Digital Mental Health Innovation Cluster Meeting

Young People and Mental Health

Tuesday 20 September 2022, 1300-1500

Digital Health & Care Innovation Centre

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Attendees please note

1. We are **recording this event** and it will be hosted on our DMHIC webpage resources so it can be watched on demand
2. If you **do not** wish to appear on the recording, you must keep your camera and microphone turned off for the duration of the event
3. As a courtesy to our speakers and guests, we ask all attendees to **turn off** microphones and cameras during presentations
4. Drop your **questions in the chat field**, where they can be answered

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Agenda: Focus on Young People

- 1300 - Welcome Joanne Boyle
- 1310 - User Requirements for Digital Services Chal Chute CTO DHI
- 1335 - Young Scot Developments – Allan Lindsay
- 1400 - COMFORT BREAK
- 1410 - Pam Dicks Childrens' Research Network
- 1430 - DigiInventors Presentation Marr College
- 1500 - Close

Welcome and introductions

Joanne Boyle, Head of Engagement, DHI

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Aim: To accelerate digital innovation and Adoption in health and care

Create	Share	Build	Seek & Solve	Opportunities
Create a collective of shared interests, expertise and skills	Share information and support knowledge exchange	Build Collaborations that are greater than the sum of their parts	Seek and solve demand led challenges	Identify funding/host challenge opportunities

Chal Chute

User Requirements

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Allan Lindsay

Young Scot Developments & Insights

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Mental Health Insights / Technology Enabled Care

Allan Lindsay
Participation and Co-design Director

About Young Scot

We support young people to thrive and make the most of their lives as they grow up.

We do this by providing universal services for young people, combined with targeted and bespoke support to address stigma, inequalities and inaccessibility.

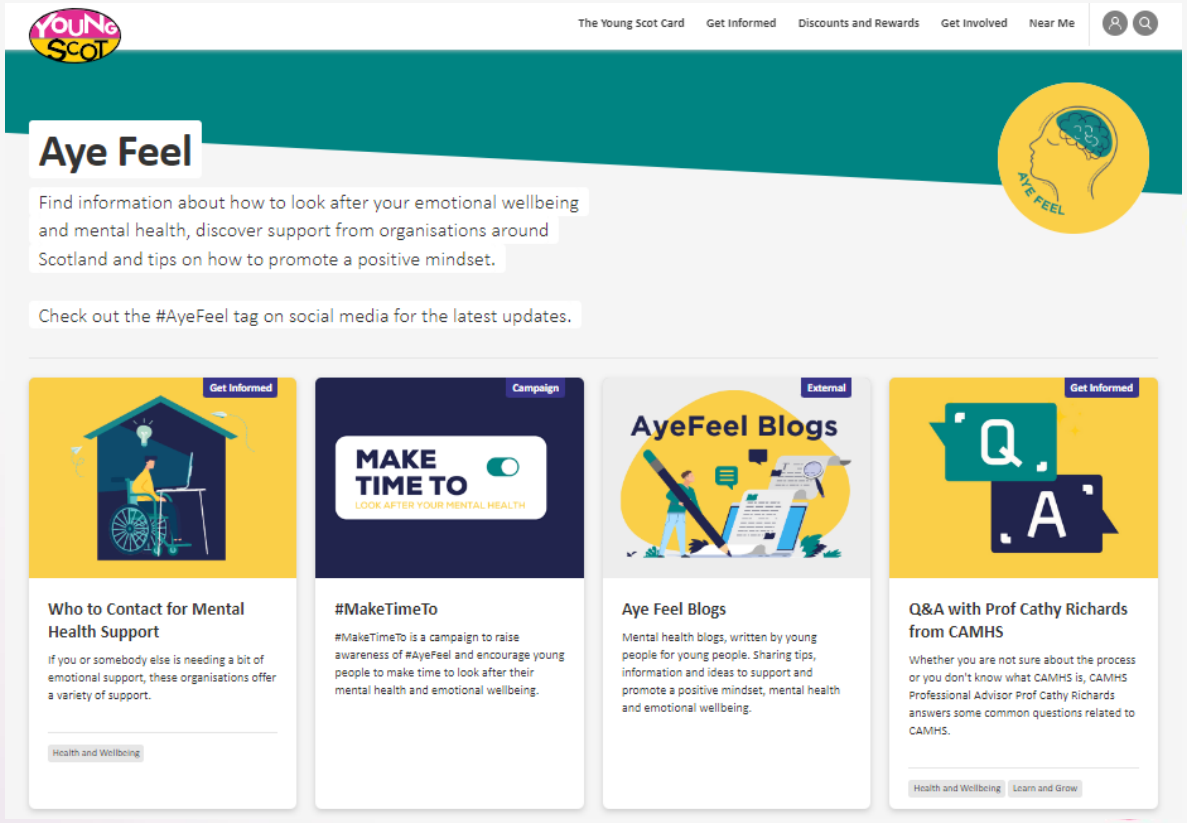
Supporting young people to thrive is a powerful way to provide reassurance in times of challenge, help build confidence and resilience, and to have fun!

