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European Young Person's Advisory Group Network (eYPAGnet)

Jenny Preston
University of Liverpool, Senior Patient and Public Involvement Manager
3rd Annual Nordic Conference 8-9th October 2019

OUR HERITAGE

[illegible]

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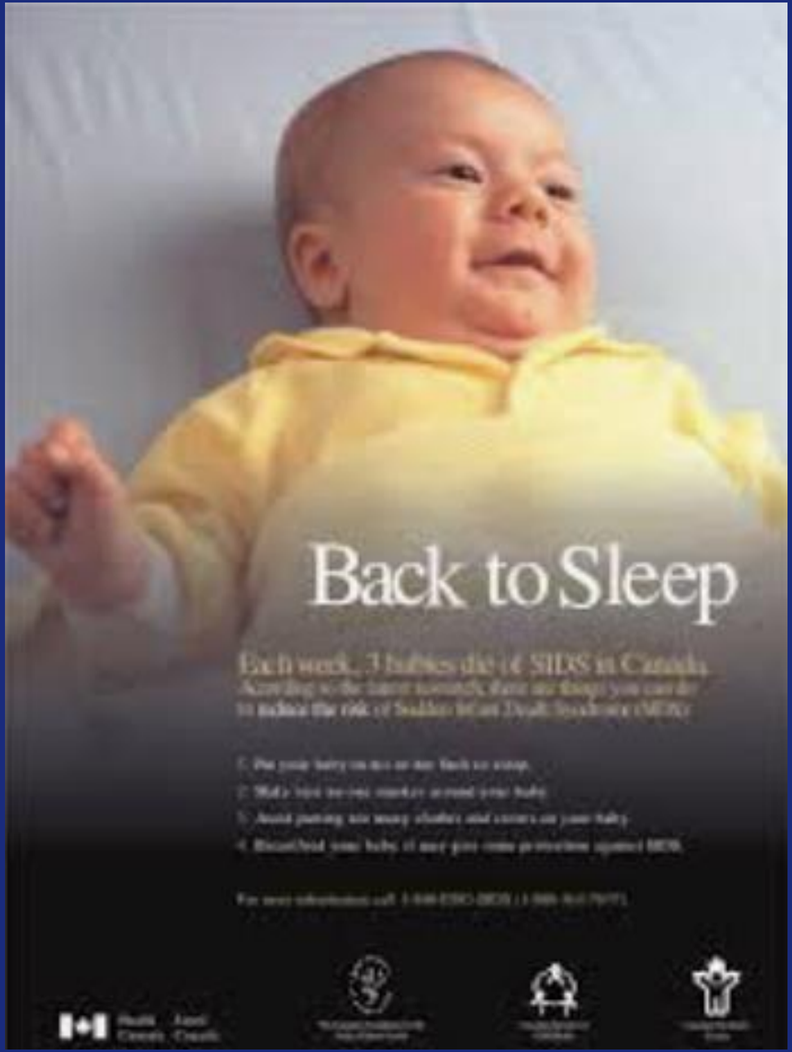
Advances in paediatric research



