

C4c-S Introducing the Patient, Parent and Young Persons Involvement Service

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Who we are...

eYPAGnet works in partnership with **patients, children and young people, families, patient associations, industry and academic researchers** to provide patient and public involvement advice and solutions to ensure paediatric clinical research is patient centred.



By kind permission of Stacey Hutchison Frankie's mum

eYPAGnet across Europe

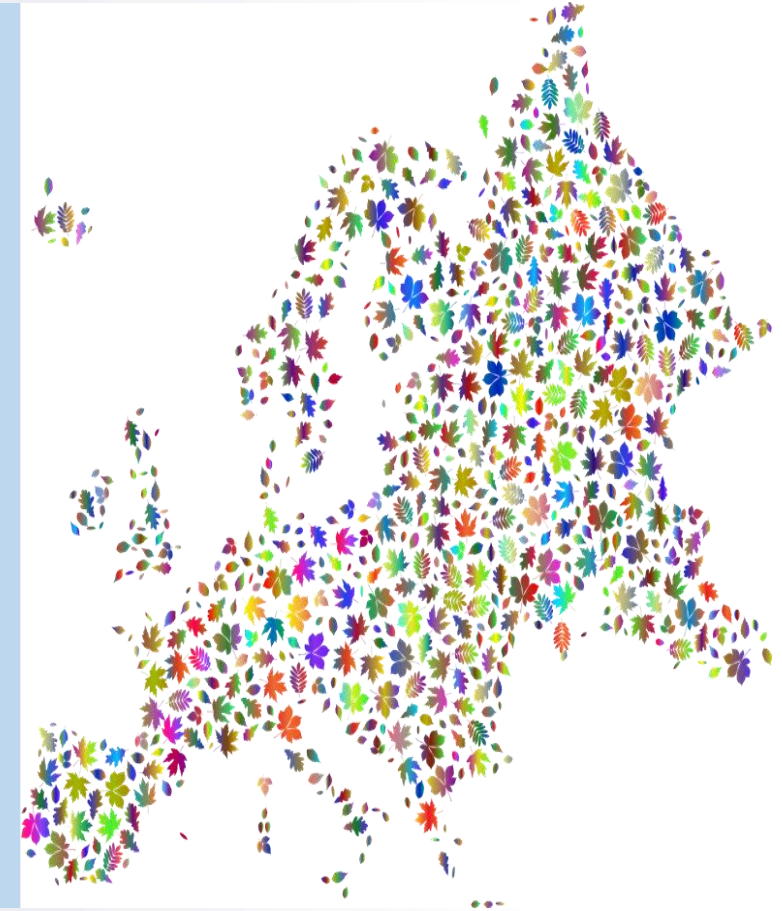
Founders and Steering Group

- Generation R: Jennifer Preston
- Kids France: Segolene Gaillard
- NHS Scot CRN: Pamela Dicks
- Kids Barcelona: Begonya Nafria

+ 30 groups working with
young people, patients and
parents across Europe

14 countries

- Belgium
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Ireland
- Italy
- Netherlands
- Poland
- Portugal
- Spain
- United Kingdom



European Network of experts in PPI

01

Professionals embedded in **Children's Hospitals and Clinical Research Facilities**

02

Alongside clinicians and research nurses conducting paediatric trials in **all paediatric specialties** including **rare diseases**

03

Direct link with **patients and parents**
Collaboration with **patients associations**

04

Experience in all clinical trials phases, longitudinal studies, non-drug interventions and medical device research

European Network of experts in PPI

05

Leading experts in **developing and delivering bespoke PPI plans** that meet the needs of the client and that are consistent with eYPAGnet core values

06

Working with

- Parents and patients living with paediatric diseases
- YPAG's
- National Patient Organisations (disease/diseases)
- National Paediatric Clinical Research Networks
- International Paediatric Clinical Research Networks: c4c-S
- Paediatric Hospital Services
- Paediatric Clinical Networks and Research Facilities
- Industry or academics partners

Core Values

Ethical Involvement and Engagement of Patients, Parents and Young People within YPAGs:

- Ensure patients are informed of actions implemented
- Reimbursement - fair market value
- Inclusive
- Supportive



Portfolio of services



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Study specific support

- Co-design of clinical trial protocols
- PROMS, PREMS, QoL...
- Development and review of patient documentation...
- etc...

Education and training of key stakeholders

- Co-creation (with children and families) educational resources
- Development of training for key stakeholders

PPI advice and coordination of patient and public involvement activities

- Development of patient and public involvement plans
- Execution of PPI plans

Reporting and measuring the impact of involvement

- Evaluation and impact assessments of involvement activities
- Development of co-created reporting tools

How we will work with c4cS?

c4cS PPI Services: operational model

c4cS:

Secretariat

eYPAGnet:

Scoping meeting with the sponsor
(needs assessment)
Preparation of the agreed PPI plan

DELIVERY OF THE PPI PLAN:

- Recruitment of patients/parents/YPAGS
- Contract with the POs+ Parents
 - CDA – Consent
 - FMV- Reimbursement

Country 1

POs-Parents- Patients -

Country 2

POs-Parents- Patients

Country 3

POs-Parents-Patients

Country X

POs-Parents -Patients

FINAL REPORT + Feedback of the sponsor (returned to the PPI participants)

Advantages of working with c4cS and eYPAGnet

c4cS PPI Services: vendor agreement with eYPAGnet- Decentralised model:

- ✓ A single point of contact with c4c-s for the sponsor
- ✓ A single point of contact with eYPAG-net for the participants in the PPI activities
- ✓ Resolve issues of companies contracting and paying patients directly
- ✓ FMV for patients/parents and professionals
- ✓ Recruitment issues through Patient Organisations
- ✓ Overcome language barriers to include patients from different countries and cultures

Thank you for your attention!

Pamela Dicks

eYPAGnet

www.conect4children.org

Twitter: @c4c_network

LinkedIn: conect4children

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