#AyeFeel

Aye Feel is Young Scot's mental health and wellbeing resource for young people aged 11 – 26 in Scotland.

In partnership with a number of Scottish mental health organisations including Samaritans, See Me, SAMH, Beat, NSPCC and Mental Health Foundation, as well as with Young Scot's Health Panel (volunteers aged 11 – 26)

A range of quality assured information responding to young people's needs.



#AyeFeel

Top 10 pieces of content on AyeFeel between May 2020 and December 2021 were:

- 10 Things People With Depression Want You To Know
- How To Look After Your Mental Wellbeing
- Things to do at Home During the Coronavirus Outbreak
- Who To Contact For Mental Health Support
- Coping with Conflict During COVID-19
- Relaxation Exercises
- Tammy's Techniques (a mental health therapist)
- Tips For Staying Positive In A Crisis
- How To Improve Your Sleep Routine
- How To Talk About Your Feelings

Vote on a Topic Weeks

Each month, Young Scot dedicates one week where young people, through our Membership platform, can vote on what topics they'd like us to share information on.

- This was introduced in August 2021.
- Mental health and wellbeing has consistently been one of the top 3 themes to emerge monthly from this survey, often being the most popular theme.

Vote on a Topic Weeks

January 2022 - Mental health and wellbeing was the most popular theme.

- Respondents identified themes of anxiety and stress in relation to school prelims as a common consideration this month.

February 2022 - Mental health and wellbeing was the most popular theme.

- Most comments surrounding mental health were made generally, however, several respondents wanted to know more about anxiety and how to best deal with it.

March 2022 - Mental health and wellbeing was the most popular theme.

- Information around self-care was a primary theme this month alongside a general want for mental health advice and tips, particularly in reflection of current events such as Ukraine and money worries.

April 2022 - Mental health and wellbeing was the most popular theme alongside current events.

- As a result, the Vote on a Topic Week focused on what is happening in Ukraine and provided support for young people on how to cope with current events and making time for themselves.

Vote on a Topic Weeks

May 2022 - Mental health and wellbeing was the 2nd most popular theme.

- A common theme around mental health this month was recognising its impacts and where to get help or support others.
- Due to content surrounding Vote on a Topic week already focusing on mental health, it was decided to focus on LGBTQIA information and resources.

June 2022 - Mental health and wellbeing was the most popular theme.

- The survey this month received responses primarily around mental health as well as issues surrounding bullying and loneliness.

July 2022 - Mental health and wellbeing was the most popular theme.

- A common theme under mental health considered general advice for signposting young people to where support is available. This was often in reflection of cost of living.This was also in reflection to results from the Money and Me evaluation survey which found that over 75% of respondents felt increases on cost of living has an impact on their life.

August 2022 - Mental health and wellbeing was the most popular theme alongside money and financial issues.

- As a result, Vote on a Topic combined these themes to inform young people about budgeting, maintaining their finances and coping with the cost of living crisis mentally.

Young People's Participation in Technology Enabled Care

Technology Enabled Care Panel

Background

- In 2018, the Scottish Government's Technology Enabled Care and Digital Healthcare Innovation Division worked with Young Scot on a short pilot project Insight: Technology Enabled Care.
- This explored how digital technology could improve young people's health and wellbeing.
- As a generation who have grown up with digital technology, young people are well placed to adopt and integrate digital technology into the ways they access health and care services and information.

