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P116 -Developing a patient survey to evaluate patient reported experience and facilitate service improvement in aHUS.

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Background

Patient experience is one of the three core areas that define quality in the National Health Service (NHS) as stated in the Darzi report in 2008. Patient experience is supported in the latest NHS Constitution (2015) and the CQC Standards (2017). The Kidney Patient Reported Experience Measure (PREM) is a national annual survey of kidney patients that commenced in 2016.

The National aHUS Service was commissioned by NHS England in 2016 to co-ordinate the management of patients with aHUS. We are working in collaboration with the Picker Institute Europe's rare disease team to identify key themes in patient experience to develop patient reported experience measures as part of our strategy to improve quality in aHUS care.

Method

We have collaborated with Picker Europe to elicit patient views and experiences of patients with aHUS. Patients with aHUS under shared care with the National aHUS Service were contacted by letter and asked if they wished to opt out of the survey. The letter also invited patients/carers to contact researchers at Picker if they wished to participate in interviews as part of the first phase of the survey design. Themes from these interviews will inform the patient survey as part of our patient related experience measurement.

Findings

A total of 170 patients were contacted by initial letter. None of patients opted out of the survey. Twelve people contacted Picker to take part in phase 1 of the survey; of these ten were chosen to take part in the interviews. Eight of the ten interviewees had a diagnosis of aHUS made prior to the commissioning of the national aHUS service. Due to the geographical distribution of the patients the interviews took place by telephone instead of focus groups.

A number of common themes emerged from the initial analysis of reported experiences, mostly from patients initially treated before the commissioning of the National aHUS Service.

- Lack of information around the time of diagnosis
- Lack of knowledge about aHUS
- Poor communication
- Isolation
- Disease burden in patients, especially those who required dialysis at time of diagnosis and those patients who had graft failure following disease relapse.

We also identified variation in knowledge of the National aHUS Service but where patients had had contact with the National aHUS Service, the experience was very positive.

Discussion

We have completed the first phase of a project to design a survey to report patient related experience measures in aHUS. Many of the themes from the initial patient interviews are similar to those reported in the UK strategy for Rare Disease (2013). The second phase of the project will focus on cognitive testing of the patient survey. Understanding patient experience using a specific survey in our cohort will help inform strategy to improve quality in aHUS care.

Conclusion

Phase two of the survey will enable improvement streams to develop, due to the generalising of the themes identified.