50%

90%

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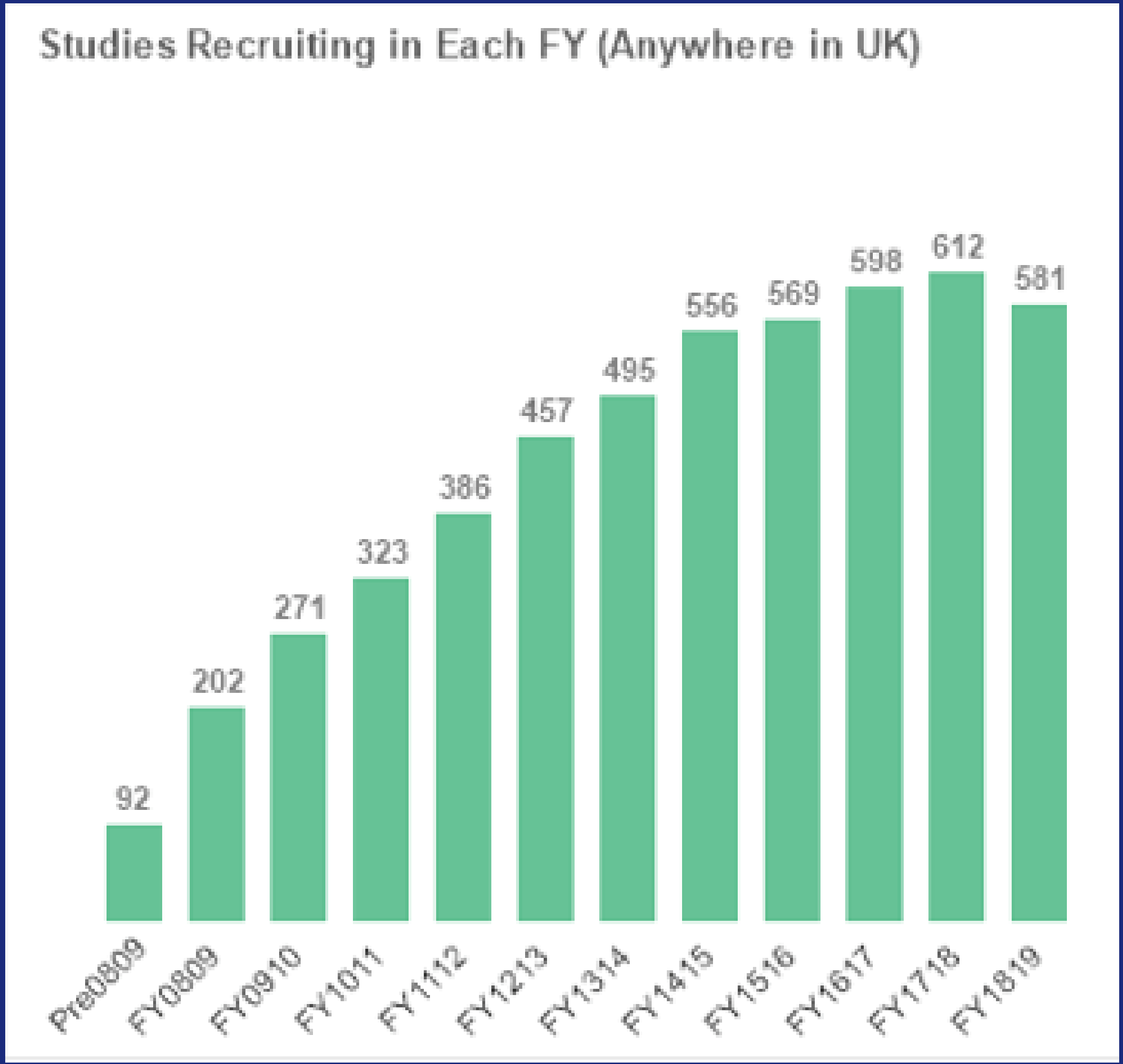

Studies Recruiting in Each FY (Anywhere in UK)


European
Commission

State of Paediatric Medicines in the EU

10 years of the EU Paediatric Regulation

Report from the Commission to the European Parliament and the Council

COM (2017) 626

Clinical Trials:
The Nation's Perspective

NHS
National Institute for
Health Research

Common misconceptions about clinical trials

2/3
of adults think that you have to be invited to participate in a clinical trial

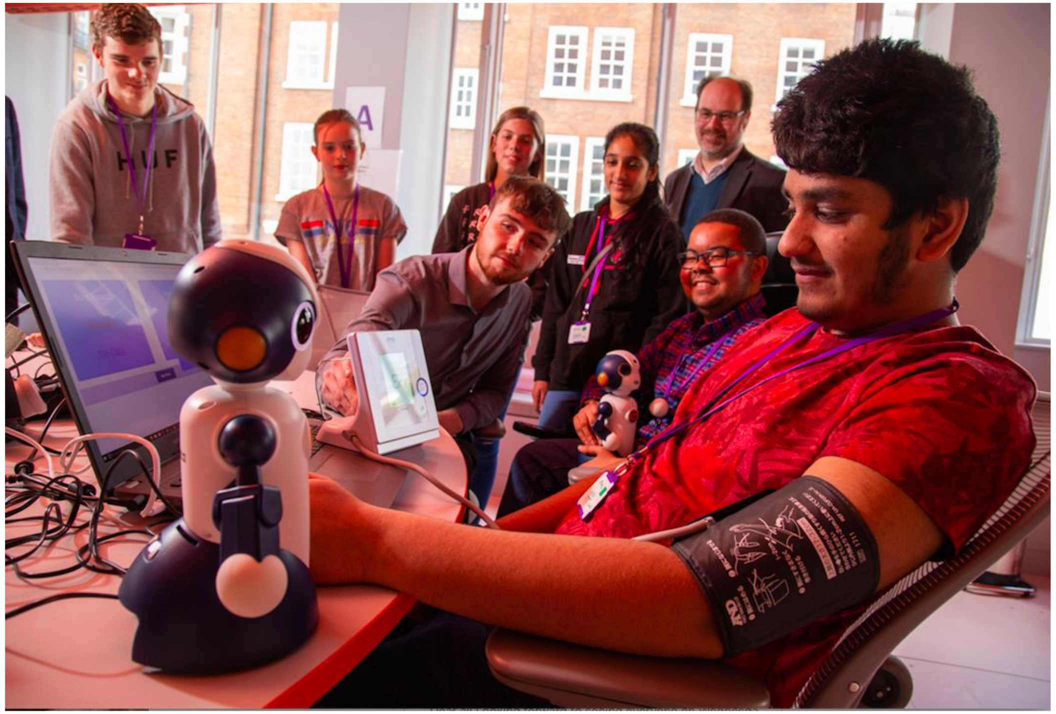
58%
incorrectly think that children are not allowed to participate in clinical trials

