
Example 2: Resources for Living (R4L) pilot: Exploring the potential of progressive cuisine for quality of life improvement for head and neck cancer survivors.

About the research

Lead researcher: Dr Duika Burges Watson, School of Medicine, Pharmacy and Health, Durham University.

Funder: National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) Programme.

Project aim: To find out if progressive cuisine (innovative cooking techniques and ingredients) can help survivors of head and neck cancer treatment to overcome difficulties related to food and eating.

Type of research: Action research.

Duration: 30 months - started July 2013.

Who we spoke to

We interviewed the project's Patient and Public Involvement (PPI) lead, Dr Sue Lewis at Durham University. Her comments are in blue below.

About the involvement

Patient / carer involvement prior to applying for funding

The lead researcher initially invited a group of academics to meet and discuss developing the proposal for this project. At the suggestion of the NIHR regional PPI officer from the local Research Design Service, they also invited a survivor of head and neck cancer, John Buckley, to meet them. He was a member of a support group run by one of the researchers.

“As a group of researchers we weren't convinced that on our own we'd be able to come up with a workable research question or project design. We needed to be sure that the way we conducted the research would be acceptable to survivors. We also wanted their help in identifying what kinds of foods would be most useful to investigate – what would be most relevant to their everyday life.” Sue

The team worked with John and his wife to develop a strategy for further involvement in working up the proposal. They applied for funding for PPI from the Wolfson Research Institute at Durham University. This enabled them to run three workshops with survivors and their partners. These workshops introduced the idea of progressive cuisine and gave survivors opportunities to sample innovative foods. John helped to plan the workshops and recruit participants.

Impact of the early involvement

The discussions at the workshops helped to refine the **methods** used in the research.

“We wouldn’t have been able to put the proposal together without the involvement. It gave us confidence that the workshop format would be acceptable to survivors. We also needed some of the study participants to undergo further tests to see how easy the new food would be to swallow. The survivors at the workshops confirmed that asking people to undergo these tests would be acceptable.” Sue

The idea for a Resource for Living also came from the workshop, helping to define the **project outputs**.

“The idea of the Resource is that it provides advice to other survivors – it will probably take the form of a recipe book that also includes lifestyle tips. There will be sections that highlight different survivors’ stories – what kinds of problems they’ve experienced, what kinds of foods they can or can’t eat and the changes they have found useful.” Sue

Working with survivors also changed the **attitudes of the researchers** and the **functioning of the research team**.

“As a team, it helped us to work in an interdisciplinary way. Having other kinds of experts working so closely with us, made us much more open to different ideas. It made us focus on the issues that are most important to survivors. We got a much deeper understanding of their experiences and a greater appreciation of the problems and frustrations they face, for example how difficulties with eating have a much wider impact on families and socialising with friends.” Sue

Continuation of involvement following funding

John Buckley became a co-applicant on the grant and continues to work with the project team. The workshop participants have also been invited to join an expert group to help with developing the Resource for Living over the remainder of the project.

During the time between being awarded the grant and starting work on the project, the team have run further workshops with the same participants and kept in touch through regular newsletters / updates. This has helped to keep people engaged and motivated to stay involved.

Lessons learnt

“Before this experience, I would have thought good PPI was about getting people in early and making space to talk to them but now I think you can be more creative than that. If you give people more time and meet with them more than once you can open the floodgate to a whole new set of ideas and possibilities. It will also give you confidence that you have a viable project to take forward. In the long run I think it will make me a better researcher – I now wouldn't consider putting together a project without taking PPI very seriously.

It's important to allow adequate time and resources for involvement, not just for meetings, but also to respond to the feedback. We had to put back the submission date for our application when we realised we needed more time to develop the proposal and to include all that we'd learnt. You need to give involvement the priority that it deserves.” Sue

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References:

INVOLVE Autumn 2011 Newsletter – [John's Cheese Sandwich](#)

Link to film of John: <http://vimeo.com/29369805>

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