

# Patient Engagement Committee

## Terms of reference

### Introduction to Findacure

*Our vision is a world in which all rare diseases have treatments - made together with patients, for patients*

Findacure is a UK charity that is building the rare disease community to drive research and develop treatments. We are here to revolutionise the world's understanding of rare diseases, and the devastating impact they have on people's lives.

### How are we achieving our vision?

-  We transform the lives of people affected by rare diseases by working directly with patient support groups, giving them the skills to professionalise their work and the confidence to recognise their own expertise in their rare conditions
-  We accelerate change in rare disease research and care by building a strong, supportive, and collaborative rare disease community that works for the benefit of all rare conditions

### Our patient group training projects

When patients or parents receive a rare diagnosis, they can feel isolated, uninformed, and overwhelmed. Patient groups are one of the few places they can turn to for reassurance and credible information.

Findacure run a series of training programmes to help these passionate and motivated individuals become effective advocates for the condition. In particular we help them: build their own support group or charity, raise awareness about their condition, provide support to patients and families, and get ready to engage with research.

To address these areas, we run four key training projects.

**Workshops:** Our workshops provide practical, hands-on guidance and training for patient groups. We unite groups at all stages of their journey, allowing them to share their experiences and find answers to their questions.

**Webinars:** Our bitesize webinars provide remote learning for patient groups who often struggle to travel. They are broadcast live and recorded, meaning they can be accessed from anywhere around the world, at any time.

**Peer Mentoring:** Our mentoring programme provides one-to-one support for new patients groups, or those facing a challenge. We match groups with an experienced mentor, allowing them to reach milestones and streamline their work.

**E-learning portal:** Our portal is an online information hub for patient groups. It contains education materials, written guides, videos, presentations and webinars to help the establishment and growth of patient groups.

### Role and purpose of the Patient Engagement Committee

The purpose of the Patient Engagement Committee (previously the Empowerment Advisory Committee) is to provide insight and advice to Findacure on our patient group training projects, so we can grow as a charity and further develop our support programmes. This may include:

-  Evaluating current projects to assess: successes in project delivery, areas which could be improved, and the on-going need for projects
-  Exploring new projects or services Findacure could offer beneficiaries
-  Advising Findacure on the needs and priorities of patient groups in the rare disease space
-  Recommending and reviewing themes for upcoming training programmes

# Patient Engagement Committee

-  Providing guidance on ways Findacure can improve outreach to patient groups, spread awareness of projects, and grow engagement with our work and the rare disease community
-  Ad hoc support and guidance on patient training projects

## Scope

Membership on the Committee is unpaid and voluntary. The Patient Engagement Committee will work in a non-executive position to facilitate delivery of Findacure's services to patient organisations and in future strategic plans in this area. Findacure staff and trustees have absolute responsibility and will ultimately decide whether advice given will be acted on.

## Committee requirements

**Attendance of meetings:** The Committee will meet a minimum of twice a year, and a maximum of three times. Meetings are anticipated to take place in January, April/May and September. Up to two meetings per-year will be hosted on Skype, and at least one meeting per-year will take place face-to-face.

Committee members are expected to attend meetings wherever feasible, and phone-in to meetings where in person attendance is not possible. Meetings will be facilitated by Findacure staff, with agendas agreed one week before each meeting. Reimbursement will be provided for travel to face-to-face meetings, in line with our [expenses policy](#).

**Involvement with Findacure:** We ask Committee members to involve themselves in a minimum of one patient training project per calendar year. This can be through attendance of a workshop or webinar, participation in our peer mentoring programme, or supporting development of an E-learning portal guide.

**Free and fair advice:** Any advice provided by the Committee to Findacure must be given freely, fairly, impartially and independent of any commercial interests.

## Committee structure

The Patient Engagement Committee will consist of at least five members, with a maximum of seven members. At least three members must be either a rare disease patient, caregiver, or support group representative.

Membership of the Committee will rotate every two years, with applications opening in January of each rotation year. Previous members may reapply but applicants will be judged against the skills required for the upcoming year.

## Skills and limitations

We are seeking up to seven members of the rare disease community to serve on our 2019-2021 Patient Engagement Committee. Ideally, we are looking for members with experience in the following areas:

-  Personal rare disease experience, either as a patient or caregiver
-  Running services or support for rare disease patients and their families
-  Communications and/or outreach
-  The UK rare disease field as a whole

## Applications

If you are interested in joining our Patient Engagement Committee, please apply by completing an [application form](#) no later than **12:00 on Friday 1<sup>st</sup> March**. If you have any questions or would like to discuss membership of the Committee in more detail, please contact our Events Manager, Mary Rose Roberts at [maryrose@findacure.org.uk](mailto:maryrose@findacure.org.uk).