38%
think all clinical trials involve testing a new drug

4 in 10
do not realise that most hospitals in this country undertake clinical trials

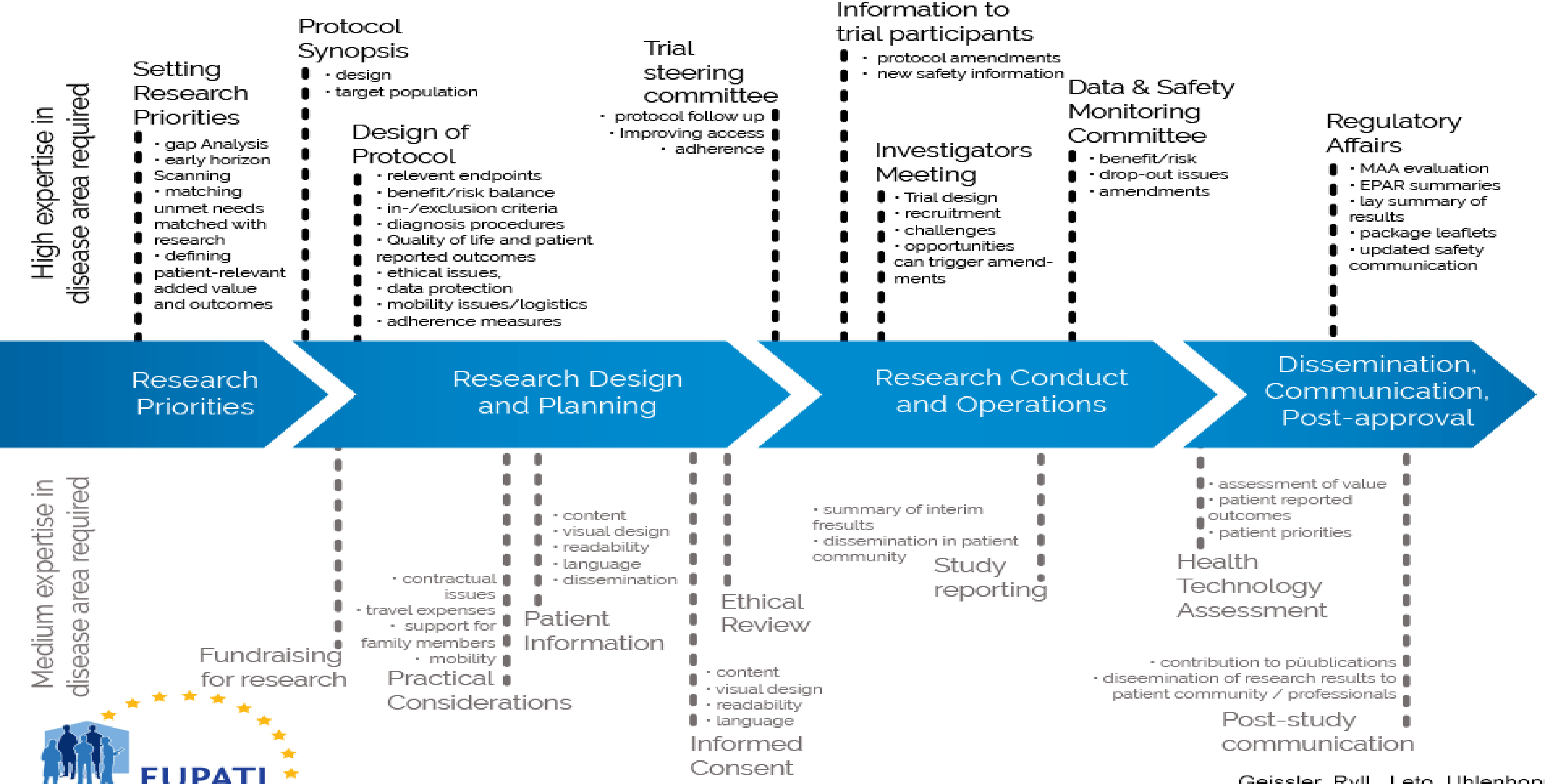
Based on an independent survey conducted by Atomik Research of 2001 UK adults, taken in April 2018.

