

As the Bell Tolls: A Foundation Study on Pancreatic Cancer Consumer's Research Priorities

Saunders et al. (2009)

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For which topic were research priorities identified?

pancreatic cancer

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

Pancreatic cancer has an extremely poor outlook in terms of early diagnosis, effective treatment and survival. Those affected by the disease generally lack opportunities to voice their needs or concerns in an organised manner, link with others affected by the condition and take part in research.

What was the objective?

to explore the views of people affected by pancreatic cancer with regard to research priorities, and to identify and address unmet supportive care needs of PC patients, and current or bereaved carers

What was the outcome?

a list of 5 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

group discussion

How were the priorities for research identified exactly?

Step 1: discussion groups: one discussion group consisted of patients with a PC diagnosis while another group consisted of current and bereaved carers of PC patients, safe space approach was used, separating participants by stakeholder group allowed for focussed discussion on issues that particularly affected each group, participants were asked to discuss the question: Where would you like to see progress in pancreatic cancer being made?. Step 2: data processing: thematic analysis

Which stakeholders took part?

Patients with a PC diagnosis and bereaved carers of PC patients. 11 participants: 5 current and bereaved carers, 6 people diagnosed with PC.

How were stakeholders recruited?

Self-selected participants were recruited from the CCNSW website and newsletter information which described the opportunities and benefits of involvement in a newly launched CCNSW Pancreatic Cancer Support Project.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.