

RDS NW case study: Shalom Srirangam

In one sense there is no doubt that Kidney Stone Disease has a huge impact, not only on the health service but the individual.

So over the last ten years, we've had a lot of national data come out.

Saying that Kidney Stone incidence is increasing but the number of procedures that hospitals are doing is increasing exponentially.

We also know that Kidney Stone related admission are increasing.

With all that in mind, we have a very good idea of the direct consequence of Kidney Stone Disease to the health service.

What we perhaps know less about is the indirect unseen impact.

Bearing in mind that Kidney Stones can affect patients at any age but largely will affect younger people. These are people who have got families, who are working.

Well what about the impact on the caregiver, on the family? What about the time off work? What about the number of times they might be seen in hospital but we don't see them but they are going to their GP because they have ongoing pain.

Sadly, Kidney Stones often need multiple treatment.

Well how do we know what the impact is when we don't see it.

So that was the basis.

How do we capture the indirect consequence of Kidney Stone Disease?

That was the question. Well capturing it was difficult and there is not validated way of doing it.

We have to make the patient the owner of telling us what had happened to them.

Now there are some validated questionnaires that you can use to ask about the quality of life, so we used those. For those where there wasn't any obvious tool, we had to use a diary and put the onus on the patient to say look this is what happened to me, I was taking pain killers for three days, I was off work for two weeks. My partner has to take time off work.

I had to go and see a GP on these days.

Which we really can't get in a simple way.

So the patient was given the onus in what we think was a helpful diary format, to be able to convey that information to us.

Specifically to the study, there hasn't really been a study that has looked at this area in the UK.

So I didn't have anything to go on. Secondly, how do I actually turn a research question that wants to look at what happens to patients away from hospital when there really isn't a validated way of picking that information up.

So it was very much a stab in the dark.

How do we collect that information?

My other concerns were that I knew I was going to need people I wanted to work with.

I had a clinical question but the research was going to look at various aspects: quality life impact, perhaps some economic data. Well I wasn't sure how I was going to go about getting those collaborators.

So with all of these things in mind, I was ready to get some help.

I think it would have been impossible really without early RDS support.

The project when I spoke to them and the level of Patient Involvement it was going to need.

An area I had not thought about is, having involvement from the patients and public early on in helping design the study.

When I spoke to one of the advisers from the North West RDS, they told me that it would be very helpful and they also told me that there is a PPI, Public and Patient Involvement Fund as well, that I could access just to set up an initial meeting, a forum to try and get some patient involvement.

Essentially, we invited a number of patients who have a vested interest. These were largely people who have suffered with Kidney Stones.

We got them along to an evening with some sandwiches.

Gave them an idea of the study, what we want to do and it was very helpful.

Essentially, I needed to know from them, is this important.

Do they think that this was worth answering and there was a unanimous agreement that it would be.

There were areas where I wasn't sure how we can gather that information.

We had put together a bespoke, homemade patient diary.

Well in my head it worked but I needed to know from patients if they would be happy filling that in.

So again getting some immediate feedback from the people who turned up there but we also gave them the chance to take it home, look at it over a period of time and write back to us and say look I think this works, this doesn't work.

It was key and again one of the key messages that I have learnt is that is you are going to do something that involves patient, you have got to involve patients early in the design.

The whole process of approaching and communicating with the Research Design Service was really very straight forward.

I sent an email and I was asked to fill in a form.

I remember it as being a very simple form.

Basically there were some questions asked about my thoughts about the study and the areas I felt that I needed help with.

I must say the areas that I thought I needed help with, I knew but I didn't know what I needed to know and I think the RDS was very helpful.

I seem to remember within three or four days I had contact from my adviser and after that, mostly we had a number of email contacts but the adviser travelled down, physically, to see me on a couple of occasions.

Even there was a drive down from Lancaster he didn't seem to mind. Really, the contact was always very prompt.

Always very specific, very willing to help.

If you are considering developing your portfolio as a researcher or setting up a study then you begin with the North West RDS.

Use them for as long as you feel the partnership is benefiting but I suspect they will probably be able to guide you through the whole process.

In my mind they are your go to person, outside the Trust, as a first port of call.