Involving patients, carers and the public, who have personal experience of or an interest in a health condition(s), in research or research related activities



An active partnership between patients and the public and researchers, doctors and other NHS staff

Patient involvement in medicines R&D



High expertise in disease area required

Setting Research Priorities
- gap Analysis
- early horizon Scanning
- matching unmet needs matched with research
- defining patient-relevant added value and outcomes

Protocol Synopsis
- design
- target population

Design of Protocol
- relevent endpoints
- benefit/risk balance
- in-/exclusion criteria
- diagnosis procedures
- Quality of life and patient reported outcomes
- ethical issues,
- data protection
- mobility issues/logistics
- adherence measures

Trial steering committee
- protocol follow up
- Improving access
- adherence

Information to trial participants
- protocol amendments
- new safety information

Investigators Meeting
- Trial design
- recruitment
- challenges
- opportunities can trigger amendments

Data & Safety Monitoring Committee
- benefit/risk
- drop-out issues
- amendments

Regulatory Affairs
- MAA evaluation
- EPAR summaries
- lay summary of results
- package leaflets
- updated safety communication

Research Priorities

Research Design and Planning

Research Conduct and Operations

Dissemination, Communication, Post-approval

Medium expertise in disease area required

Fundraising for research

Practical Considerations
- contractual issues
- travel expenses
- support for family members
- mobility

Patient Information
- content
- visual design
- readability
- language
- dissemination

Informed Consent
- content
- visual design
- readability
- language

Ethical Review

Study reporting
- summary of interim fresults
- dissemination in patient community

Health Technology Assessment
- assessment of value
- patient reported outcomes
- patient priorities

Post-study communication
- contribution to püublications
- diseemination of research results to patient community / professionals

Geissler, Ryll, Leto, Uhlenhopp
EPALCO/EUPATI (2015, unpublished)

EUPATI
European Patients' Academy on Therapeutic Innovation
www.eupati.eu

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Voice is not enough!

CHILDREN'S RIGHTS

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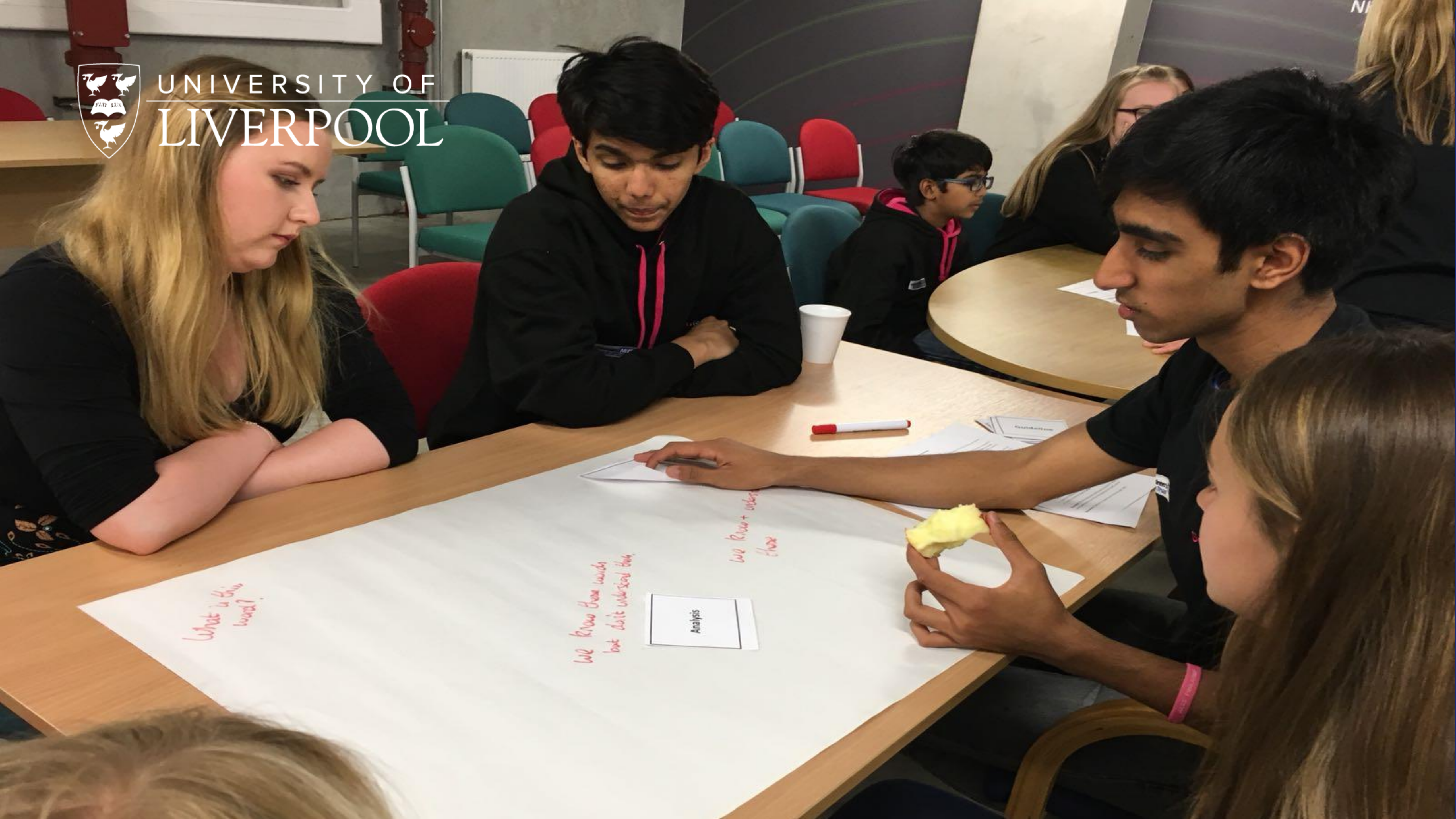

