

BMJ Open Patient involvement in research priorities (PIRE): a study protocol

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ABSTRACT

Introduction: Patient involvement in healthcare has expanded from the clinical practice setting to include collaboration during the research process. There has been a growing international interest in patient and public involvement in setting research priorities to reduce the risk of discrepancy between what patients with cancer and their relatives experience as important unanswered questions and those which are actually researched. This study aims to challenge the conventional research process by inviting patients with life-threatening cancer (primary malignant brain tumours or acute leukaemia), relatives and patient organisations to join forces with clinical specialists and researchers to identify, discuss and prioritise supportive care and rehabilitation issues in future research.

Methods and analysis: This is an exploratory qualitative study comprising two sets of three focus group interviews (FGIs): one set for primary malignant brain tumours and the other for acute leukaemia. Separate FGIs will be carried out with patients and relatives including representation from patient organisations and clinical specialists to identify important unanswered questions and research topics within each group. The FGIs will be video/audio recorded, transcribed and thematically analysed. This study will contribute to a patient-centred research agenda that captures issues that patients, their relatives, clinical specialists and researchers consider important.

Ethics and dissemination: The study is registered at the Danish Data Protection Agency (number: 2012-58-0004) and the Scientific Ethics Review Committee of the Capital Region of Denmark (number: H-15001485). Papers will be published describing the methods applied and the supportive care and rehabilitation issues that are identified as important for future research.

Trial registration number: ISRCTN57131943; Pre-results.

INTRODUCTION

Traditionally, researchers and funders determine which research topics are worth pursuing. This study will challenge the conventional research process by inviting patients with life-threatening cancer (primary malignant brain tumours or acute leukaemia), their relatives

Strengths and limitations of this study

- This study will contribute to the future research agenda regarding supportive care and rehabilitation within haematology and neuro-oncology from a user and clinical specialist perspective.
- The focus group interviews centre on issues that are important for a small, select group of participants, which may limit the generalisability of the results.
- This study represents the initial step in what could become a larger multicentre international research programme involving various populations with life-threatening cancer diagnoses.

and patient organisations to join forces with clinical specialists and researchers to identify, discuss and prioritise issues for future research. Patient involvement is no longer limited to issues related to clinical practice, but has expanded to include collaboration during the research process, including setting research priorities.^{1–7} Taking the patients' point of view into account makes research tangible, relevant and valuable for patients and their relatives.^{1 8 9} Patients report feeling more confident and satisfied as a result of contributing knowledge to research processes.³ Furthermore, co-operation built on mutual respect is reputed to be educational for all involved.^{6 10} Healthcare users' involvement in research priorities challenges the attitudes and convictions of researchers and clinical specialists regarding current research practices.^{8 11 12} The traditional clinician–patient relationship will change as patients become involved in research collaborations.⁸ Some researchers are concerned about the extent to which users are capable of contributing to research processes and whether involvement may lead to patients lobbying for their own agenda.¹² User involvement in healthcare in Denmark is not a new phenomenon. For several years, the user perspective has been incorporated to improve the quality of available treatments. An example of a patient involvement initiative in Denmark is the annual nationwide patient survey that

uses patient feedback as a tool for developing quality. Moreover, the Planetree model is in the process of being implemented at Rigshospitalet, University of Copenhagen, Denmark.¹³ A Scandinavian questionnaire study consulted Danish patients diagnosed with rheumatoid arthritis to identify and prioritise research topics, and found that patients were able to collaborate with researchers to identify important research fields.⁶ Kjekken *et al*⁶ recommended that researchers share the study results with the participants to express appreciation for their valuable contribution. To the best of our knowledge, there is only one international internet-based study that involved patients, relatives and clinical specialists in identifying and prioritising research topics related to brain tumours (mixed population includes spinal tumours).¹⁴ The top 3 of 10 clinical priorities identified were the effect of lifestyle factors on tumour growth, the effect of interval scanning to detect tumour recurrence on prognosis and whether earlier diagnosis improves outcomes.¹⁴ Only one Internet-based study involved patients with haematological malignancies to identify research priorities.¹⁵ The highest priority being given to psychosocial issues in the newly diagnosed patients and during active treatment.¹⁵ In another study, Grundy and Ghazi¹⁶ identified research priorities by including haemato-oncology nurses. Thirty-three research topics were outlined, including chemotherapy, psychosocial issues, provision of information, the psychological support needs of nurses, ethical considerations, palliative care and nurse-led services and guidelines. A number of international organisations have been established to support and expand patient and public involvement within the healthcare system. The purpose of the British organisation 'INVOLVE' is to develop and evaluate consumer involvement while providing inspiration for researchers and consumers on how to involve the public in research. Their national advisory group, funded by the National Institute for Health Research, draws together expertise, insight and experience in the field of public involvement in research (invo.org.uk). The James Lind Alliance (JLA), (lindalliance.org) based in the UK, provides researchers with a step-by-step guide to the processes involved in a JLA Priority Setting Partnership, while the American Patient-Centered Outcomes Research Institute (PCORI), an independent non-profit, non-governmental organisation (pcori.org), funds research to improve the quality and relevance of available evidence to aid in healthcare decisions for patients, caregivers, clinical specialists, employers, insurers and policy-makers. In Denmark, the Knowledge Center for User Involvement in Health Care (VIBIS.dk) was established in 2011 with the purpose of developing a knowledge base for the involvement of patients and their relatives in the Danish healthcare system. Such organisations are important collaborators, for example, in recruiting patients to projects,¹⁷ as they have contact with individuals who have experience with the condition being investigated,¹⁸ and can thus provide expertise on patient and public

