



## EUROPAR Patient Group:

CRISP – **C**ommunity for **R**esearch **I**nvolve**m**ent and **S**upport for **P**eople with Parkinson's

### **TERMS OF REFERENCE**

#### **1. What is CRISP?**

CRISP is a Community for Research Involvement and Support for People with Parkinson's. It is a patient and public involvement group in line with INVOLVE, a government initiative to empower patients and the public to involve their views in research and actively take part in translating current research into treatment. Hosted at King's College Hospital, CRISP reviews, advises and enables "real life" research in Parkinson's.

#### **2. Who is (are) CRISP:**

##### **a. Patients, Carers & Representatives**

##### **b. NHS Trust staff, including:**

- ✓ EUROPAR manager/member
- ✓ King's Research & Development department
- ✓ CRN (Clinical Research Network) London South
- ✓ PD Specialist nurses

Number should ideally not exceed number of Patients, Carers & Representatives

##### **c. Minimum number for the group to run (Quorum):**

- 2 Patients, Carers & Representatives
- 2 NHS Trust staff

#### **3. How does CRISP work?**

- CRISP meets on a quarterly basis at King's College Hospital or other sites in South London.
- Meetings take 1.5 – 2 hours.
- Agenda/supporting material can be circulated in advance of each meeting and minutes are circulated following each meeting.
- Between meetings, urgent projects can be discussed by email or post
- Travel expenses can be reimbursed for all patients, carers and representatives
- Refreshments are provided at all meetings

#### **4. What does CRISP do?**

Tasks of CRISP include:

- ✓ Contribute to design and development of research projects e.g. rating scales, questionnaires, patient information sheets etc. and therefore using a patient's perspective to input into research
- ✓ Review current research (e. g. EUROPAR projects or looking at poorly recruiting studies) in Parkinson's or related areas
- ✓ Giving a patient representative opinion on planned projects, that are introduced in meetings, so that patient and public input can be taken into account
- ✓ Developing ideas for future projects highlighting unmet needs from a patient perspective

#### **5. What is CRISP linked with?**

##### **a. EUROPAR**

EUROPAR is a non profit multi-disciplinary organisation of key opinion leaders across Europe dedicated to improving care for people with Parkinson's and delivering excellence in clinical research. In order to empower people with Parkinson's and hear their voices in relation to research in line with INVOLVE, EUROPAR has led to the formation of CRISP. All current EUROPAR research projects have been reviewed by CRISP.

##### **b. Parkinson's UK**

Parkinson's UK is a leading support and research charity, which has been working for more than 40 years to find a cure and improve life for everyone affected by Parkinson's.

##### **c. Clinical Research Network: South London (CRN)**

CRISP is based at King's College hospital and involves members from the Clinical Research Network: South London.

#### **6. How can CRISP be contacted?**

For any queries please contact Alexandra Rizos, EUROPAR manager at King's College Hospital on 0203 299 7153 or email [Kch-tr.PDresearch@nhs.net](mailto:Kch-tr.PDresearch@nhs.net).