TEC Scot Panel

Phase Two (2019 – 2020)

- Following the success of this pilot, the Scottish Government partnered with us to establish a national Strategic Participation Panel – the **TEC Scot Panel**
- The aim of the panel was to bring young people from across Scotland together to look at how digital technology could improve young people's health and wellbeing – and sustain and improve services for the future.
- 23 young people aged between 11-26
- Ran for 18 months during 2019 - 2020.

YouNg Scot
YouthLink
Scotland
TEC Scot
YouNg Scot
TEC Scot

TEC Scot Panel

The Scottish Government's Digital Health and Care Strategy was a foundational document for TECScot, and the six key domains in this strategy have links to the themes we identified.

Recommendations related to each of the six domains are represented in the themes summarised here:

- National Direction > Access, Citizen Participation, Development
- Information governance, assurance and cyber security > Diversify Digital Services, Development, Promotion
- Service transformation > Citizen Participation, Development
- Workforce capability > Education and Training
- National digital platform > Access, Diversify Digital Services
- Transition process > Access, Citizen Participation, Development

TEC Scot Panel

View the report: https://youngscot.net/ysobservatory/tecscotland-health-and-care-in-a-digital-future

TECScot Panel Vision Statement

Our vision for TEC in Scotland is for a digital health system integrated into and complementing current health and care services. It should ensure that people are empowered to choose and use digital or face-to-face channels of communication and engagement for their health and care.

TEC must be easy to access, inclusive and user-friendly, particularly for those experiencing additional barriers to engaging in digital health services. Also, the Scottish Approach to Service Design should be embedded in the Scottish Government's TEC strategy. People will be at the heart of TEC, from creation to continuous evaluation and improvement. Citizen participation and accessibility should not be an afterthought – but central to collaborative system change and service transformation.

TEC in Scotland should support self-management and aim to anticipate deterioration in health conditions early to pre-empt emergency primary care admissions. TEC should provide avenues for early intervention within home and community settings, helping people identify and respond to their health and care needs in an effective and meaningful way. This should help reduce the need for urgent or critical care. Mental and physical health conditions should be treated with parity when planning, funding, developing and implementing TEC.

Underpinning this vision for how TEC should be developed and used is the need for trusted TEC which respects people's personal information and data, and increased education and training for health and care practitioners as well as TEC users. Promotion of TEC should be increased to raise awareness and extend the reach of TEC for the people of Scotland in the future.

Case study – Mental Health First Aid app

The market for mental health TEC is quite a busy one, and along with clinically assessed TEC interventions such as computerised cognitive behavioural therapy (cCBT) and self-help guides are providing young people with many options to access mental health support

One gap in this market however is in empowering young people to support their friends and family through periods of poor mental health. Friends and family can often be the first place young people go to seek support for their mental health, and being trained to deal with this situation as a mental health first aider would help young people to respond to these situations with confidence.

Public Health Scotland currently run Scotland's Mental Health First Aid courses around the country which means there is an established body of teaching and learning content that an app could draw from. The benefits of an app over a face-to-face training course are increased accessibility for more people, learning at your own pace and direction, and having a 'quick reference' guide to hand when you need it.

There is great value in face-to-face training, which is why Mental Health First Aid should be delivered in schools and workplaces nationally, however while this is being established an app could provide a valuable tool for young people who are already supporting each others' mental wellbeing informally. Furthermore, an app could act as a complementary tool when delivered alongside a face-to-face course.

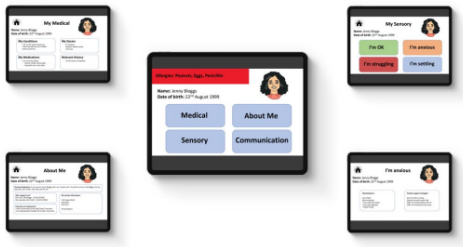
Case study – Personally Held Health Record

Young people with socio-communication difficulties, such as those with learning disabilities, autism, or social anxiety, can often struggle to communicate effectively with health and care practitioners. This could affect their ability to describe symptoms or provide a medical history, demonstrate understanding of the medical care they are being offered, or give consent to treatment being recommended.

Following interactions where they have not been able to communicate their needs, young people may feel like they haven't been listened to, and may not understand the next steps they need to take.