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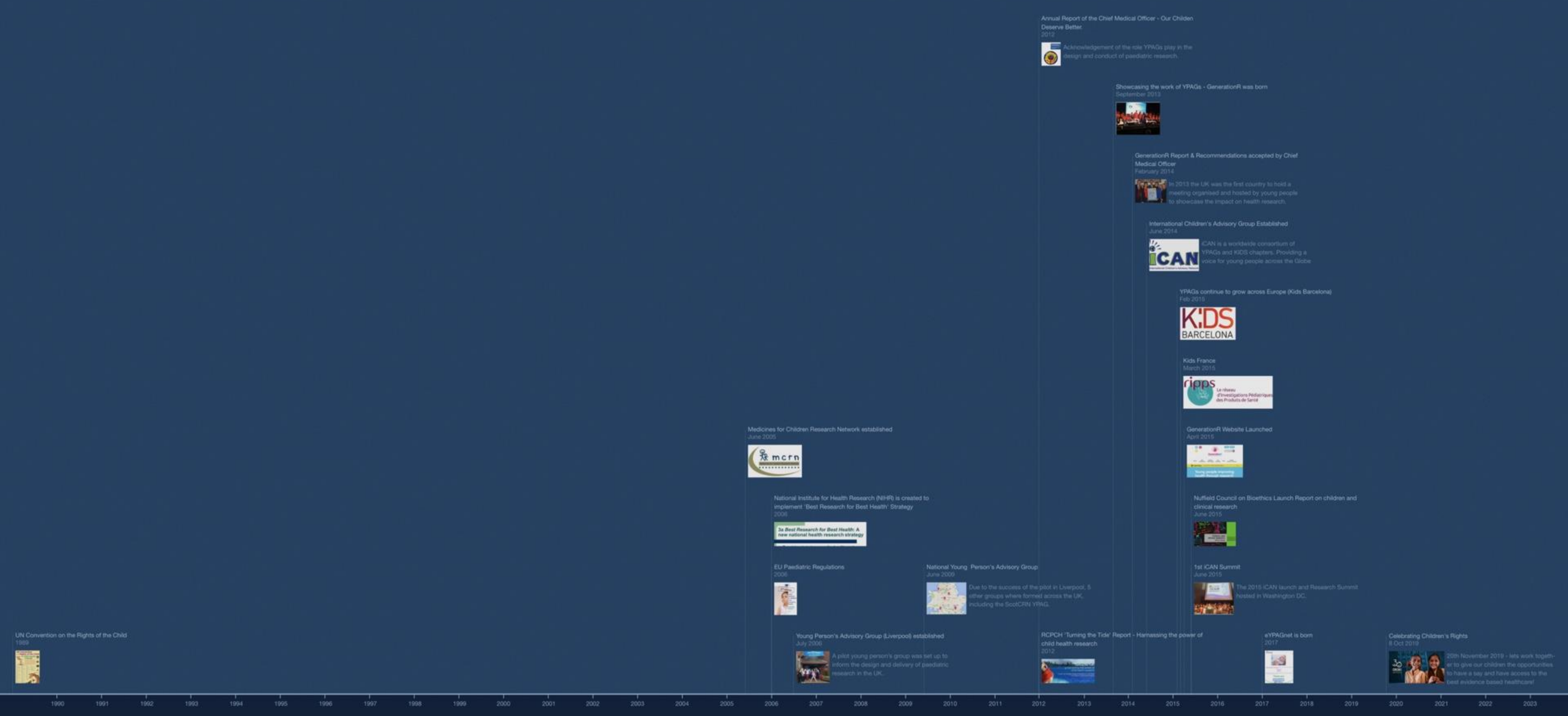
Role of a YPAG

