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Background/Aims

Patient and public involvement (PPI) initiatives are important to ensure patient-centered research. However, traditional focus groups can present challenges including the recruitment and retention of patient partners. Additional challenges to patient involvement have also arisen due to the coronavirus pandemic (COVID-19). The University College London (UCL) Patient Partners in Rheumatology Research initiative has been developed to explore novel ways to boost patient involvement and foster an active collaboration between basic researchers and patient partners.

Methods

Two online surveys were designed to obtain information with regards to the expectations and practicalities of this initiative. One survey was sent to patients who had registered an interest in being patient partners and the other survey to rheumatology researchers at UCL and University College London Hospital (UCLH).

Results

We received responses from 25 researchers and 21 patients. The majority of patients who responded (71%) had not previously been involved in PPI. Most of the researchers (84%) had previously utilised PPI, however 20% of those had some difficulty accessing it.

Most patients (86%) were interested in becoming a patient partner. Amongst those with reservations, one stated that "I don't think I have the qualifications to be involved with scientists and researchers". Over half of patients (52%) were happy to participate in PPI more than five times a year and most researchers (84%) expressed that five times a year was acceptable. Patients favoured (52%) conducting PPI meetings after office hours (5-8pm) during the working week. Due to social restrictions because of COVID-19, we asked both patients and researchers their preferred mode of meeting. Both groups favoured a mixed (virtual and face to face) meeting arrangement (81% for patients and 68% for researchers). A third of patients (38%) expressed that they would need technical assistance accessing a virtual meeting. Almost all patients (95%) were happy to contribute to lay summary reviews remotely via email.

Conclusion

Based on the insights gained from the survey results, our PPI initiative meetings will be hosted in a hybrid virtual/face to face format. These will be held at a time and frequency that is convenient for the patient partners to increase participation across wider demographics. This survey has highlighted that we have to be mindful of certain patient perceptions of PPI which creates a barrier to patient involvement and that some individuals may require further support in accessing virtual meetings. By designing a PPI initiative that creatively addressed the needs of both the researchers and patient partners we hope to create a platform for productive dialogue and collaboration to ensure patient-centred research, despite the changes brought about by the COVID-19 pandemic.

Disclosure

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P074 INSIGHTS INTO CREATING A VIRTUAL PATIENT AND PUBLIC INVOLVEMENT INITIATIVE

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