

What is CRISP?

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Academic studies in PD with a focus on non motor symptoms,
improving care for people with Parkinson's and delivering excellence in
clinical research

Part of IPMDS NM PD Study Group



What is CRISP?



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







What is CRISP?



Community for
Research
Involvement and
Support for
People with Parkinsons

EUROPAR patient group "CRISP" Meeting
 Tuesday, 27th May 2014, 4pm
 King's College Hospital, Seminar Room

Minutes prepared by RI

Attendees:

Steven Roberts	(SR)	Karen Summerskill	(KS)
David Charlton	(DC)	Anne Martin	(AM)
Karen Summerskill	(KS)		
Suzanne Pitts	(SP)		
Foster Murphy	(FM)		
Flora Hill	(FH)		
Eros Bresolin	(EB)		
Alex Rizos	(AR)		
Prof K Ray-Chaudhuri	(KRC)		
Miriam Parry	(MP)		
Rona Inniss	(RI)		
Emma Saunders	(ES) (CRN)		
Claire Stevenson	(CS) (Parkinson's UK)		
Kami Paulson	(KP) (guest)		
Anna Sauerbier	(AS) (guest)		

Apologies:

- A PPI group in line with INVOLVE
- Hosted at King's College Hospital
- Meeting quarterly (email contact in the interim)
- Travel expenses paid, refreshments provided
- Agendas/ minutes circulated by email



Who is CRISP?

- Patients, Carers & Representatives
- NHS Trust staff, including:
 - EUROPAR manager
 - PD Specialist nurses
 - Research nurses
 - CRN (Clinical Research Network): South London
 - Parkinson's UK representation
 - Professor of Neurology





Who is CRISP affiliated with?



EUROPAR is a non profit multi-disciplinary group of researchers across Europe dedicated to improving care for people with Parkinson's and delivering excellence in clinical research.



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.



Clinical Research Network: South London (CRN) members are part of CRISP

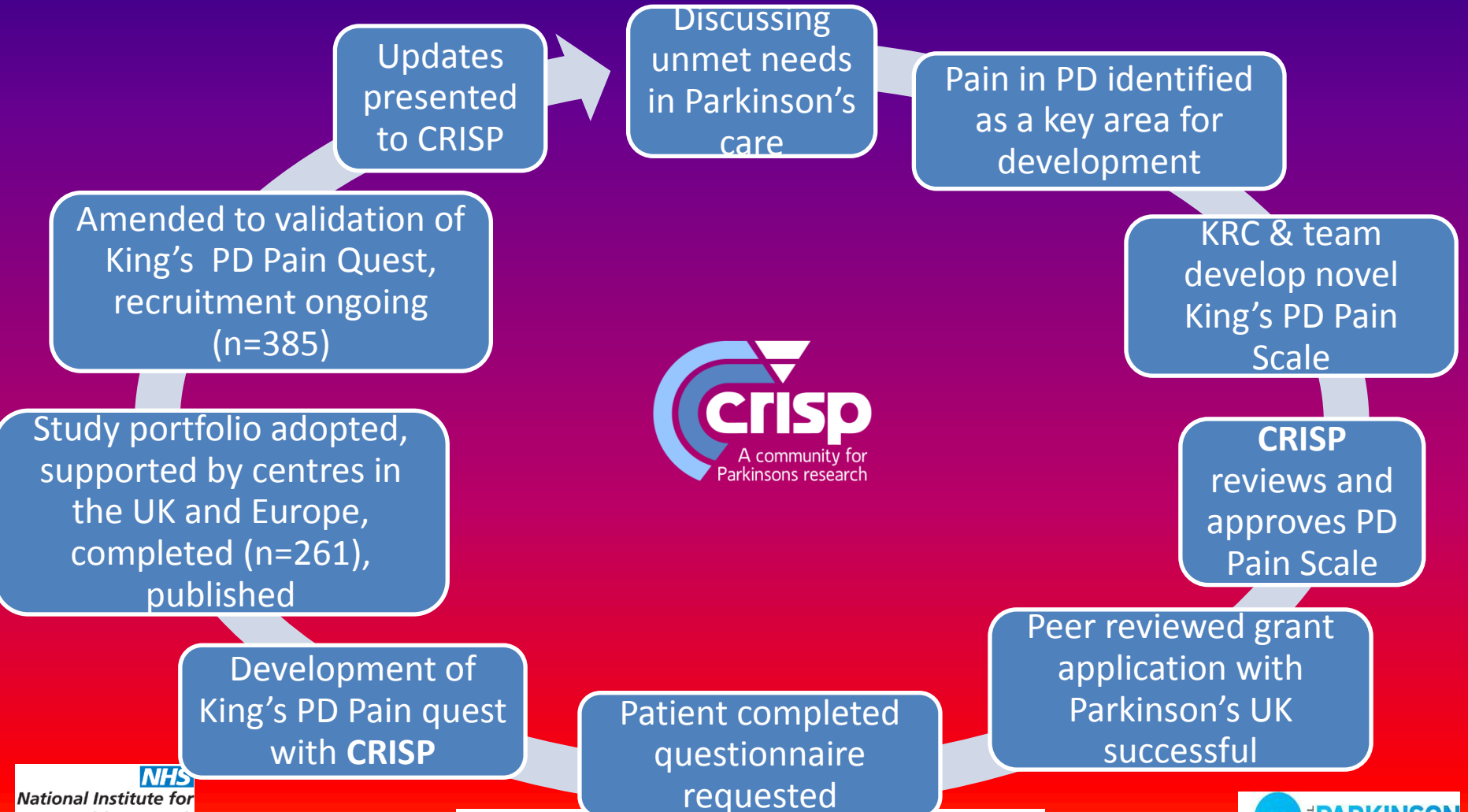


What does CRISP do?

- Contribute to **design and development of research** projects, giving a patient representative opinion
- **Review current research** in Parkinson's or related areas
- Developing **ideas for future projects** highlighting unmet needs from a patient perspective
- Project work on **research encouragement** (e. g. letters, banners, videos...)

How does CRISP work ?

Example: PD Pain Scale



The CRISP video



Purpose:

- **Raise awareness of research**
- Highlight the **importance of participation** of people (specifically with Parkinson's) in clinical research
- Encourage patients and their carers to **ask about clinical research** when with their consultant
- Try and **change the "guinea pig" perception**
- Communicate **what it means** to be involved in research
- Highlight **how it can benefit patients** taking part and beyond

The CRISP video



Result:

- Patients produced short films, compiled to 10 mins CRISP video
- Shown within Parkinson's clinics waiting area
- CRN: South London website
- Access via YouTube (NIHR TV)
- Liaise with the national team at NIHR to use within national projects.

You are invited!

- Discuss studies in setup with CRISP, to get expert opinion
- Present studies to get patient endorsement for grant/ethical approvals
- Review under-recruiting studies to identify potential hurdles

Research related projects, e. g.

- Info leaflet regarding falls in PD while double-tasking
- CRISP TV