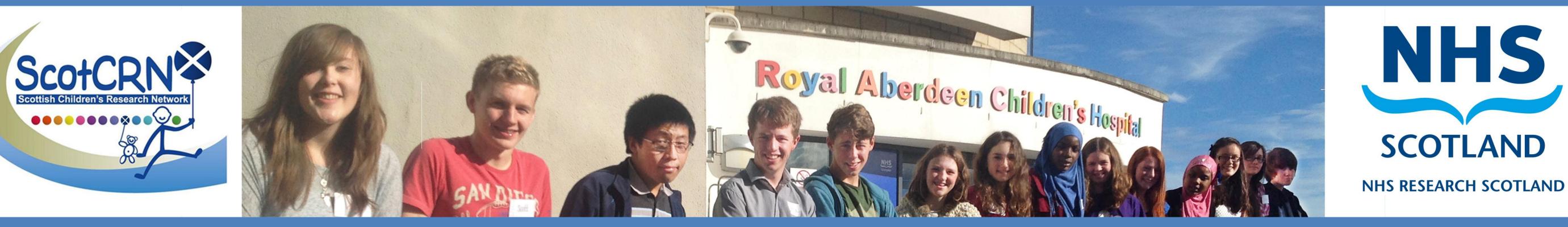
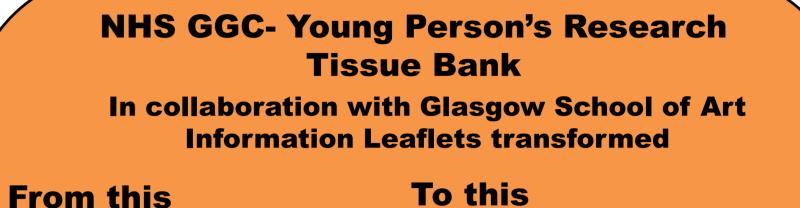
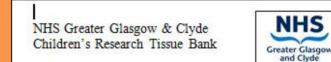
Scottish Children's Research Network



Young Person's Group







As part of your routine care in hospital your 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

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.

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

INFORMATION SHEET FOR CHILDREN AGED 8-12 YEARS

Sometimes when you are in hospital, doctors or nurses need to take small samples of blood, wee, poo, saliva or little bits of tissue or tumour (if you are having an operation) for testing. Testing samples gives the doctor information they need to find out if you are ill and how to make you feel better. However these samples can also help with research!

At the moment after the doctors have tested samples for all the tests they think necessary, the leftovers are destroyed. We are asking all patients if we can store the leftovers of blood, wee, poo or saliva or pieces of tissue and use them for research. The samples will be stored in a special place called a tissue bank which keeps them all safe and at the correct temperature.

Sreater Glasgow and Clyde

INFORMATION SHEET FOR YOUNG PERSONS AGED 12-16 YEARS

As part of your routine care in hospital your doctor or nurse may take blood, urine or tissue samples to be tested to find out why you are unwell. Normally only a small amount of these samples is required for tests. We are asking if you would donate the

This leaflet will give you all the information you need to decide. Take as much time as you want and speak to your parent's, legal guardian or any of the doctors or nurse

Whatever you decide it will not affect your care. No extra tissue will be removed and

The human body is made up of many cells that are grouped together into tissues. Some tissues form organs such as the lungs, the heart or the appendix. Other tissues are present throughout the body, for example, the bone and skm. Body fluids such as

The hospital would normally keep some of your tissue as part of your medical record so that it can be examined again if you are ill in the future. However with bigger operations and blood samples most of the tissue left over from testing would be

We are not asking one to do: We are not asking you to do anything extra, but to if you agree we will use some of the tissue left over, after all the tests have been done by your doctor. We would also like you to donate any old samples that your doctor may have taken in the past, that are not needed for your care. If you say yes, this is called giving your <u>consent</u>. This will be recorded electronically.

o. It is up to you to decide if you want to donate surplus tissue. Your decision will not affect your treatment and care in any way. If you decide to take part, you can nge vour mind at any time. You don't need to give a reason. When you arrive a bital a member of staff will ask you whether or not you wish to take pa

lood, urine and saliva also contain cells and are called tissue.

Why is human tissue required for research and teaching

What normally happens to my left over tissue?

The doctor will not take more tissue or body fluids than is needed for your ca

left over' bits for medical research and teaching

no one will be upset if you say no

What are you asking me to do

What is tissue?

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This leaflet will give you all the information you need decide. Take as much time as you want and speak to your parent/s, legal guardian or any of the doctors

Whatever you decide it will not affect your care. No

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What are you asking me to do'



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.

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.



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

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

Successes

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**

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

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!

For further information or access to the group contact Pamela Dicks Network Manager 01224 438474 p.dicks@abdn.ac.uk or Julia Subedi Network Pharmacist 01224 438480 juliasubedi@nhs.net **Royal Aberdeen Children's Hospital Aberdeen AB25 2ZG**

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