

Involving patients in follow-up care

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With many thanks to our project team members

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What are the challenges of remote consultation?



Patient feedback from national survey

- Difficulties in communicating changes in their health and problems they were experiencing
- How they were feeling
- Difficulty being honest
- Less opportunity for the conversation to develop
- Difficult to discuss topics that are particularly distressing or causing fear.

What could be the solution?

- 1 year QI project funded by the Health Foundation
<https://q.health.org.uk/idea/2019/reducing-unnecessary-out-patient-appointments-in-kidney-care/>
- Partners: Kidney Care UK and Barts Health NHS Trust
- Industry partner Cievert Ltd <https://cievert.co.uk/penguin/>

*....a web-based platform that allows clinicians to **automatically ask patients** questions, based on their diagnosis and course of treatment. The patient can answer these questions from a smartphone/tablet/computer at home.”*

What did we do?

- Focus on transplant clinic
- Project team plus patient group
- Started with validated questionnaire
- Asked patient group to add/remove items
- Asked clinical team to review and edit
- Patient group 'tested' questionnaires using Cievart system – gave feedback
- Questionnaires finalised – one for 'follow-up' and one annual review
- *Live testing with 5 patients at Barts Health NHS Trust*

BMC Nephrology

Research article

Open Access

**Reliability and validity of the ESRD Symptom Checklist –
Transplantation Module in Norwegian kidney transplant recipients**
Knut Stavem*^{1,2} and Rüdiger Ganss¹

Section 1: Main problems

What do you see as your main health concerns today? (list up to 3)

Free text

Main problems
Emotional health
Physical health
What questions do you have?

Section 2: Your emotional health

How do you feel your emotional well-being has changed since last year?

- Improved
- Stayed the Same
- Got worse

Transplant failure

Are you experiencing any worry about the transplant failing?

- Not worried
- A bit worried
- Very worried

What did we find?

Interviews with patient group to explore “**Added value**”

- potential to empower patients
- speed up the communication between the GP and acute care
- patients have more time to think about the online questions
- *“I think it was really positive and there’s been a lot of thought put into designing these and tailoring them and making them really clear, so I think the questions are very easy to understand.”*
- the practice of self-management

Living with kidney disease perspective

Shashi Matharu

Patient Advisory Group member, Kidney Care UK

What matters to you with respect to remote care?

What 'added value' does this project bring?

What are our next steps?

End of project April 2021 – report to Health Foundation

Barts Health to facilitate **'live testing'** with 5 patients
Incorporate triage; 'two-way' conversation; link blood results

Further evaluation

Dissemination

Happy to share methods/questionnaires with other Trusts

What are our key messages?

1. Involve people with kidney disease in any service development
Look at Kidney Patient Involvement Network (KPIN) if you need support
<https://kpin.org.uk/>
2. Review the national survey findings and reflect on your current remote provision – what matters to you may not be important for patients
3. Start early with Information Governance ICT teams
4. Pin down your evaluation and sustainability plans at the outset