

# Scottish Children's Research Network



## Young Person's Group

### Our YPG

Received training in Clinical Trial Design, Licensing of Medicines, Research Ethics, Research Governance and Information Sheets

### What We Do

24 young people aged 11-17 years old. 16 Female, 8 Male

We meet at least 8 times a year

We are advocates for young people participating in medical research

We comment on and redraft patient documentation, questionnaires and posters

Commented on books given to children at a hospice, their relevance and age appropriateness

Discuss ethics of research and who should consent and assent

Talk with doctors and researchers about their future research and what is important to us

### Our Successes

Our comments and suggestions improved a questionnaire for young people and resulted in a 49% return rate (780 15 year olds responded)!

Commented on guidance for transition clinics for teenagers involved in medical research

Our input has helped to make patient documentation more age appropriate and relevant

Commented on National Research Ethics Guidelines

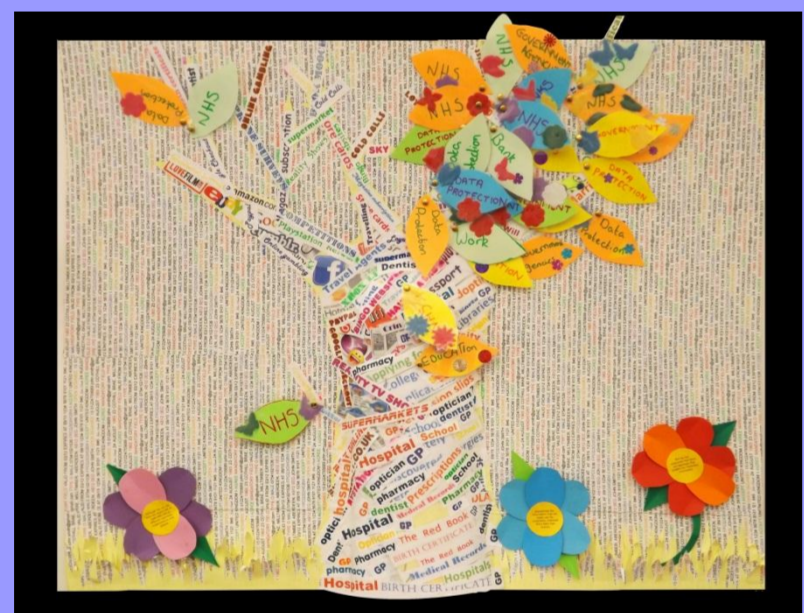
Very positive feedback from researchers on our redrafting of patient information sheets

### The British Science Festival 2012



Members of the ScotCRN YPG were invited to present a scripted focus group debate as part of a public engagement event entitled 'Your life story in our hands: A walk through life with your healthcare data', during the highly prestigious British Science Festival, which took place in Aberdeen in September 2012. The event explored the complex practical and ethical issues centred around the linkage of healthcare data such as GP, hospital and birth records, to provide researchers with a more complete picture of population health from birth through to death and thus greatly enhancing the scope of future research projects.

### The Data Tree Project



The ScotCRN YPG collaborated with a local artist to create an art work influenced by the views of young people on the use and storage of personal data for medical research.

The final work entitled 'The Data Tree' will be exhibited at the University of Aberdeen.

### WHAT WE CAN DO FOR YOU



## DO YOU REQUIRE PPI FOR YOUR STUDY?

We are a group of highly motivated, informed 11-17 year olds. We can help you ensure your Patient Information Sheets are age appropriate and contain the information young people need and want, to make informed decisions about their participation in your trial. Our service is FREE.

**Adults Don't Always Know What Information Young People Require, WE DO!**

### NHS GGC- Young Person's Research Tissue Bank

In collaboration with Glasgow School of Art Information Leaflets transformed

**From this**

**To this**

### Transition Guidance

In order to develop guidelines to support young people moving from a child CRF to an adult CRF, the UKCRF paediatric forum met with the ScotCRN YPG to get their opinions. The YPG were presented with three scenarios relating to transition and asked to feedback what they considered important to them.

Outcomes:

- The informed consent process – should allow the young person to have a full and honest discussion about the study, so that they feel able to make a considered decision
- Patients should feel respected and treated as adults
- Teenagers should have an opportunity to speak with staff without their parents around
- The use of modern communication methods like email, text or Facebook can be used as reminders or to provide information
- Transition should be considered and managed over a period of time
- Flexible appointments, including evenings, to avoid this could interfering with important or favourite subjects at school