Hereditary renal cancer patient and public involvement group: a collaborative, consensus decision-process to develop a communication tool for patient use

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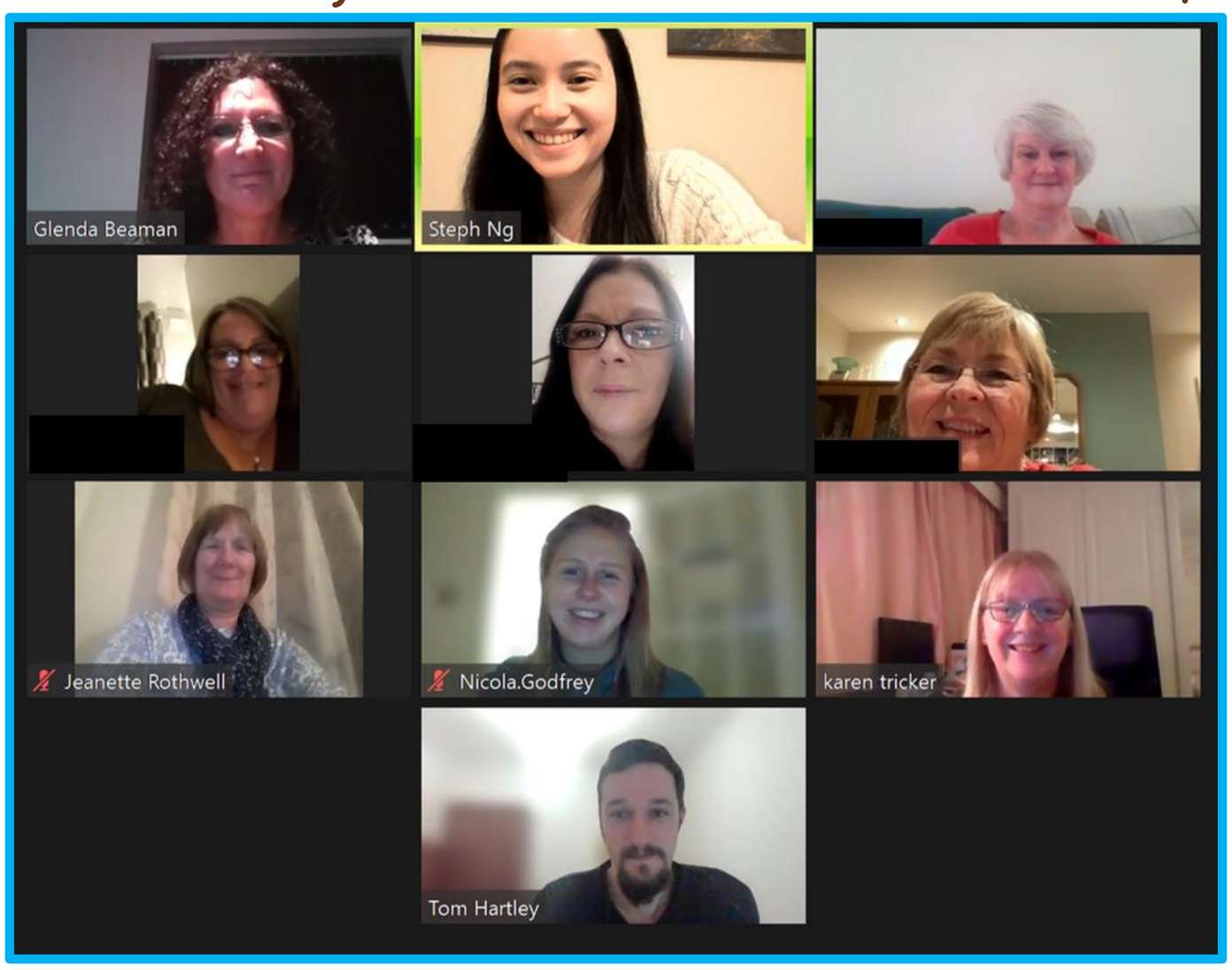
Background

A hereditary renal cancer Patient and Public Involvement (PPI) group was developed to discuss patients' priorities and needs for future cancer early detection research.

Aim

Create an active partnership between the clinical research team and patient-participants to ensure translational outcomes are patient-led and meet patient needs.



Session 1

Methods

Recruitment from the ACED-funded 'Early Detection of Hereditary Renal Cancer (ELECTRIC)' study: contacted by telephone call and invitation letter

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Enrolled in the virtual 1st PPI focus group session

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PPI Group shared their experiences during a semi-structured discussion with open-ended questions tool

Results

Participants shared difficulty in relaying complex genetic information and conveying the significance of diagnoses and related implications for other at-risk family members

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Participants identified the need for a patient information sheet (PIS) as a communication tool to equip them for these challenging conversations

Session Contributors	1st PPI Session (n)	2nd PPI Session (n)	Characteristics
Patients	4	4	Patients present with von Hippel-Lindau disease (VHL) and Hereditary Leiomyomatosis and Renal Cell Carcinoma (HLRCC)
Public	0	1	Patient Trustee from VHL UK & Ireland Alliance
Researchers	5	5	Research practitioner (n=1), research associate (n=1), consultant clinical geneticist (n=1), research assistant (n=1), clinical trials manager (n=1), and project coordinator (n=1)

Session 2

Methods

ELECTRIC Participants invited to a virtual 2nd PPI focus group session

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Enrolled in the virtual 2nd PPI focus group session and sent draft PIS prepared by research team

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PPI Group and research team discussed and edited the PIS during the focus session until consensus was reached on the context

Results

PIS implemented in the Genetics Clinics, with Clinical Geneticists and Genetic Counsellors distributing to patients with hereditary renal cancer syndromes to pass on to their relatives

Conclusions

- Creating a patient forum with open questions can ensure research meets patients' needs and have beneficial outcomes to both researchers and participants.
- Patients with hereditary cancer predisposition syndromes can find it challenging to relay complex genetic information to relatives. Communication tools, such as Patient Information Sheets, may help patients feel better equipped for difficult conversations.
- The hereditary renal cancer PPI group was formed for a specific patient cohort; however, the process implemented can be employed for other disease types and hereditary conditions.

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