Learn about health and clinical research in monthly meetings

Support and **work** in partnership with researchers in the delivery of health research

Provide input and **collaborate** with key organisations to promote young people’s involvement in research (RCPCH, EMA, HRA)



UN Convention on the Rights of the Child
1989

Medicines for Children Research Network established
June 2005

National Institute for Health Research (NIHR) is created to implement 'Best Research for Best Health' Strategy
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3a Best Research for Best Health: A new national health research strategy

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National Young Person's Advisory Group
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Due to the success of the pilot in Liverpool, 5 other groups where formed across the UK, including the ScotCRN YPAG.

Annual Report of the Chief Medical Officer - Our Childen Deserve Better.
2012

Acknowledgement of the role YPAGs play in the design and conduct of paediatric research.

RCPCH 'Turning the Tide' Report - Harnassing the power of child health research
2012

Showcasing the work of YPAGs - GenerationR was born
September 2013

GenerationR Report & Recommendations accepted by Chief Medical Officer
February 2014

In 2013 the UK was the first country to hold a meeting organised and hosted by young people to showcase the impact on health research.

International Children's Advisory Group Established
June 2014

iCAN is a worldwide consortium of YPAGs and KIDS chapters. Providing a voice for young people across the Globe

YPAGs continue to grow across Europe (Kids Barcelona)
Feb 2015

Kids France
March 2015

GenerationR Website Launched
April 2015

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June 2015

1st iCAN Summit
June 2015

The 2015 iCAN launch and Research Summit hosted in Washington DC.

eYPAGnet is born
2017

Celebrating Children's Rights
8 Oct 2019

20th November 2019 - lets work together to give our children the opportunities to have a say and have access to the best evidence based healthcare!

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K:DS
BARCELONA

Kids France

March 2015

ripps
Le réseau d'Investigations Pédiatriques des Produits de Santé

Europe (Kids Barcelona)

KIDS
BARCELONA

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Report on children and

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2018 2019 2020 2021 2022 2023

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2017

Thank you!

www.eypagnet.eu

info@eypagnet.eu

@eYPAGnet

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6

2017

2018

2019

2020

2021

2022

2023

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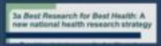

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1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021 2022 2023

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Vision

To develop patient centric research projects that are meaningful for children and young people

Mission

To use transparent and ethical processes for working with children and young people (CYP) and families, thereby ensuring that paediatric clinical trial development can flourish in an informed and inclusive environment.