involvement.¹⁹ International literature testifies to a growing level of experience and knowledge on the inclusion of patients in partnerships to identify research priorities, including patients with asthma,²⁰ skin disease,^{21–23} kidney disease,²⁴ Parkinson's disease,^{25–26} neurological disabilities,²⁷ neuromuscular disease,⁹ urinary incontinence,²⁸ eye disease,²⁹ dementia³⁰ and burns.³¹ To the best of our knowledge, few studies (surveys only excluded) have invited patients with cancer, for example, prostate cancer³² and mixed cancer diagnoses,³³ to collaborate on identifying research topics. Lophatananon *et al*³² generated a list of 11 primary uncertainties identified by patients with prostate cancer and clinical specialists. Wright *et al*³³ showed that patient and caregiver involvement in participatory cancer research strengthened the relevance and appropriateness of the research findings and methods. Systematic reviews on involving patients with cancer in research provide an overview of the existing challenges and opportunities.^{10–19–33} One challenge identified was that the preferences of patients with cancer change according to the stage and seriousness of the disease.¹⁰ Further, studies show that involved parties may find it difficult to participate in research meetings if their role and contribution is not made clear at the outset.¹⁹ A growing body of literature provides methodological recommendations for research collaboration with patients^{1–6–12–34–39} that include systematic guides and models.^{5–7–8–40} Various methods have been applied to involve patients and/or relatives in identifying research priorities including surveys,^{21–23–28–41} focus group interviews (FGIs),⁴² workshops^{43–44} and mixed methods.^{25–30–32} The studies that conducted FGIs^{9–25–42} conclude that this method was feasible; however, participants questioned whether their involvement would have an impact.⁹ Systematic representation of patients and relatives in establishing priorities in Danish research is a novel concept that offers interesting perspectives and potential. There can be a disparity between what patients, relatives and clinical specialists view as important unanswered questions and those which are actually researched.

AIM

The aim of the study is to identify, discuss and prioritise future research issues within supportive care and rehabilitation in patients with primary malignant brain tumours and acute leukaemia during the cancer trajectory.

METHODS

Study design

This qualitative study will carry out FGIs in two disease groups, primary malignant brain tumour (n=3) and acute leukaemia (n=3). Data collection, analysis and evaluation will be carried out separately for each disease group. Separate FGIs will be conducted with patients, relatives and specialists, respectively, to create a comfortable group dynamic within each FGI.⁴⁵ A representative

from a relevant patient organisation will participate in the FGIs for patients and relatives. The recommended suitable size for an FGI is between 8 and 10 participants.⁴⁵ The FGIs will be conducted by the same moderator (KHP) and an assistant moderator (KP or MJ). A semistructured interview guide, inspired by the JLA method,³⁷ (table 1) and guidelines for planning, carrying out and evaluating the FGIs have been developed for each FGI.⁴⁶ The interviews will focus on issues important to the specific group of FGI participants (patients, relatives or clinical specialists), for example, experience with communication/information, symptom management, perspectives on decision-making, psychosocial issues, rehabilitation and needs and challenges of daily life. To meet potential concerns about whether user involvement will have an impact, each participant will be provided with the published results, including a Danish summary. Study participants will be asked to complete a written evaluation after each FGI to assess their level of satisfaction with the interviews' structure, procedure and content.

Participants

Two separate patient with cancer groups with life-threatening diagnoses will be recruited for the FGIs: (1) patients with acute leukaemia, relatives and representatives from the Danish patient support organisation for lymphoma and leukaemia (LyLe), and acute leukaemia clinical specialists and (2) patients diagnosed with a primary malignant brain tumours and relatives, including representatives from the Danish patient brain tumour organisation and neuro-oncology clinical specialists. Participants must be ≥ 18 years, and speak and

understand Danish. Patients must have undergone at least one round of chemotherapy and/or radiotherapy. Relatives will be appointed by the patients. The clinical specialists must have worked within their field for a minimum of 2 years.

Recruitment of patients, relatives and patient organisations

The researchers (KP and MJ) and the clinical specialists jointly select the participants (patients and relatives) that are representative of the diagnosis in focus (brain tumour or acute leukemia). Representatives from the patient organisations LyLe and the Danish Association for Brain Tumour Patients (HjernetumorForeningen) will be recruited by KP and MJ. Potential participants will be provided with oral and written information, and written consent will be obtained. Patients and relatives will be reimbursed for travel and parking expenses.