This communication passport aims to provide health and care practitioners with a standardised information and communication profile about the young person accessing their services. This includes the young person's medical details, contact information, communication methods, and techniques to support them in crisis. As well as enabling and facilitating understanding between professional and the young person, improving communication will empower young people to be heard in their health and care decisions.

The Personally Held Health Record (PHHR) is designed for use on a variety of devices and can be taken to any appointments or emergency service interactions. The information on the PHHR will be entered and maintained by the young person and their family, and will be securely protected. The PHHR would be free to download for anyone who might need to use it, training provided for frontline staff across health and care services.



Conclusion

The young people on the TECScot Panel immersed themselves in the TEC sector in Scotland, coming to the project with a keen interest in young people's health and wellbeing.

Throughout the project they saw how TEC can and does benefit the lives of people across Scotland, but also found out about the challenges in implementing widespread and consistent use of TEC.

During the project, the pandemic brought TEC to the forefront of healthcare, and illustrated how TEC can be embedded in health and social care services with the right support and with many people working in collaboration.

While the Panel are supporters of TEC, a theme running throughout their recommendations, is the idea of public engagement and empowerment in all aspects of TEC, underlining the fundamental belief that good design requires the involvement of service users.

Additionally, young people as frequent users of digital technology, can lend a valuable dimension to such initiatives. The Panel were pleased with the inclusion of the Scottish Approach to Service Design in the Digital Health and Care Strategy and embrace this approach in their recommendations.

Central to many of the Panel's recommendations too, is the understanding that TEC will only become an embedded part of Scotland's health and care landscape if people are at the heart of new initiatives.

From training, to promotion, to TEC leads, to user guidance, to community support, people need to be supported to choose and use TEC appropriately and with informed consent. Both the general public and health and care staff need to be brought on the TEC journey, becoming active participants in the rollout of TEC services to ensure that they truly are accessible and useful for everyone in Scotland.

TEC Scot Panel

Phase Three (2022 - 2023)

- 12 month programme
- New TEC Panel formed - 22 young people from across Scotland aged 11-25
- Working with the Scottish Government, NHS and other partners, the Panel will explore
  - the use of technology in health and social care
  - how the care and wellbeing of people in Scotland can be improved by making best use of data and digital technologies in the design and delivery of policy and services.
  - The introduction of a ‘Digital Front Door’, including an app being developed to support citizens in Scotland to access health and social care services. The work of the TECScot Panel will support Scottish Government to ensure they gather valuable information and views from young people to inform the delivery of the Digital Front door and other key strategic priorities.
  - How young people can support the Digital Health and Care Directorate’s vision: 'To improve the care and wellbeing of people in Scotland by making best use of digital technologies in the design and delivery of services.’
- First meeting of the Panel was on Saturday 17 September in Edinburgh
- We can support you to connect with the panel

Questions and Discussion

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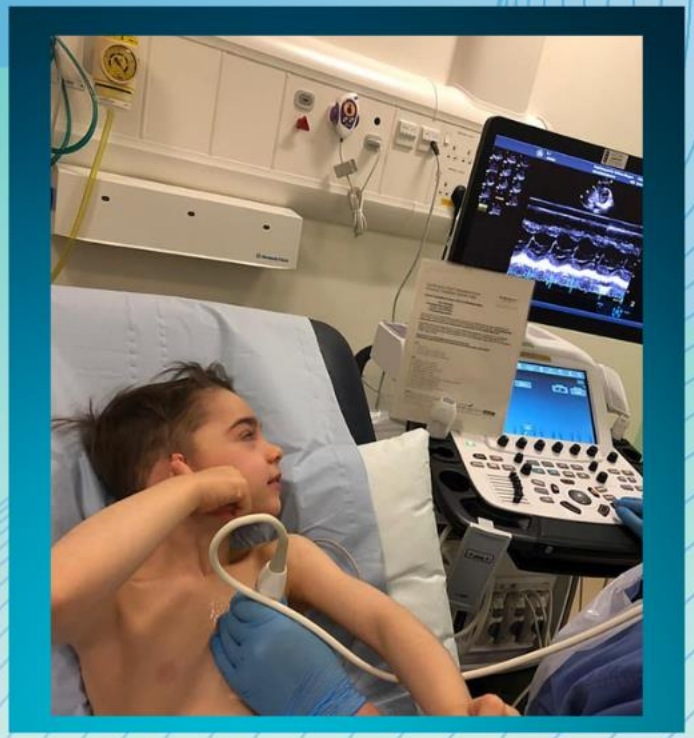
YoungScot

