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BENEFITS OF PATIENT AND PUBLIC INVOLVEMENT IN CANCER RESEARCH: LITERATURE REVIEW

Benefícios do envolvimento dos doentes e do público na investigação do cancro: Revisão da literatura

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ABSTRACT

Currently, cancer research allows for earlier diagnosis and more effective treatments. The complexity and socio-economic impact of the disease require innovative approaches such as patient and public involvement in research.

The aim of this review is to identify the benefits of patients and public involvement in cancer research.

The scale for non-systematic reviews, Scale for the Assessment of Narrative Review Articles (SANRA), was followed.

There are individual, ongoing research, ethical and social benefits from this holistic approach that meets the expectations and demands of people and those involved in providing healthcare to people with cancer. Ensuring that the needs, perspectives and concerns of these people are taken into account leads results that promote transparency and trust for the scientific community and clinical practice.

In conclusion, patient and public involvement in cancer research contributes to improving the quality of research.

KEYWORDS: Cancer; Narrative review; Patient and public involvement; Research.

RESUMO

Atualmente a investigação no cancro permite diagnósticos mais precoces e tratamentos mais eficazes. A complexidade e impacto socioeconómico da doença exigem abordagens inovadoras como a participação dos doentes e do público na investigação.

O objetivo desta revisão é identificar os benefícios do envolvimento dos doentes e do público na investigação do cancro.

Foi utilizada a escala para revisões não sistemáticas, Scale for the Assessment of Narrative Review Articles (SANRA).

Destacam-se benefícios individuais, no contínuo da investigação, éticos e sociais decorrentes desta abordagem holística que atende às expectativas e exigências das pessoas e dos envolvidos na prestação de cuidados de saúde à pessoa com doença oncológica. Garantir que as necessidades, perspetivas e preocupações destas pessoas sejam consideradas permite resultados promotores de transparência e confiança para a comunidade científica e na prática clínica.

Em suma, o envolvimento dos doentes e público na investigação do cancro contribui para melhorar a qualidade da investigação.

PALAVRAS-CHAVE: Cancro; Revisão narrativa; Envolvimento dos doentes e do público; Investigação.

Introduction

According to the latest World Cancer Report, an estimated 20 million new cases of cancer and 9.7 million deaths from cancer are projected for 2022. Approximately one in five men or women will develop cancer in their lifetime, while one in nine men and one in twelve women are expected to die from the disease[1].

Cancer is a problem with a major social, public health and economic impact, accounting for approximately one in six deaths (16.8%) worldwide, causing three in ten premature deaths among adults aged 30-69 years and ranks as one of the three leading causes of death in this age group in 177 of the 183 countries surveyed[1].

In Portugal, as in Europe, oncological diseases are the main cause of premature death and years of healthy life lost. These diseases hinder increases in life expectancy and are associated with significant social and macroeconomic costs[1,2].

Open science is a comprehensive approach to scientific research that promotes transparency, accessibility, and collaboration across all disciplines. It aims to make scientific knowledge and the production process available to everyone, benefiting both the scientific community and society at large. This approach emphasises not only the accessibility of scientific findings but, also, ensures the creation of knowledge is inclusive, equitable, and sustainable[3].

In recent decades, the open science movement has been a significant driver of the utilisation of patients and public involvement (PPI) in health research[4]. The success of this involvement is contingent upon the processes of involvement in service users, researchers, and the communities involved in health research. It is thus imperative to optimise this involvement and the context in which it is developed in order to derive the greatest benefit from this resource in the context of research[5].

Since the 1950s, health care users in the United Kingdom (UK) have actively campaigned for their perspectives to be included in health care decisions. These efforts challenged conventional assumptions and provided the ways for advocacy, political lobbying, the provision of alternative forms of services and care, and user-led research and training. This movement was catalysed by the high-profile medical scandals of the time[6].

In the 1970s and 1980s, emancipatory approaches to user-led research emerged, countering to the traditional medical model of knowledge. However, there was an inherent resistance to recognising lay knowledge in biomedical research[6,7].

By the 1990s, the acceptance of patients and public involvement in research began to increase. In 1996, the UK established the INVOLVE[6,7] group, which emphasised flexibility, funding, shared values, and the political philosophy in advancing this area. Legislation on PPI in health research has, subsequently, been consolidated and integrated into research funding streams, requiring researchers to demonstrate how such involvement has influenced proposals and will continue throughout the study [6,7].

