

Case study three

A survey of carers of people with heart disease

Aims of the project

To find out about the experiences of carers of people with heart disease.

How you found people to involve

The whole project really came from May [Griffiths, the co-researcher]. It was her idea. I met May when I was working with the Patient and Public Involvement (PPI) group in Blackpool where she was a member. I was supporting the promotion and development of an educational DVD for people using cardiac services and seeking feedback from the PPI group. That was when May said she would like to do some work on the experience of carers of people with heart disease. Her husband had had a heart attack and bypass surgery which had not been as successful as we would have expected. She had gone through all that stress and her husband had then died of heart failure. She had all these thoughts about how she could help other people and how she could have been helped in better ways. So her idea was to do some kind of survey to find out how carers felt about the support that was available for them – and to see what could be done to improve it.

At that point in time, because of the National Service Framework for heart disease, all the services were being looked at and redesigned and quality improvements were being made – but the carers didn't have as much emphasis. So this project filled a major gap. So I approached my manager at the Network and she agreed to fund the project. It was the right question at the right time.

How you involved people

May was co-researcher on the project and was involved at every stage of the project, from coming up with the research question through to disseminating the results. The project involved sending out a questionnaire to carers in Blackpool. The findings from the survey led to the establishment of a local expert carers' programme and a review of the discharge process at local hospitals to ensure that carers' views and needs would be taken into consideration.

What training and support did you offer?

What made our collaboration work well was that myself and May were partners. It made it quicker that it was just the two of us. We didn't have to have a lot of formal meetings. We could just phone each other, even at night – it was very informal. We had a personal relationship really, that made it a lot quicker. May also had all the necessary skills – I didn't have to teach her anything. She was familiar with looking at research, writing reports and adding references. So all the work was much easier. I was also very mindful about expenses. When you're working with service users or carers you can't expect them to pay for phone calls, ink jets and stationery – they may not have an income. And you can't expect them to communicate in the way you do – they might not have the internet or an answering machine. So I did a little bit extra. I'd print things out and take them to her house, after work or at weekends. I'd email or call her first to say I'd be round and then take the report round and talk about what we had to do. But I didn't expect her to download anything. Anything you can do to reduce costs is worth doing.

What difference did public involvement make?

May kept it real. She kept it focused on the person not the service which made it a lot richer. We stayed focused on what carers said and what they wanted. May also brought a lot of skills that I didn't have. I don't know anything about living with heart disease – May did know – she knew how it felt. But

she also had her own experience – her life skills. She was good at communication and engaging people. She also had good contacts. At the beginning, she used her contacts with social services and the carers' network to bring them on board as partners in the project. That was essential to getting our questionnaire out to carers and finding the right people to work with. We also had a lot of press coverage because of May. She was able to organise a press release with the patient involvement people. So we got a full page spread discussing the outcomes from the project and interviews with carers saying what a good idea it was that they'd been consulted.

At the end of the project, because May was a member of the patient forum, she was able to take our report back to them. They then took it to the Overview and Scrutiny Committee, who then asked the Primary Care Trust for an action plan – this drove the recommendations forward. If it hadn't gone to the patients' forum I am not sure if the outcome would have been as positive. So through May we were able to take our report to a forum that would drive forward the recommendations. Change is still evolving, it's the NHS and changes take time to implement, you've got to be up front with people about this.

What would you advise other researchers about involvement?

You have to involve people because what else are we doing it for? Is it just for a bit of kudos or do we really want to make a difference? Where are the gaps, what are the problems – you've got to ask people. It's why we're doing it. It's got to be of importance to them otherwise they won't answer – they won't be bothered. When you're working with service users and carers, you've got to take a risk and let other people take on responsibilities in the project – not thinking that as a health professional you are the be-all and end-all of everything you do. Beware the funding issues. Get support from higher management, because you have to spend a lot of your work time on supporting and working with people. Be honest and don't give false hopes. We can't promise change when we do

research. We can only say we will put things forward. Choose a topic wisely that's topical or of very high importance to the people you're working with – then you're more likely to get their engagement.

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Acknowledgement

This case study first appeared in Blackburn H., Hanley B. and Staley K. (2010) [Turning the pyramid upside down: examples of public involvement in social care research](#), INVOLVE, Eastleigh.