Pam Dicks

Childrens' Research Network

NHS-Research Scotland- Children Scottish Children's Research Network

Young Person's Advocacy Groups -what they are and how they shape research in children's healthcare



Dr Pamela Dicks
Network Manager

ScotCRN

CHIEF SCIENTIST OFFICE

NHS SCOTLAND
RESEARCH SCOTLA

Our Remit

To promote and facilitate high quality clinical trials to improve the availability, efficacy and safety of medicines and health care for children in Scotland.

Core funding Scottish Government since 2006

Clinical Lead Prof J Schwarze

Network Champions Prof S Turner, Prof S Cunningham, Prof M Kirkpatrick and B Reynolds

NHS-Research Scotland- Scottish Children's Research Network

How

Champions and Lead Research Nurses

Feasibilities – identify right people
Support consultants – research nurses and governance
Promote Scotland with industry
Liaise with UK and EU partners, networks
Encourage naïve researchers
Support protocol development, PIS
Provide training in consent and assent of children to clinical trials

Paediatric Research

Basic Science

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Intervention Change in Practice

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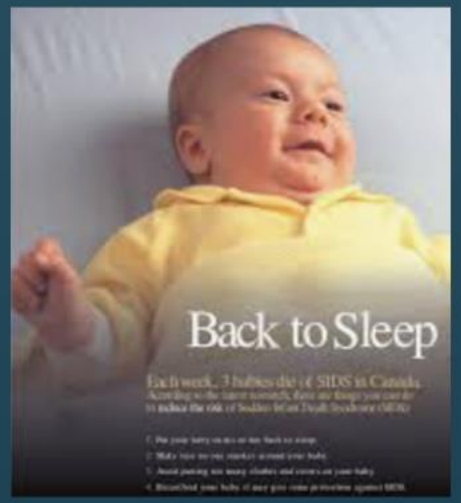

Observational Natural History Disease

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Development of New Medicines or Prescribing Practice of Existing Medicines

All Specialties within Paediatrics

Snapshot of commercial paediatric studies open on portfolio

Nerology	Psychiatry	Renal	Metabolic	Neonatology	Respiratory
Multiple Sclerosis	ADHD	Chronic Kidney Disease	Hyperkalaemia	Incubator comparison	Cystic Fibrosis
Migraine		Renal Transplantation	x-linked hypophosphataemia		Asthma
Cerebral Palsy					
Deuchenne MD					

All Specialties within Paediatrics

Snapshot of public funded paediatric studies open on portfolio

Rheumatology	Endocrinology	Neurology	Emergency	Cardiovascular	Neonatology	Respiratory
JIA	Diabetes	Epilepsy	Fractures	Cardiomyopathy	Feeding	Cystic Fibrosis
Lupus	Hypergonadism	SMA	Mananagement of oxygentation		Respiratory Distress Syndrome	Asthma
Biological Therapies	Obesity	DMD	Surgery			RSV
Uveitis						Cold Virus
Dermatomyesitis						Spirometry methodology

Patient Public Involvement

Young Persons Advocacy Group (YPAG) is a voluntary group of children and young people that advocate for children involved in research and advise researchers and sponsors on clinical trials and medical technology design.

Different from adult PPI- adapt to their needs

Model of YPAG - meet together regularly, work in groups supported by a facilitator and provide advice from a young person's perspective on a full range of activities.

