

Toward meaningful and effective consumer involvement in cancer research: A systematic review on codesign methods and processes

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BACKGROUND & AIM: Although the benefits of consumer involvement in research and health care initiatives are known, there is a need to optimise this for all people affected by cancer. This systematic review aimed to synthesise and evaluate the application of codesign in the oncology literature and develop recommendations to guide the application of optimal codesign processes and reporting in oncology research, practice and policy.

METHODS

- Systematic search of four databases for studies on codesign and oncology
- 5652 titles/abstracts screened, resulting in 66 eligible publications reporting on 51 unique studies
- Four frameworks applied to describe codesign initiatives (Fig. 1)
- Codesign process used with expert stakeholders to generate recommendations based on the findings of the review

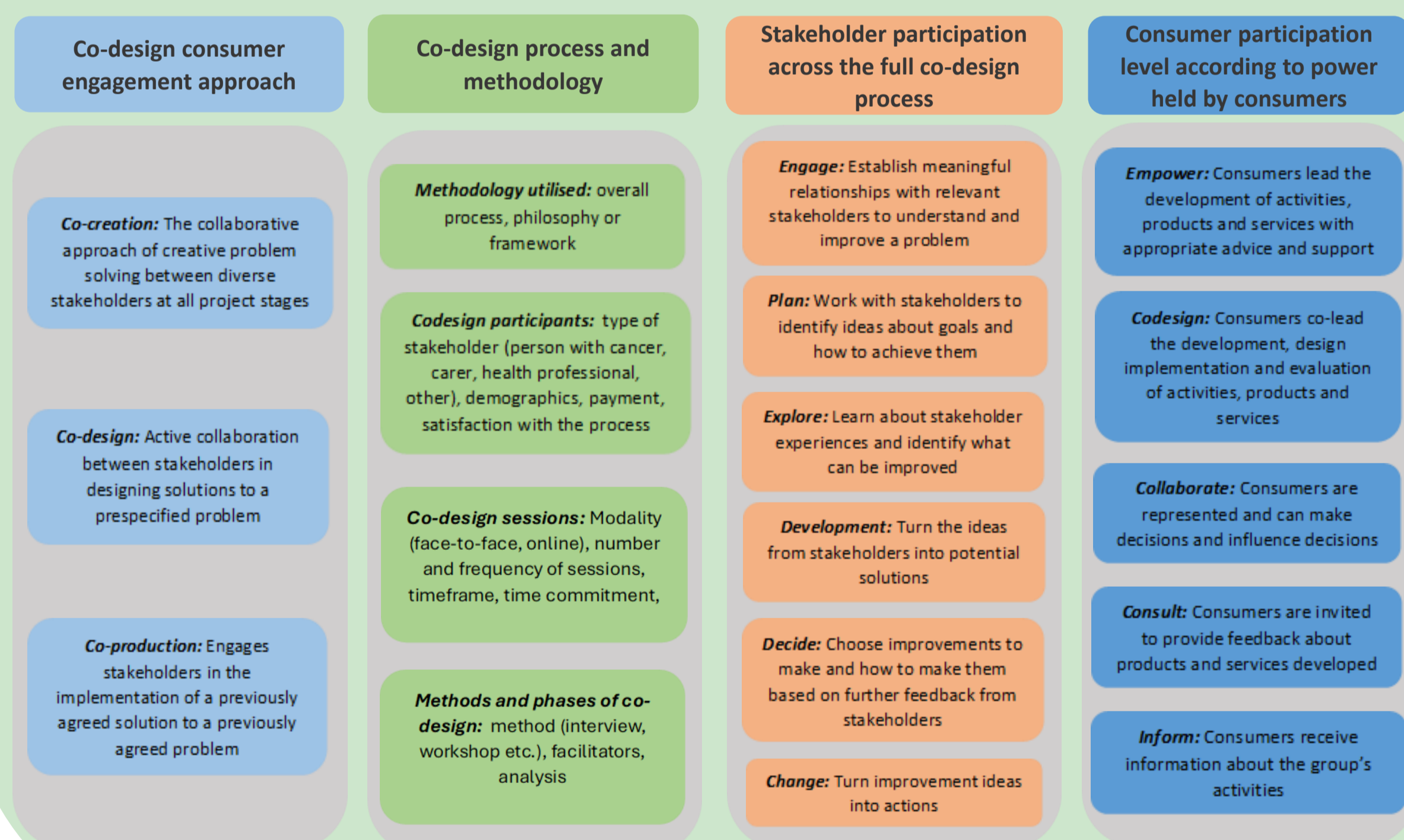


Figure 1: Description of the frameworks applied to analyse the co-design initiatives.

RESULTS

Overview of studies

- 74% of codesign initiatives were designed for an outpatient setting
- 27% digital resources and 23% apps

Consumer engagement

- Most (49%) of studies used a co-production approach to consumer engagement

Codesign methodology

- 70% provided no overall description of their approach
- 12% used no framework or methodology

Codesign stakeholders

- Reporting was poor for participant details and level of involvement (frequency and time commitment of codesign sessions)

Stakeholder participation

- Stakeholder participation was predominantly 'development' (98%) and explore (94%)
- Consumer participation level was mostly 'collaborate' (49%)

RECOMMENDATIONS

Themes from the codesign process with expert stakeholders generated recommendations presented in Figure 2.

METHODOLOGY

- Consider the approach that fits the goals and purpose of the initiative:
 - Co-creation when broad improvement is desired, but the problems are not established.
 - Co-design when the problem is known but there is limited knowledge of the solution.
 - Co-production when the problem and solution are understood but optimal implementation is required.
- Use a framework for the co-design process that suits the purpose of the initiative and the anticipated power dynamics between co-design participants.
- Incorporate all elements of co-design, with particular attention to establishing relationships and working with consumers to identify and achieve goals, to support early and iterative inclusion of consumers in the process.

CO-DESIGN PARTICIPANTS

- Ensure diversity in consumer participants that is representative of the sociodemographic and clinical profile of the target group of the initiative.
- Involve other stakeholders (e.g., health professionals, carers, policy makers) with academic, clinical and policy knowledge pertinent to the topic at the appropriate stage of the initiative development.
- Appropriate recognition of consumer contribution to the co-design process through remuneration +/- authorship on publications.

EVALUATION

- Embed evaluation of participant experience of the co-design process into the overall program of work.
- Following development, evaluate the effectiveness of the co-designed initiative against the intended purpose.
- Measure and report on the elements of the co-design process that effectively influenced uptake and outcomes of the co-design initiative.

Figure 2: Recommendations for researchers, clinicians and consumer advocacy organisations for the application of codesign in oncology

CONCLUSION: There are opportunities to improve the application of codesign in oncology research. This review has generated recommendations to guide 1) appropriate choice of methodology, 2) recruitment and engagement of codesign participants to reflect the target group of the initiative, and 3) evaluation of the codesign process. These recommendations can help drive appropriate, meaningful and equitable codesign leading to better cancer research and care