



Co-producing evaluations: putting people affected by cancer at the heart of understanding what works and why

Macmillan Research Showcase

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Why co-produce evaluations?

- **Co-production is at the heart of Macmillan's Redesigning the System programme, and this should be reflected in the evaluation too**
- **So that evaluation is guided by PABC: helping to define what counts as success, making sure the evaluation focuses on what matters most to people with cancer**
- **Evidence and experience suggests that peer research can contribute to gathering richer and deeper insights, and can be a more enjoyable process for participants**
- **The approach builds local capacity for evaluation, rather than simply being a 'external' process**
- **Why not? Time, complexity, ethical challenges, recruiting people to act as peer researchers.....**

What do we mean by involvement?



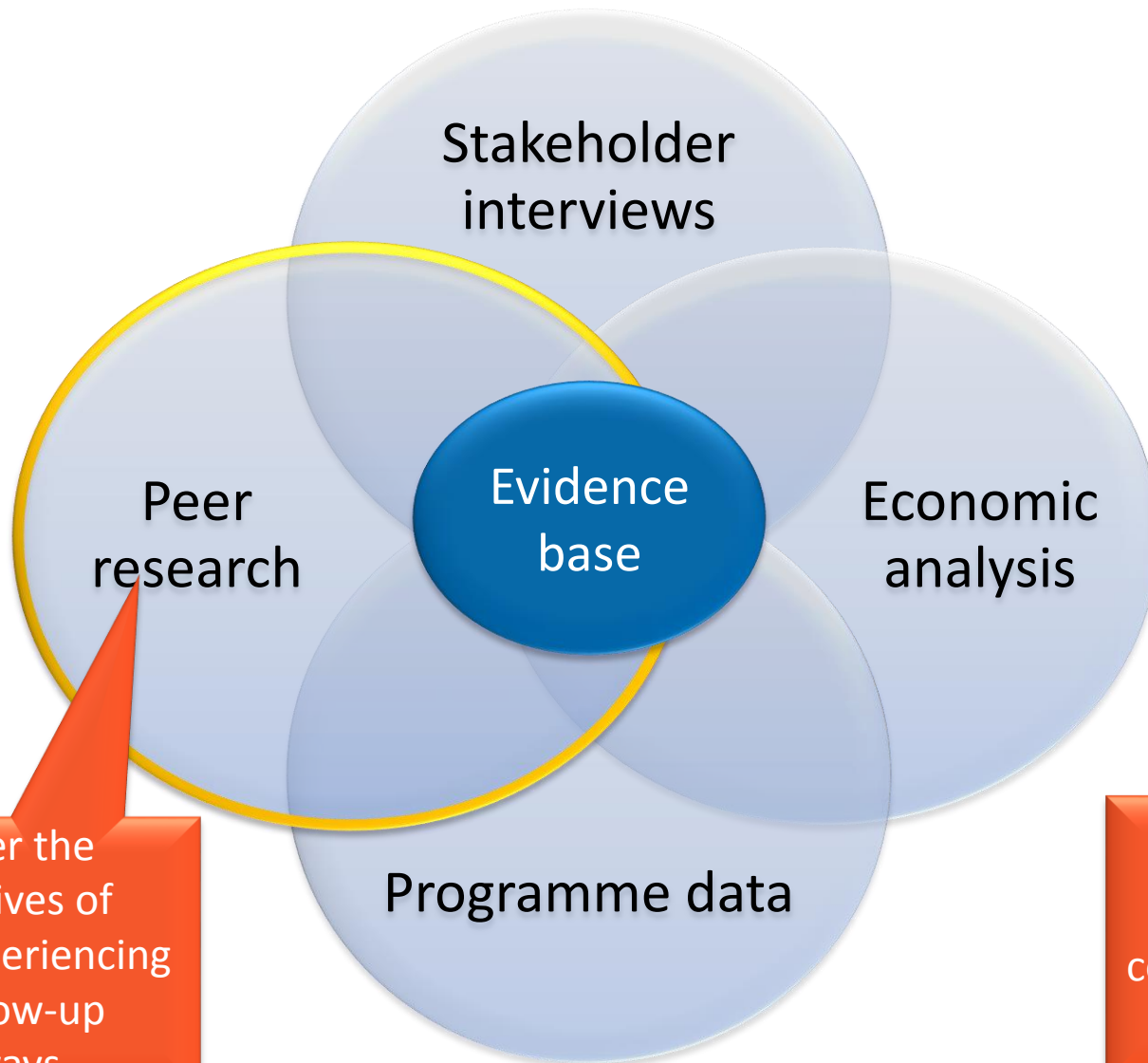
Consultation

Collaboration

User controlled

- **Involvement needs to be meaningful, not tokenistic**
- **And it needs to be integrated into a project, not an 'add on'**
- **It needs to be supported**
- **And the contribution needs to be recognised and rewarded**
- **The critical factor is commitment, not the 'right' method**

Peer research used as part of a mixed-methods approach to the evaluation of the MacMillan North Trent Survivorship Programme



To gather the perspectives of patients experiencing new follow-up pathways

Focused on the change to colorectal pathways in Sheffield

The nuts and bolts of the peer research process

Peer research is not an easy option and it's certainly not a way of doing research 'on the cheap'. It takes time, commitment, and a lot of planning.