WHO we are

eYPAGnet

Begonya Nafria

Joana Claverol

Jennifer Preston

SJD Sant Joan de Déu Barcelona · Hospital

GenerationR young people improving Research

Steering Committee

Pam Dicks

ScotCRN Scottish Children's Research Network

Segollene Gaillard

KiDS France

Activities to date

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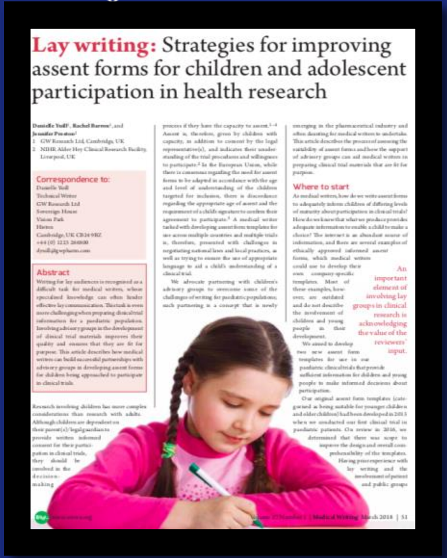
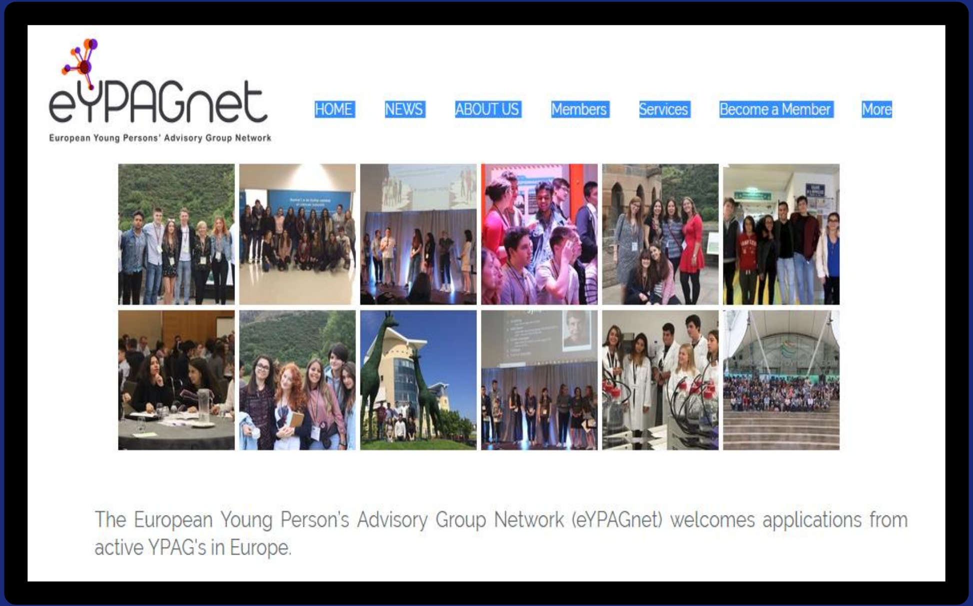

Lay writing: Strategies for improving assent forms for children and adolescent participation in health research

Correspondence to:

Abstract

Where to start

Improving the quality of studies

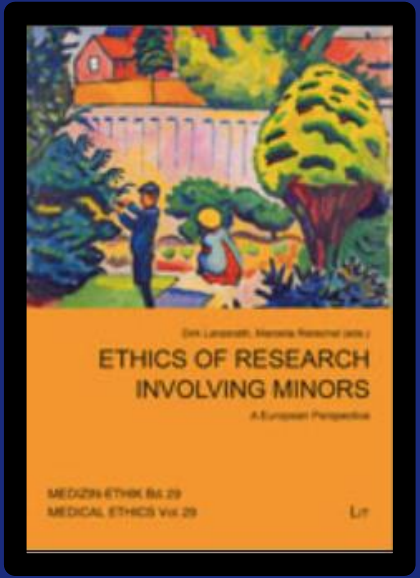

eYPAGnet

European Young Persons' Advisory Group Network

The European Young Person's Advisory Group Network (eYPAGnet) welcomes applications from active YPAG's in Europe.

Co-authored journal articles & book chapters

YPAG Strategy & SOPs (financial, membership etc.)


ETHICS OF RESEARCH INVOLVING MINORS

A European Perspective

MEDIZIN ETHIK Bd 29

MEDICAL ETHICS Vol 29

Lit

Established an Advisory Board & hold GA meetings


EUROPEAN MEDICINES AGENCY

SCIENCE MEDICINES HEALTH

Principles on the involvement of young patients/consumers within EMA activities

Co-presented at International Conferences

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Opportunities for collaboration

Collaboration on EU projects with other YPAGs

A patient-centered approach: children and families play an active role in clinical trial development

