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[Home](#) > [Comment](#) > BMJ 2010;340:c1845, doi: 10.1136/bmj.c1845 (Published 14 April 2010)

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Views & Reviews

Personal View

Where are the clinicians when you need them?

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Having spent the past 12 months working with patient groups and clinicians on a project to identify treatment uncertainties in prostate cancer, I have been amazed at the way people and organisations working in the same field don't speak to each other. Have we become so competitive that we can't see that working together is good, if not essential?

My frustration is growing, and the *BMJ* seems a good place to ask doctors: "Why the lack of communication?" Where is your culture of collaboration in my field of prostate cancer? Do you feel you have your own show, and all the answers?

We're currently fighting our way towards an exciting collaboration between patients and clinicians designed to agree priorities in treatment research. There is so much we don't understand about prostate cancer and no agreement as to the most important research. Our partners are the James Lind Alliance (an organisation established to help identify and confront the uncertainties about the effects of treatment), several other prostate cancer charities, the main patient support groups, and the Prostate Cancer Charter for Action. Progress is now being made, but getting to this point has been uniquely painful.

Our initial attempt to identify the big treatment questions in prostate cancer comprised asking 50 of the top researchers in the field to come up with 10 questions each. They gave us a total of 42. Encouraging.

We took this list to the Prostate Cancer Support Federation, an organisation of patient led support groups, to see if we could combine patients' questions with those from our "top minds." We were amazed when only four people responded. But it soon became clear that these patients weren't opening up because they couldn't—they didn't have a clue what the experts were saying.

That was when we decided to follow the model used by the James Lind Alliance: forget researchers for the time being and concentrate on finding consensus between clinicians and patients.

We invited 90 organisations to an initial meeting to find out more about the James Lind Alliance and to become involved in our project.

About half replied—a poor response rate given that all these organisations have a vested interest in this work. Surely most, if not all, these organisations would have felt duty bound to reply? And more importantly, why didn't large organisations that represent research and patient interests want to join in?

Undeterred, we arranged to gather in London a group of the most enthusiastic supporters. We inadvertently picked a tube strike day in June. Thirty people turned up, but only one a clinician. I tried hard to believe doctors are more affected by a tube strike than the rest of us, and then I stopped making excuses for them.

I'm known for being rather enthusiastic and energetic. Given this constitution and despite a growing sense of despair, when we met in London I was again convinced that our project was interesting, exciting, and vital to drive the research agenda forward. We might only have one clinician, but we were at least giving patients a voice they'd never had before.

It didn't take long for my enthusiasm to wane. Many of the patients came with personal questions centred only on their diagnosis, which made life difficult for those of us trying to see the bigger picture. The researchers were clearly apprehensive, and the appearance of one valiant clinician can hardly be called "involvement."

It quickly became clear that guiding these disparate voices would be tough. I'm eternally grateful to one patient who pointed out that this piece of work may not help those in the room who had prostate cancer—indeed, he would be dead before any substantive results emerged—but he was still interested. And similarly appreciative of the man worried about the poor communication with black and minority ethnic groups about their increased risk of prostate cancer (it's three times more common in black than white men) and their treatment options. By the end of the day I still believed, as I do today, that this work could mean only good things for prostate cancer and those it affects.

We continue to collect research questions that could address treatment uncertainty, but we are still struggling hard to get clinicians to participate. I really do get the point about busy work loads, but there's no reason to assume that it is tougher for doctors to get involved than for patients, many of whom have been so easy and keen to engage. Indeed, for this latter group, prostate cancer is not the day job. For doctors who work in the field of prostate cancer it is. Where do you lie on this spectrum?

We set out to make our project an equal partnership between patients and clinicians, but doctors won't come to the party. Do I still believe in collaboration? You bet, and by hook or by crook we plan to have our top 10 jointly agreed research priorities by summer 2010.

We need to be answerable to our stakeholders—patients, families, and those who donate money—and fund

the best research. For so long, what we do with our funds has been decided by "professionals" who take little heed of those who have lived with prostate cancer.

Do you just not like us treading on your turf? Is guarding your territory paramount? We have more than fully engaged a wonderful Cambridge clinician, Vincent Gnanapragasam, and he's as baffled as we are as to why his medical colleagues don't seem to want a say in what we're getting up to with—and for—their patients.

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