific research priorities

The research priorities identified are focused on areas in which there are specific patient and family needs and scientific opportunities. Priority areas have been identified where a co-ordinated research effort has the potential to enhance the quality of care and support for patients with cancer. The following factors have played a key role in shaping this strategy:

- the research priorities should be defined by patients' needs;
- the specific needs of patients for psychosocial support at all stages of their disease—through diagnosis, treatment, palliative and end-of-life care (if needed) and for those defined as survivors:
- cancer's immense impact on the family, particularly the spouse and children of the patient, and the possible need for social and psychological support;
- the particular needs of specific groups of patients—children, adolescents, elderly, ethnic minority groups, deprived and disadvantaged, those with a low level of educational attainment, those lacking family support, etc., should be specifically considered.

9.5. Meeting information needs—making informed choices

An important requirement of patients is information at different stages of their disease. Little is known as to how to best present this in terms of content, approach or mode of presentation (e.g. by healthcare professionals, in leaflets, over the internet or by other means). The approach needs to be tailored to the various subsets of patients listed above. Issues which need to be addressed include: the difficulties and uncertainties associated with translating data obtained from populations or cohorts into information which is meaningful at the individual level; the presentation of information on the consequences of different treatment options (particularly in the context of the likely course of disease in the individual patient); palliative care options (both those directed towards the tumour and those designed to control symptoms and improve quality of life) and the forms of psychosocial support required. Meeting these information needs is essential to permit the patient, together with his/her family members, to make informed choices and retain autonomy.

Research is needed to determine the most effective way of delivering relevant, reliable and accessible patient information at all stages of the disease to meet the needs of different patient groups and provide details of the disease, treatment options and psychosocial support available.

9.6. Defining social and psychological needs

Little is known currently of the social and psychological needs of patients through diagnosis and treatment and those of survivors whom it is known may have significant psychosocial problems even though they may be regarded as 'cured' using conventional measures of therapeutic success (e.g. 5-year survival rates). Patients' needs should be defined at the cohort level, at the level of specific subsets of patients (see above) and at the individual level.

Research is required to:

- *identify pre-treatment or treatment factors which may predict psychological problems during diagnosis and treatment which will permit the development of preventive strategies;*
- *understand the psychological consequences of different treatment options and their impact on quality of life;*
- *understand and manage the psychosocial consequences of a diagnosis of cancer—e.g. concerns relating to impact on family life, ability (or desirability) of having children, consequences for future employability or obtaining insurance, etc.;*
- *identify the frequency and nature of the psychosocial problems of survivors living with or without cancer;*
- *develop methodologies to evaluate the impact of interventions on psychological outcomes;*
- *correlate psychological outcomes with clinical and pathological markers of the stage of disease and treatment modalities in prospective large-scale pragmatic clinical trials.*

Many of the studies in the last category need to be carried out on large cohorts and organised through interdisciplinary networks. These could build upon existing resources (e.g. large well-characterised populations established for epidemiological studies or cohorts recruited for major multicentre RCTs).

9.7. Psychological and social support and rehabilitation

The principal goals of interventions are to provide support during treatment (this should be an established part of routine treatment), improve the quality of life, rehabilitation, social (re)integration and enhancement of the ability of patients and their families to cope with cancer. There is a need to develop and test a range of interventions since it is not clear at present if psychoanalytical, cognitive or educational approaches (or a combination of these) is likely to be most beneficial for patients and their families. The evaluation of the efficacy and effectiveness of interventions should be a component of all studies to ensure that these are delivered in the most cost-effective manner.

There is a need to develop research programmes to:

- *examine the short- and long-term effects of cancer diagnosis and treatment;*
- *develop specific outcome measures to evaluate the impact of interventions and survivorship (evaluating positive and negative outcomes—short- and long-term);*
- *optimise the patient environment to ensure that supportive interventions are delivered in the most cost-effective manner;*
- *evaluate the roles and activities of self-help groups to shape 'best practice';*
- *to enhance the communication skills of healthcare professionals.*

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