



Policy on association with patients and patient representatives

1. Introduction

- 1.1 The International Society for Gastrointestinal Hereditary Tumours (InSiGHT) is an international multidisciplinary, scientific organization. The mission of InSiGHT is to improve the quality of care of patients and families with any hereditary condition resulting in gastrointestinal tumours. Therefore, InSiGHT wants to connect with patients and patients' representatives.

2. The aims of this policy

- 2.1 To ensure that the voice and needs of patients and families with gastrointestinal hereditary tumours are taken into account.
- 2.2 To set out actions to create a bridge between InSiGHT and the patient community with gastrointestinal hereditary tumour syndromes.

3. Actions

InSiGHT will deliver these aims through undertaking the following activities:

- 3.1 Support plans to hold a workshop with patients and their families, national patients' representatives, community organisations such as patient support groups, lecturers and a delegation of InSiGHT council members during the biennial InSiGHT conference.
- 3.2 Ask for the patients' perspective and experience during the biennial workshop with patients, and contribution to the development of research priorities to ensure these priorities meet patients and families' needs.
- 3.3 Engage with patient communities for disease specific activities carried out by InSiGHT.
- 3.4 Promote research engagement with patient and support organisations.

4. Membership

- 4.1 InSiGHT welcomes all healthcare professionals and scientists with an interest in gastrointestinal hereditary tumours to join as a member.

5. Review

- 5.1 This policy will be revised based on experience gained and in line with the developing needs, specificity and functions of InSiGHT.

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