Recruitment

We recruited four peer researchers through the Weston Park Cancer Information and Support Centre. The role was advertised through the centre and interested people were asked to complete an application form. DBS checks were carried out on successful applicants.

Training

Three workshops, two before the interviewing stage and one post. First two sessions covered: overview of the survivorship programme; evaluation aims and approach; active listening sharing stories; understanding social research; ethical issues; interviewing skills; practical arrangements. Third session covered: reflections on the process; thematic analysis of interviews; next steps for the evaluation

Support

During the second workshop PRs were given the opportunity to identify their support needs. PRs given a named key contact both locally and at ICF who were contactable at every stage of the project. PRs contacted on regular basis to check all ok.

Payment

PRs informed of payment policy at recruitment. PRs paid for the time they spent on the project including the for the third workshop. Payment was in the form of high street vouchers. Travel costs also reimbursed. To claim payment PRs asked to fill out a timesheet.

Undertaking the research

Co -designing the research tools

- Second workshop session involved peer researchers reading and reviewing the interview topic guides.
- Topic guides were re-drafted taking account of peer researcher comments.

Interviewing

- The peer researchers interviewed 18 patients who had been discharged to primary care follow-up on the revised pathways.
- ICF recruited patients through the colorectal team at STH, and worked with the peer researchers to schedule interviews.
- Interviews were undertaken at the Weston Park Cancer Information and Support Centre. Recordings were encrypted and sent to ICF.

Analysis and review of findings

- At the final workshop PRs identified key themes arising from interviews.
- ICF shared key themes from their analysis and explored with PRs.
- Interview transcriptions were then shared with peer researchers who analysed in pairs
- Draft report was reviewed by PRs who were invited to make changes/edits/additions.

Factors that promoted success (and one that didn't):

- The peer researchers themselves – they were all pretty brilliant.
- The involvement of the Weston Park Cancer Information and Support Centre who supported us with recruitment, providing training and interviewing rooms and with administration.
- Identifying a dedicated member of ICF team to undertake the whole process and provide a single point of contact and support for the PRs.
- Having a genuine commitment to peer research and real understanding of the value of what peer researchers can bring.
- ICF-led recruitment of patient participants.
- Being flexible and adapting to constraints and opportunities.
- Deadlines and time constraints worked against involvement across the whole life-span of the evaluation.

Reflections on the value of peer research – from the peer researchers

- Peer researchers described how they had greatly valued the opportunity to participate in the evaluation. They were keen to be involved throughout the process and worked hard to ensure they had sufficient knowledge - of the programme and interview skills- in order to carry out the interviews.
- Peer researchers discussed how the patients they interviewed found it very rewarding to be interviewed by people who had been in similar situations to them.

"I've really enjoyed the process from start to finish...I am really looking forward to seeing the report. Thanks for all your hard work [names ICF trainer]. It has been a real pleasure working with you."

"I would applaud the decision to have peer evaluation of the project rather than having the interviews with patients undertaken by researchers. I know the patients appreciated that too. They specifically commented on the fact that they felt more able to talk freely to someone else who would understand what they had been through".

Reflections on the value of peer research –on the research process and outcomes

- Benefits to the evaluation were mainly around the richer data gathered from an approach where interviewees speak to ‘peers’ who have also been affected by cancer.
- Feedback from the peer researchers (previous slide) indicated how interviewees appreciated being interviewed by peers. This is a valuable outcome in terms of ethical research with potentially vulnerable people.
- It is also valuable for the evaluation itself, in terms of the data gathered – if interviewees are able to establish a stronger rapport with interviewers then the likelihood of them being more open and candid in sharing their views is greater.
- Peer researchers also made insightful recommendations based on their experiences in the research which were included in the report.

“The peer researchers were a privilege and a pleasure to work with. Their approach to the whole process – from participating in the training, to setting up interviews and carrying them out - demonstrated their commitment and skill. They added real value to the evaluation and I learnt an enormous amount from them.”

“Patients should be helped to better understand the rationale for early discharge. In particular that this is not simply about saving money. Patients should be helped to understand the low detection rate of recurrence of cancer at hospital clinic visits”.

