SINV HNC Patient and Public Involvement (PPI) Committee & Network

Terms of reference and membership

Role of PPI Committee:

The role of the PPI committee is to develop and co-ordinate Patient and Public Involvement (PPI) in HNC related research activities and service development in South of Ireland.

Background:

Patient and public involvement in research and service development is now accepted as best practice[1]. PPI can improve the quality, design, relevance and impact of research by introducing patients' lived experiences, psychological perspectives, appreciation of side-effects, providing skills and helpful contacts that may not exist within the research team.

PPI can also help to highlight practical barriers to patient enrolment, assist with recruitment, funding access, dissemination of results and media. Patient and public involvement is increasingly promoted by funding agencies and provides increased transparency on how public funds are spent. Inclusion of patients in the development of services has been shown to improve the delivery of care in an effective and compassionate way.

HNC PPI Committee Responsibilities include:

- Committee should meet at least 6 times a year, with additional meetings in the initial stages
- Committee meetings' minutes will be kept by a minute's secretary and agreed by all members who attended the meeting
- Develop a sustainable model of PPI activity with appropriate documents and policies to support the development and maintenance of a HNC PPI Network.
- Establish a HNC Patient and Public Involvement Network comprising 8-20 individuals who are directly affected by HNC – patients, family, carers
- Develop a recruitment process and selection protocol for Network members
- Select appropriate PPI Network candidate members based on team recommendation
- Issue invitations/interview selected candidates to assess suitability
- Provide support and training for Network members

- Data management plan to be agreed – digital and electronic information to be stored in shared folders o SINV Network with hardcopy data stored in Prof Sheehan's office in SINV under the governance of the SINV Data Protection Officer. Access available through Prof Sheehan to members of the PPI Committee as appropriate.
- Preparation of relevant documents to be sent to Network members
- Provide two key liaison Network contacts to ensure clear communication pathways. Contact will be via email and phone for the foreseeable future due to Covid.
- Providing a forum for discussion of progress.
- Treat Network members with respect and courtesy at all times, recognizing their value as a significant resource in research activities and service development.
- Be mindful of the well-being of network members. The Irish Cancer Society have kindly agreed to provide support for Network members via the ICS Nurse Helpline should any topic being discussed cause any distress or conflicting emotions to these members. This is the same support mechanism offered to the ICS PPI Reviewers.
- Arrange Network meetings virtual and physical as appropriate

HNC PPI Network

The PPI Network is defined as a network of 8-20 individuals directly affected by head and neck cancer (patients, family and carers) who volunteer to meaningfully and actively collaborate in the governance, priority setting and conduct of research, as well as in summarizing, distributing, sharing and applying its resulting knowledge. Membership would normally last for a period of two years but there would be the opportunity to continue if requested by committee. After two years the opportunity to participate would be opened up to new people. Rotation of the membership will be staged to ensure that continuity is maintained. Membership is voluntary and currently no funding is available to meet any expenses incurred.

Network Members Responsibilities include:

- Participation in network meetings which will be held at least four times a year.
- Read any documents sent to members before each meeting

- Meeting minutes will be kept by a minutes secretary and agreed by all members of the Group who attended the meeting.
- Members must engage in active, meaningful, and respectful collaboration with other Network Members, committee contacts and relevant projects
- Members may be contacted between meetings for advice should the need arise.
- Sub-groups may be formed on occasion to work on specific issues as appropriate.
- Individuals may be co-opted to provide specific advice and expertise as required.
- Maintain appropriate contact with the named key contact personnel (EOS & DC currently)

Core Skills for Network Membership

- Passionate about head and neck cancer services and keen to get involved in Network
- Good communication skills
- Adequate IT skills – able to undertake online meetings, phone calls, emails
- Available – time to engage with Network activities

Ideally, we will strive for diversity in gender, age, site, therapy, stage, SES. However, in reality, it will depend on volunteers available.

[1] European Patients Forum (EPF) https://www.eu-patient.eu/about-epf/about-us/; ICS, Health Research Charities Ireland, INVOLVE UK