



Interventions to support patient decision making about taking part in health research: a systematic review

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Background

- Gaining informed consent from participants is a vital but challenging aspect of conducting clinical research.

Aim

- We systematically reviewed interventions designed to support communication and decision making about participation in health research.

Methods

- We searched five databases (1990-2022), Google Scholar, and reference lists of included papers for peer-reviewed articles reporting any intervention-focused study design.
- Eligible interventions aimed to improve decision quality by enabling adult patients to:
 - Address their information needs (e.g., question prompt list) and/or
 - Incorporate their values into decision making (e.g., decision aid).



Question Prompt List – Clinical Trials (QPL-CT)



Results

- We included 15 studies (13 in cancer) of which 9 were randomised trials (all in cancer) and 3 were quasi-experimental.
- In 5 papers, resources addressed participation in a specific study (3 cancer); the other 10 were generic but focused on clinical trials.
- In 7 studies, tools were on paper; 8 were computer- or web-based, facilitating greater interactivity and/or tailoring.
- 9 of the 15 papers cited a relevant psychology or decision-making theory/model and/or established framework/standards.
- 11 studies reported knowledge post-intervention vs control. Among these, 6 found a positive effect of the intervention.
- 10 studies reported research participation (actual/intended) post-intervention vs control. Of these, 8 found no group difference.

Intervention type	Study ID	Knowledge	Attitudes	Decisional conflict	Participation (actual/intended/hypothetical)
Randomised Controlled Trials					
DA	Juraskova 2014	▲	—	—	—
	Politi 2016	▲	—	▲	—
	Christy 2022	—	—	—	—
	Meropol 2016	▲	▲	—	—
Information + QPL	Sundaresan 2017	▲	—	▲	—
	Ellis 2002	—	—	—	▼
Quasi-experimental Studies					
QPL only	Tattersall 2017	—	—	—	—
DA + QPL	Okada 2021	▲	—	—	—
DA	Sorenson 2004	—	—	—	—
	Morgan 2022	—	▲	—	▲

▲ indicates more favourable outcome in intervention vs control group. ▼ indicates less favourable outcome in intervention vs control group. — indicates no significant difference between groups.

Study ID	Study design	Setting	Intervention type	Intervention format
Ellis 2002	RCT		Information + QPL	Printed booklet
Kass 2009	RCT		Information + QPL	Computer-based + video
Dear 2012	RCT		Information + QPLs	Website
Juraskova 2014	RCT		DAs	Printed booklet
Politi 2016	RCT		DA	Web-based
Christy 2022	RCT		DA	Web-based
Meropol 2016	RCT		DA	Web-based + video
Tattersall 2017	RCT		QPL	Printed
Sundaresan 2017	RCT		DA	Printed booklet
Sorenson 2004	Quasi-experimental		DA	Printed
Okada 2021	Quasi-experimental		DA + QPL	Tablet (computer)-based
Morgan 2022	Quasi-experimental		DA	Web-based
Juraskova 2015	Mixed methods		DA	Printed booklet
Fleisher 2020	Mixed methods		Information + QPL	Web-based + video
Gillies 2014	Qualitative		DAs	Printed booklet

Conclusions

- This review highlights the potential utility of tools for patients considering health research participation.
- However, most interventions targeted cancer clinical trials. Future interventions should address other clinical settings and research designs, and important emerging areas like genomics and precision medicine.
- Digital technology offers opportunities to tailor content, enhance interactivity, and optimise support for diverse communities.



Proudly supported by Cancer Institute NSW