Receive training, vouchers and supportive environment

CYP Perspectives Different

School work –time commitment - exams

Conflict between consent and privacy

Family dynamics, Pregnancy testing, Contraception

Alcohol/smoking/recreational drugs/legal highs –honesty

Self image concerns about side effects such as weight gain, loss, acne, IBS, flatulence

Peers- publicity

Technology-texts, apps, wearable, social media, Un-blinding via social media

Transfer to adult service, Contact : relocation to University/college

Upfront costs -travel

Side effects such as tiredness, apathy, depression

YPAG Members Profile

Over 100 members aged between 11-21

Healthy - but had hospital experience as out patients and acute illnesses, siblings

Patients with – poly-systemic JIA, JIA, Crohn's, Cardiac, Scoliosis, Diabetes, Anxiety, Eating Disorders, Self Harm, Acne, Asthma, Severe Allergies and ALL

Only specification Improve Medicines and Health Care for Children

Highly Motivated

YPAG Activities

VOICE

Raising awareness of YPAG's and PPI with regulators, sponsors, investigators and medical staff

Speaking at conferences on the value of PPI

Educational Programmes Research Active Hospitals

C0-DESIGN

Clinical Trial Design
Patient documentation, leaflets, PIS, diaries, self reporting forms

Apps, wearables, electronic reporting diaries

INPUT

Recruitment strategies
Schedule of Events

Comment on Patient documentation, PIS, diaries, QOL

Electronic consent / assent

Educational materials

LEARN

Clinical Trial Design
Ethics
Paediatric conditions
Rare Diseases

Research Ready Population

PPI aware employees

Partners in Research

Diversity within PPI recognised issue- YPAG's

Hard to reach groups, outside of the standard medical settings, barriers to participation and patient participation

Strengths

Patients

Medical needs

Meetings in hospital environment

Risk Assessments

Age

11+ representative

Language

Attend school in English diff from adults

Additional needs –

Workshops, age range, games task based, oral feedback, group work accommodate different academic abilities

Diversity within PPI- YPAG's

Hard to reach groups, outside of the standard medical settings, barriers to participation and patient participation

Weaknesses

Hard to reach CYP

Not engaged with services

Not engage with school

Looked After Children

Children excluded from school,

Children without support

Recruitment to YPAG

Open Day
Invite via Schools,
Specialist Nurses,
Doctors, Research
Nurses, Leaflets

Gatekeepers

Professional and Incidental

Opportunity to CYP that represent school/parents/ friends
Invite families that are engaged with school or clinical services

Work with gatekeepers that actively promote social diversity and inclusion and giving all CYP a voice.

Youth Workers and School Nurses

PPI networking event – SHMU Station House Media Unit Charity in 2003, is one of the core cultural organisations in North East Scotland, and is at the forefront of Community Media development in the UK, supporting residents in the seven regeneration areas of Aberdeen in radio and video production, traditional and on-line publications, music production and digital inclusion.