The United States, through the National Cancer Institute, has also actively promoted PPI in cancer research through countless initiatives such as the Cancer Moonshot, which aims to catalyse scientific discovery about cancer, increase collaboration and improve data sharing[8]. Portugal has also joined to the 'Europe: United Against Cancer' initiative 2020[9], aiming to improve cancer research and implement PPI. A recent study concluded that the majority of national organisations show strong interest in involving across all phases of oncology research to ensure that results meet the patient's real needs. However, this involvement should be greater and more meaningful in practice[9]. To address economic and social inequalities in European cancer care, innovative research themes are crucial. These included person-centred care, big data, mobile digital technology and molecular and genetic profiling, which facilitate collaboration between patients and research centres throughout the oncological care pathway, from prevention to diagnosis, treatment and care[10]. The European Cancer Patients' Coalition emphasises placing patients' needs at the core of cancer policy, care and research. Collaborating with European Commission and other collaborators, the coalition promotes cancer health policies, emphasising the significance of patients' involvement in innovation and education[11]. In 2020, the European Standard EN 17398:202 was published as reference framework for the implementation and development of patient involvement in healthcare[10]. Close collaboration among researchers, healthcare professionals, patients and the public can bring significant benefits for all stakeholders involved. In this sense, it is essential to encourage and value the active participation of the public and patients at all stages of oncology research[12,13].

PPI in research is typically divided into four phases: 1) setting research priorities; 2) research design and planning; 3) research conduct and operation; 4) dissemination, communication and post approval activities. There are 16 opportunities for involvement associated with these phases: communication of results, regulatory aspects, health technology assessment, study report, information to participants, information and safety committee, study steering committee, meeting with researchers, ethical review, informed consent, patient information documents, funding, practical considerations, research protocol design, research protocol synopsis, identification of patient needs[14]. In turn, Roquette et al.[9] organised opportunities to get involved according to the stages of cancer research, as shown in Table 1.

Given the growing recognition of the importance of incorporating patient perspectives into healthcare, as also has emerged as a vital component of cancer research, a robust level of evidence of this involvement supporting this involvement is therefore required. Therefore, this narrative review aims to identify the benefits of PPI in cancer research.

Methodology

In developing this article, the SANRA[15] scale was used to contribute to improving the standard of this non-systematic review. A narrative review was employed to identify the benefits of involving the patients and public in cancer research. These benefits include improvements in health outcomes for users, from prevention and diagnosis to treatment of cancer, as well as improvements in the methodological quality and dissemination of cancer research results.

Narrative literature reviews are a common feature of health research, accounting for the largest share of text types in medicine[15]. Despite the absence of the rigour characteristic of randomised studies, literature reviews in their development or assessment of methodological quality, their impact on clinical practice and research is notable. Recent studies indicate that these reviews are employed to address research questions that encompass broader or more comprehensive themes[15–17].

This narrative literature review was conducted with the objective of providing an answer to the research question: 'What are the benefits of patients and public involvement in cancer research?'

In order to guarantee a comprehensive search, primary and secondary studies, encompassing both qualitative and quantitative research, were included as criteria for inclusion, as well as other types of literature, without restriction as to time or language.

A literature search was conducted on MEDLINE (via PubMed) between April and June 2024 with the objective of identifying published studies that address the aforementioned research question.

The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were employed in the development of the search strategy for MEDLINE (Table 2). Manual retrieve of all the studies selected for critical appraisal were subjected to further analysis to identify any addi-

Table 1. Phases of research & opportunities for patients and public involvement in cancer research

PHASES OF RESEARCH	OPPORTUNITIES FOR PATIENT AND PUBLIC INVOLVEMENT IN CANCER RESEARCH
Research priorities	Identification of patients' needs
Research design and planning	Study's synopsis design Protocol design Practical considerations Fundraising Patient information leaflet about the project Informed consent Ethical review
Conducting research and operations	Project monitoring investigator meetings Trial Steering Committee Data and Safety Monitoring Committee Information to participants Study reporting
Dissemination, communication and post-approval	Health Technology Assessment Regulatory affairs Post-study communication

Adapted from Roquette et al., 2024

tional studies. The review included studies published in all languages from the date of publication to the present, and which included participants of all ages.

Table 2. Search strategy developed in MEDLINE (via Pubmed).

PESQUISA	ESTRATÉGIA DE PESQUISA	RESULTADOS
#1	(((((((((((("patient engagement"[Title/Abstract]) OR ("patient involvement"[Title/Abstract])) OR ("patient participation"[Title/Abstract])) OR ("public and patient involvement"[Title/Abstract])) OR ("public engagement"[Title/Abstract])) OR ("citizen participation"[Title/Abstract])) OR ("citizen science"[Title/Abstract])) OR ("patient public involvement"[Title/Abstract])) OR ("public involvement"[Title/Abstract])) OR ("co-research"[Title/Abstract])) OR ("research participation"[Title/Abstract])) OR ("Patient Participation"[MeSH Terms])) OR ("Citizen Science"[MeSH Terms])	46,909
#2	((("Cancer research"[Title/Abstract]) OR ("Oncology research"[Title/Abstract])) OR ("Cancer investigation"[Title/Abstract])) OR ("Oncology investigation"[Title/Abstract])	23,005
#3	#1 AND #2	250

Following the completion of the search, all identified citations were collated and uploaded to Mendeley Reference Manager v.2.117.0. Duplicate articles were excluded, and all others were screened based on their title and abstract to determine their suitability for inclusion in this analysis.

