

FINNISH YPAG

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BACKGROUND

- General attitude related to patient involvement in clinical trials increased rapidly during the past few years (e.g. EUPATI)
- Active patient advocacy groups and experience experts in HUS (adults)
- HUS is a beneficiary of c4c which includes patient and public involvement (PPI)
 - Setting up Young Person's Advisory Groups (YPAGs) in Europe as a part of PPI activities

→ YPAG Helsinki to be set up

YPAG HELSINKI

- Active patient advocacy groups in different specialty areas in HUS
 - Consistency between different groups: training, processes, reimbursement
 - Will be adjusted to be suitable for young people
- Setting up YPAG Helsinki still in progress in HUS
 - The aim is to fulfill both eYPAGnet and HUS criteria

PROCESS SO FAR...

May 2019: eYPAGnet meeting

Aug 2019: Meeting with HUS lawyer and patient advocacy coordinator

Oct 2019: meeting with a larger group in HUS (different advocacy group representatives, lawyers, patient advocacy coordinator etc.)

Oct 2019: eYPAGnet meeting

OCTOBER MEETING IN HUS

Very positive and excited reception

No legal obstacles; however, a lot to keep in mind

- contracts, GDPR
- reimbursement
- special features of minors
- translations, equality
- recruitment

TARGET GROUP

- Group size approx. 10
- Age: 15 to 18 years in the beginning, "easy start"
 - legal differences 14yo vs. 15yo
 - more independent
 - better skills in English language?
- Gradual expansion of the target age when the YPAG starts running smoothly

KIITOS! THANK YOU!

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