

Implementing the Your Health Survey in a Low-Clearance Clinic

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Why we got involved?

One of the pre-treatment team's main roles is to engage and educate patients on the different treatment options available, as well as help them look after themselves and preserve their kidney function for as long as possible. Many of the patients we see may be about to begin renal replacement therapy, so are in a period of transition; therefore understanding and being engaged in their care and treatment is important.

When I heard Dr Veena Reddy talking about the Transforming Participation in CKD programme, the concept of patients ability to self-manage being measured by a Patient Activation Measure (PAM) as well as measuring the potential **symptom burden they may carry**, I thought this would be a good opportunity to better understand the patients in the clinic, and in partnership make decisions that are right for them.

What we wanted to achieve

My initial goal was to survey all patients who attend the nurse-led Tuesday afternoon clinic (each clinic usually has around 23 patients).

Over my years of practice, one of the things that has surprised me is that a proportion of patients – even when they are about to commence renal replacement therapy – do not understand or have little knowledge of their disease and the impact this may have on their lives. When this happens, you realise that either through fear, denial or other reasons, little of the information you have given them over the years has gone in. It does not happen regularly but when it does it is a real shock. I am hoping that by reviewing patient's activation levels and symptom burden with them during clinic and other appointments we have the potential to engage with patients who are overwhelmed earlier, in a different way and work with them to tailor information and education accordingly.

For example, if we find someone who is clearly struggling with their treatment or is unwilling to engage, we could re-visit them at home on a one-to-one basis rather than waiting to see them in clinic, and build up their confidence gradually using a different approach.

What we did

I offered the survey out to everyone who attended my clinic for a period of 10 weeks, after which the same patients began returning. I now bring a few surveys down to clinic with me each week to capture anyone who may not have participated. At the moment we are not planning on re-surveying the patients until we have agreed on potential **interventions** that we could implement.

I have found it most successful implementing the survey myself, as I understand and can get across the benefits of taking part to the patients, and encourage them with the fact that the results will be fed back to them via **Patient View** and reviewed with them to plan and inform their care in the future.

My colleague has helped to hand out some of the questionnaires but only if I was around to answer any questions patients may have. Most patients have completed the survey in the out-patient

department – some whilst waiting for transport, some whilst waiting to be seen in clinic; one even finished her survey off with her arm strapped to an iron infusion!

I try not to sit and read with them as there is not much privacy in the clinic and I also know how important it is not to affect patient responses, but I would always say to others implementing the survey to make sure you are available close by to respond to any queries.

Challenges

- During nurse-led clinics and pre-treatment discussions with patients I have been unavailable to hand out any Your Health Surveys. Successful implementation of the surveys to a wider patient population would really require more or all of the pre-treatment clinical team to be involved with the project
- Due to the clinic being multi-disciplinary, patients may see three or more clinicians during their visit, so at times they were called away before we had a chance to consent the patients to complete the survey
- Patients who have been involved in a research study before tended to think they had done it already and needed an explanation
- Patient answers on the survey may vary depending if they think it might change the course of their treatment. For example we did have a patient who was frantically resisting dialysis who began filling out her survey. Her daughter then arrived and began crossing out all the answers declaring “I’m going to tell you how she really is!”

Dos and don'ts

- Always explain that this is not another tick box survey – it will eventually be used to assist their care and become part of their consultation
- Tell the patients they will be able to see their results – this definitely made them more interested and take more care with their replies
- Tell the patients that their survey is going to the UK Renal Registry and is part of a national programme, rather than a localised study. They seemed to be more interested knowing this, and knowing that it would help us improve the way we look after patients
- Don't let patients take surveys home! A few said they would need their spectacles and took them home – I estimate only two have brought them back
- One week I asked the reception staff to hand out the surveys, which was the only time a few patients declined to fill it in. I feel the survey is better explained by the nursing staff

Outcomes

Our team has yet to scrutinise the results from our patient cohort, but the collection of the survey alone has opened up conversations that may not have occurred otherwise. Symptoms for example, are often normalised for patients with a long term condition, and become part of everyday life. Recording it on the Your Health Survey acknowledges these experiences, encourages discussion and helps us to discuss how we can work in partnership to improve lives. I'm looking forward to looking in detail at these specific patient results and using them to inform our care into the future.

Do you have any queries about implementing the TP-CKD programme in a low clearance setting? You can get in touch by email to deborah.douglas@sth.nhs.uk.