The titles and abstracts were screened by an independent reviewer for compliance with the established inclusion criteria. The pertinent studies were retrieved in their entirety, and the complete screen selection was subjected to a thorough examination by the independent reviewer to ascertain their compliance with the established inclusion criteria. The SANRA-Scale for the Assessment of Narrative Review Articles[15] was attended to contribute to improve the standard of this non-systematic review article.

The theoretical and practical relevance of this research lies in its potential contribution to the development of person-centred care and participatory research.

The methodology employed is appropriate for addressing the research question developed, as it permits comprehensive exploration of the subject matter and facilitates the organisation of existing evidence on this topic, which remains relatively unexplored.

Results

In accordance with the established inclusion criteria, a total of 16 studies published between 2012 e 2024, were included. Most of the included articles were primary[9,18–20] and secondary[5,12,13,21–24] studies. However, other type of literature[7,14,25–27] were also included. The majority of these studies were conducted in European countries[5,7,9,12,14,18–23,25,26], specifically Denmark[12], Portugal[9], and the United Kingdom[5,7,18,19,22,23,25,26]. However, studies were also conducted in Australia[13], Canada[24], and the United Arab Emirates[27].

Development

When linked to cancer research, close collaboration between researchers, patient organisations, healthcare professionals, patients and the general public has the potential to yield substantial benefits for all parties involved. It is therefore vital to foster, recognise and facilitate the active involvement of the public and patients at all stages of oncology research[12,19,27].

This review identified four main benefits of public and patient involvement in cancer research: individual benefits, benefits to the research continuum, ethical benefits and societal benefits.

Individual benefits for participants

A number of individual advantages are listed for the involvement of the PPI in research such as improvements in self-confidence and self-esteem, greater health literacy, particularly with regard to one's own illness and to research, development of personal skills, intellectual stimulation, feelings of hope, appreciation, validation, altruism, and personal satisfaction resulting from the experience, integration into support networks, and rewards of various kinds, such as comfort or economic rewards[18,22].

The motivation and determination of the researchers, who were inspired by the resilience, innovation and tenacity of the volunteer research participants[22].

Collaborative work offers advantages for the public, patients and researchers alike[19]. These include increased knowledge about the conditions of participation, interventions to be developed and the amplification of research perspectives; reduction of atria or imbalances between participants and researchers; establishment of reciprocal relationships of respect between research participants and the obtaining of more meaningful perceptions due to the proximity between research participants[19,22].

Benefits for the research continuum

Involving the patients and public at various stages of cancer research offers distinct advantages.

Defining and setting priorities

The necessity of defining and prioritising at the outset of research is now well established. Involvement facilitates the identification of pertinent research areas by incorporating the perspectives of patients and researchers in the topic selection process, enabling the identification of relevant knowledge gaps, assisting in the resolution of practical issues, and delineating emerging research trends[13,20,22].

Research design and planning

In the research design and planning phase, the benefit of this collaboration is evident in the optimisation of the study design; in the definition of research questions that are pertinent to patients and focused on their needs, which would otherwise not have been foreseen; in the design of the research objectives; in the development of different interventions throughout the study and in the advancement of the discourse about the most appropriate methodology, thereby promoting a more comprehensive and inclusive approach[9,12,13,22,23].

Conducting the investigation and operations

In terms of the methodology employed and the procedures undertaken, there were clear benefits to be gained from the assessment of the suitability and development of data collection instruments; the amendment of the wording of these instruments through the identification of poorly worded questions in preliminary questionnaires; the adaptation and enhancement of the sensitivity of research language in information leaflets developed for patients to plan language; the invitation extended to people to participate in the study; the selection of an optimal time to deploy the data collection instruments in the community; the increase in the level of recruitment to the studies; and the improvement of retention rates[12,14,20,23]. The involvement of the patients and public in the analysis and writing up of research results has a beneficial impact on the quality of research reports, ensuring that they are based on user experiences and reach their full potential[5,20,22]. Ellis et al.[24] review revealed a plethora of terms used to describe the involvement of patient and public authors in research. However, only 11%[24] of studies identified them as members of a panel or advisory board. Additionally, just 27%[24] of reviews provided detailed descriptions of the roles of co-author partners, and there was often a paucity of information regarding the specific contributions of co-authors to the review process[24]. Furthermore, the authors indicate that only 14% of the articles in question made any mention of the involvement of the public and patients as authors in the abstract. This was typically only indicated in the affiliation of authors, the methodology, or the contributions section.