Recruitment of specialists

Six clinical specialists within haematology and six clinical specialists within neuro-oncology/surgery, selected in collaboration with the departments' clinical management, will be recruited for each FGI. Participants will include nursing staff, doctors, physiotherapists and other relevant staff with clinical specialist experience. The specialists will be notified and invited to participate by e-mail. On acceptance, written consent will be obtained. Participation is voluntary and the FGIs that are conducted outside regular working hours will be reimbursed in accordance with the employee's terms of employment.

Project organisation and partners

The PIRE project working group is managed by the principal investigators (MJ, KP) and will include an FGI moderator (KHP), a research assistant and an information specialist. MJ and KP will establish a steering committee during the project's preparatory phase. The steering committee will comprise representatives from the management at the Departments of Haematology and Neurooncology, Copenhagen University Hospital, the Danish Cancer Society, two patient organisations, the University Hospitals' Center for Health Research, the University of Copenhagen and the Department of Acute Pain Management and Palliative Medicine, Rigshospitalet. In collaboration with MJ and KP, the steering committee will provide guidance and monitor the development of the project. MJ and KP will be responsible for arranging and conducting the steering committee meetings and coordinating activities and communication between the steering committee and the PIRE project working group.

DATA COLLECTION AND ANALYSIS

FGIs will be audio and video recorded and transcribed in full, and transferred to the software programme NVivo (Skorkjær Binderkrantz A, Bøgh Andersen L.

Table 1 Examples of interview questions for focus group interviews with patients

Opening question	Please tell us your name and briefly tell us about your current disease status and treatment situation
Introductory questions	Thinking back to when you were diagnosed—what comes to mind as important?
Transition questions	Which three main issues related to your care and rehabilitation would you like to discuss today?
Key questions	How was the information/communication you received/experienced during the course of treatment? What symptoms have you experienced and how have they affected your daily life? Please talk about the kind of support you need/needed and what type of help/support you have received. How did you experience the transition from hospital to home (everyday life)?
Ending question	Are there any issues we still need to address?

Guide to NVivo 9. 1.th edn. Hans Reitzels, 2011). This will ensure an audit trail for the analyses and transparency in the process from raw data (interview transcripts) to comprehensive understanding, thus increasing the credibility and reliability of the findings.⁴⁷ Three researchers (MJ, KP, KHP) will carry out the analyses to strengthen the internal validity of the study.⁴⁸ A hermeneutic approach will be applied to interpret and understand the narratives of the study participants.^{45–49} A thematic analysis will be conducted on the basis of the Braun and Clarke approach.⁵⁰ MJ, KP and KHP will read each transcript to become familiar with the content. Two members of the research team will code the transcripts (KP will be responsible for the brain tumour FGIs, and MJ for the acute leukaemia FGIs). The coding reports will then be discussed by the three researchers. MJ and KP will initially identify and classify the data into main topics and subtopics.⁵⁰ Incongruities will be discussed until consensus is reached and further analyses will identify research questions/issues. The researchers will examine the literature for existing evidence concerning the identified issues. An appraisal tool suitable to the study design, such as the Critical Appraisal Skills Programme (CASP) 2014, will be used to assess the existing evidence,⁵¹ which will then be outlined according to the evidence hierarchy.⁴⁸ Finally, the overall research questions and evidence review will be presented and approved by the steering committee. This process will be carried out separately for the acute leukaemia and primary malignant brain tumour groups.

ETHICS

Written consent will be obtained from each participant, including permission to record the FGIs and to use anonymised quotes in publications. Ethical aspects will furthermore be based on experience gained from similar processes,³⁸ for example, not placing a burden on the involved patients and relatives.¹² The study registration number is: ISRCTN57131943.

DISCUSSION AND PERSPECTIVES

Employing user involvement in research represents a challenge to conventional research practice in Denmark, which is why this research project requires careful preparation and evaluation.^{6–10} Issues to consider include role distribution, preparation of patients/relatives, mutual respect for different skills and dissemination of research practice and findings in common language.^{6–8, 12, 38–53} By addressing these issues, we anticipate promising potential for Danish research. Future publications will discuss the challenges and advantages of patient involvement that contribute to broader collaboration in cancer research. Validity and rigour will be met through the transparency of an audit trail and researcher triangulation.⁵⁴ This project is of value to clinical practice as it takes into account the perspectives of both healthcare users and clinical specialists in the

identification of future research fields targeting supportive care and rehabilitation. Establishing a partnership between patients, relatives, clinical specialists and researchers within haematological and neuro-oncological malignancies can potentially broaden perspectives within Danish research as new important research issues may be identified. This study represents the initial step in what could become a larger multicentre international research programme involving various populations with life-threatening cancer diagnoses.

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Contributors KP devised the study concept and drafted the manuscript. KP and MJ designed the study in collaboration. MJ provided substantial scientific contribution and critical revision of important intellectual content.

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Competing interests None declared.

Ethics approval The study is registered at the Danish Data Protection Agency (number: 2012-58-0004) and the Scientific Ethics Review Committee of the Capital Region of Denmark (number: H-15001485).

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