PATIENT CENTRICITY ON TRIAL

Increased opportunities for young people

Training Opportunities

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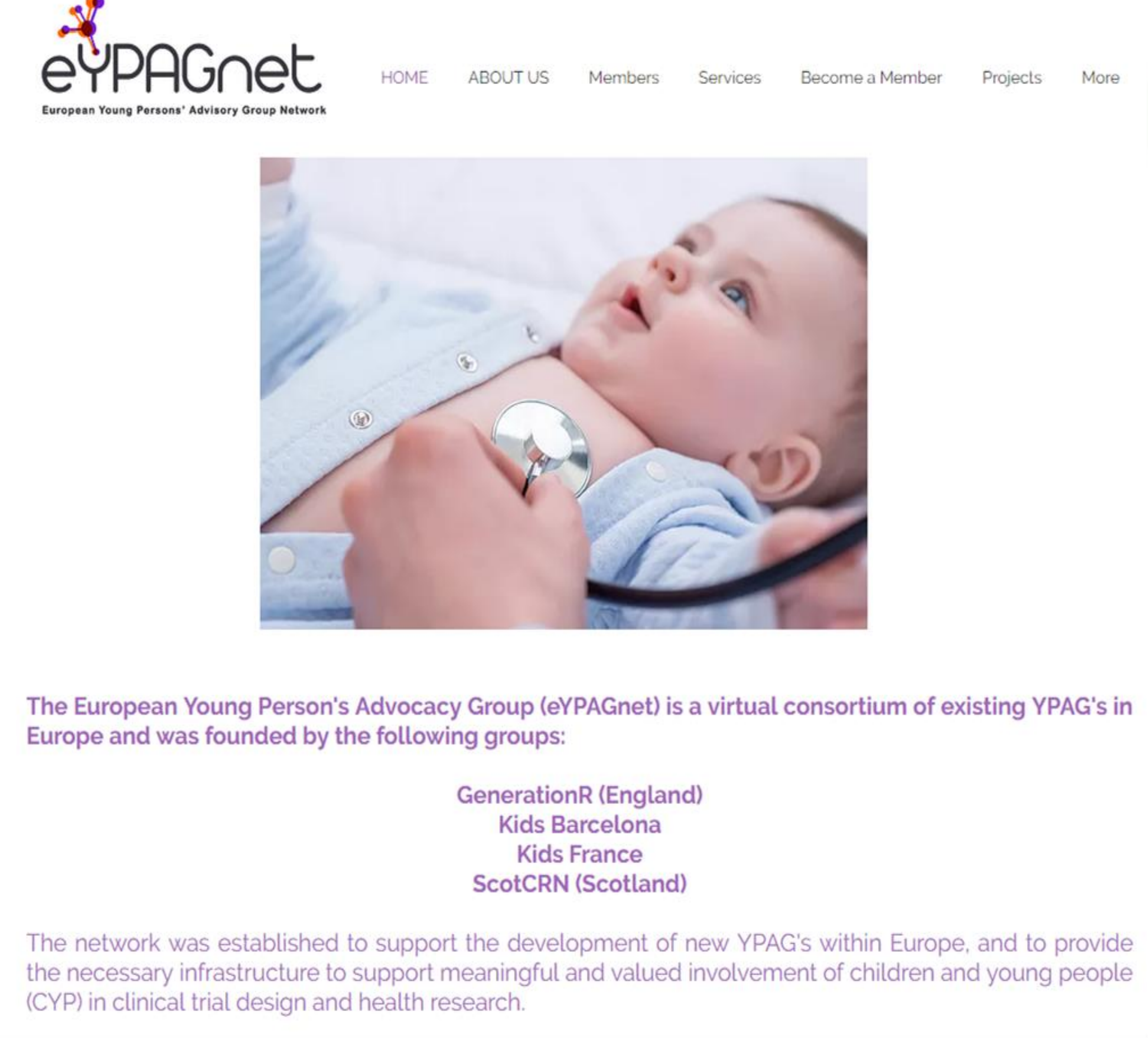
Become a member

Minimum Criteria for full membership

- Coordinator knowledge - short CV
- Youth membership- demographic
- Number of meetings- frequency, duration, dates
- Demonstrate involvement- previous projects involved with
- Agree to deliver training specified- statement

Benefits of becoming a member

- Membership of a European network of YPAG’s
- Shared training resources and ideas
- Presence on website
- Support from other experienced members
- Access to members area on website
- Involvement in projects underpinning conect4children



The European Young Person's Advocacy Group (eYPAGnet) is a virtual consortium of existing YPAG's in Europe and was founded by the following groups:

GenerationR (England)
Kids Barcelona
Kids France
ScotCRN (Scotland)

The network was established to support the development of new YPAG's within Europe, and to provide the necessary infrastructure to support meaningful and valued involvement of children and young people (CYP) in clinical trial design and health research.

Thank you!

www.eypagnet.eu
info@eypagnet.eu
@eYPAGnet

INVOLVING young PATIENTS IN THE DESIGN and DELIVERY of PAEDIATRIC DRUG DEVELOPMENT

Cystic Fibrosis Canada

Think Link graphics

inked by Liisa Sorsa.

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Jenny Preston BA (Hons)
Senior Patient and Public Involvement Manager
University of Liverpool
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