Dissemination, communication and post-approval

Finally, in the dissemination and outreach phase of cancer research, this approach facilitates the interpretation, sharing and appropriateness of results through the important relationships and influence of participants in the community. Promoting researchers' access to participants helps to improve recruitment, response and retention rates, improves the quality of the data obtained, allows for the inclusion of groups rarely included in research, and optimises the dissemination of study results by ensuring relevant education and information that can help to reduce health inequalities[7,12,14,23,26].

The positive contributions of PPI are cross-cutting and can be seen throughout the cancer research process, namely in improving study design, better prioritisation of research, the quality of materials provided to patients, the development of research questions that are relevant and meaningful to patients, the appropriateness of methodology, the development of data collection tools, the analysis of data and research results. Other positive aspects include securing and improving the recruitment strategy and increasing response rates, disseminating research results more widely and, finally, making studies more robust by ensuring that research and its results meet the real needs of patients rather than the perceptions of professionals[12–14,18].

Ethical benefits

The evidence outlines the ethical advantages of public and patient involvement in enhancing the relevance, utility, and benefit of clinical research for patients. This is achieved by ensuring that research and its outcomes align with patients' unmet needs, by assisting in defining what is deemed acceptable to participants, particularly on sensitive or contentious issues, and by facilitating improvements. The informed consent document provides clarification regarding the nature of the study and the potential risks involved. It also optimises the experience of participating in research by adapting amenities and respecting participants' time and needs. Finally, it improves the dissemination and sharing of research developments and results between researchers and the public and patients[20,25].

Social benefits

The social benefits of this collaboration can be enumerated as follows: the development of research designs that include aspects that, without the consultation and participation of volunteers, would not be considered by researchers; improved policies and access to research funding; positive social influence in reducing the stigma of minority communities; inclusion of populations that are still underrepresented in research; development of people-centred healthcare and more meaningful treatments for patients[14,18,20,22].

Nevertheless, the advancements that have been achieved thus far, the strategy in question has yet to be fully integrated into the broader landscape of cancer research[9,12].

There is a conspicuous absence of PPI throughout the research process[13,21]. While there was some involvement in the initial design of the study, it was minimal in the subsequent phases.

In summary, it is recommended that efforts be made to encourage and disseminate the implementation of this precursor resource at the national and international levels. This will facilitate the active integration of public and patient perspectives, ensuring that research and clinical practices are aligned with their needs and priorities. This approach is patient-centred and integrates perspectives in cancer research and treatment, which can significantly contribute to improving the quality and relevance of the studies developed. It also guarantees applicable results in clinical practice and promotes transparency in research and trust in the scientific community[7,9,14].

In developing this review, limitations were identified in relation to the complexity of the concept of PPI. This made the database search process challenging due to the complexity of the search strategies employed and the selection of studies to be included in the review. Another limitation is the selection of articles only be done by two researchers as also the no involvement of a librarian expert in reviewing the searches. In an effort to address any potential selection bias, we have taken several steps to ensure a fair and objective process: the clarification of eligibility criteria, the pilot testing of the selection process, and the attainment of a consensus resolution.

However, by compiling and disseminating the benefits identified, we aim to promote the implementation of public and patient involvement in cancer research and contribute to improving healthcare for people with cancer.

Future research would benefit from exploring the benefits of community and patient involvement in cancer research from the perspectives of researchers, policy makers, funders, patients and the public, as well as identifying potential barriers to its implementation and strategies to overcome them.

In clinical practice, investing in participant literacy, increasing community and patient support group involvement, publicising initiatives and introducing rewards for participants can significantly improve the quality of care for people with cancer and reveal previously unrecognised benefits of public and patient involvement in cancer research.

Conclusion

The detrimental impact of cancer on global health and the urgent need to eradicate this disease, together with the open science movement, have led to a growing interest in involving the patients and public in this area of research.

This approach has proven to be crucial in promoting more significant scientific advances in cancer prevention, diagnosis and treatment. It does this by ensuring the relevance of research, including the needs and priorities identified by the public and patients; improving the methodological quality of research; increasing recruitment and response rates; and contributing to a better public understanding of the disease. In essence, PPI is central to promoting transparency, collaboration and relevance in oncology research. It enables a person-centred approach that takes into account a diversity of perspectives and produces better results. Collaboration between researchers and the community can facilitate innovative discoveries, more effective clinical practice and greater community involvement in research.

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Ethics Committee Approval

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Conflict of Interest

The authors declare that there is no conflict of interest.