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shmu

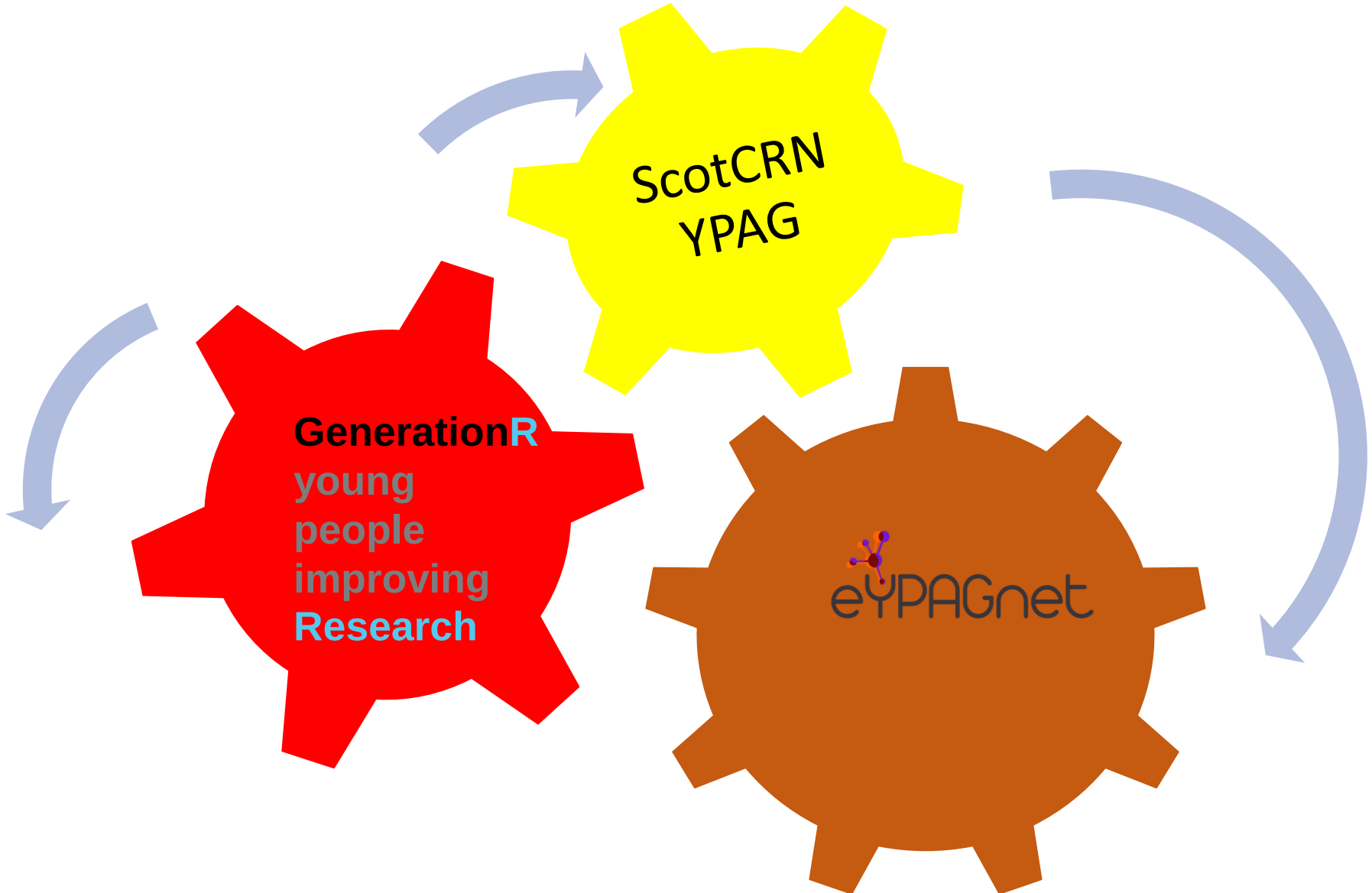
The group has a full time Youth Worker Megan Rollo
Youth Group involved in own producing radio station - strong science content.

At present there are 25 young people volunteering on a weekly basis, presenting 8 hours of live radio broadcasts every week

New Model of YPAG- working with an existing group
Develop materials and activities

Highly Motivate and Engaged

COLLABORATIVE WORKING



GenerationR

- **Collaboration of YPAG's in UK**
- **Share Good Practice- YP have understanding of research methodology, ethics, children's rights**
- **Events – joint**
- **Projects**
  - **SBRI event**
  - **Aberdeen**
  - **Manchester**
  - **Expands number of young people we can work with.**

eYPAGnet a community of YPAG's

- **YPAG's –Young Person's Advocacy Group**
- **one model of Patient Public Involvement**
- **Develop methodologies- not adult PPI**

- **To empower children and young people to have a voice in Europe that is valued.**
- **To improve the quality and frequency of collaboration between children, young people, and stakeholders who participate in the research process and development of innovative drugs.**
- **To promote and support the creation of new groups.**
- **Measure IMPACT- evidence**

- **Share ideas and good practice with our TOOLKIT**
  - **Toolkit Archive - @eYPAGnet**

NHS-Research Scotland- Children Scottish Children's Research Network

Dr Pamela Dicks

#DigiInventors Challenge Winners 2021

Marr College -You Wish We Assist

Digital Health & Care Innovation Centre

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WELCOME
You Wish We Assist
By Amy, Ashlyn, Laura and Savanna
You Wish We Assist

Final comments

UK Research and Innovation

Mindset Programme: 2022 - 2025

Research & Development Competition
02 September 2022 – 12 October 2022

julia.glenn@iuk.ukri.org
Design Innovation Lead,
Healthy Ageing Challenge

Next meeting

- Tuesday 13 December 2022, 1300-1630

Event feedback – help us shape future events

- https://www.surveymonkey.co.uk/r/33P9QK7

Digital Health & Care Innovation Centre

UK Research and Innovation

DMHIC - Get involved and learn more

Join our network

www.dhi-scotland.com/join-our-network

Visit the DMHIC webpage

www.dhi-scotland.com/innovation/innovation-clusters

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