ADVICE LEADING TO PUBLIC HEALTH ADVANCEMENT

ALPHA

DECIPHER's RESEARCH ADVISORY GROUP OF YOUNG PEOPLE

Involving children and young people in the design and conduct of health promotion research

CARDIFF UNIVERSITY PRIFYSGOL CAERDYₐ

Llywodraeth Cymru Welsh Government

Ymchwil Iechyd a Gofal Cymru Health and Care Research Wales

Y RHWYDWAITH YMCHWIL IECHYD MEWN YSGOLION

SCHOOL HEALTH RESEARCH NETWORK

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Welcome

Sophie Jones, Senior Public Involvement Officer

Jeremy Segrott, Senior Lecturer in Public Health

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Workshop Outline

Key aim: Provide participants with an understanding of how to involve children and young people in the design and conduct of research. Split into three parts:

- The Health and Care Research Wales Public Involvement Standards and approaches to involving children and young people in research

- Case study examples to illustrate the key approaches, what facilitates and what can hinder Public Involvement, and the possible impacts

- Practical session where delegates can apply learning to develop a plan for involving children/young people in their own current research projects or research ideas

Learning outcomes

- Identify the Principles and Practice of involving children and young people in research

- Understand practical methods, facilitators, barriers and the impact of involving young people

- Know how to develop strategies for researchers to involve young people

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9:00		Welcome, and Expectations
9:15		Public Involvement – What, why and how?
10:00		Break
10:10		Public Health Priorities – Menti.com
10:20		Case studies: Involving children and young people in the design and conduct of studies
10:50		Break
11:00		Group activity – planning public involvement work within a research study
11:30		Summary, Evaluation and Close

Expectations

Activity Name: Post-It Storm
Activity Type: Development

Go to Menti.com

Public Involvement in DECIPHer

- Commitment to involve the public at all stages of the research process, from idea development to dissemination

- Key public involvement activities
  - ALPHA group
  - New national student advisory group using an online platform
  - Involvement of parents/carers
  - Annual training course

- Centre public involvement strategy with input from a steering group comprising stakeholders and members of the ALPHA group

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DECIPHER'S RESEARCH ADVISORY GROUP OF YOUNG PEOPLE

- Young People's Advisory Group aged 14 - 24

- Set up in 2010

- Brings together Young People with different experiences and opinions to help our research reflect what is important.

- 10 weekend session throughout the year lasting approx. 3 hours.

- Currently zoom meetings once a month.

- Projects including alcohol advertising, drug prevention and sexual health intervention.

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Public Involvement – What, why and how?

Bakery owner Rich Myers from Leeds (Image: © Glen Minikin)

Baker's rant leaves people in stitches after council ban his 'illegal' sprinkles

Rich Myers was gobsmacked when a Trading Standards officer told him that he was being investigated over his colourful choice of decorations for his best-selling cakes

By **Rosaleen Fenton**, Audience Writer
19:01, 13 Oct 2021

19 COMMENTS

A fuming bakery owner's rant went viral after a customer reported his 'illegal sprinkles' to
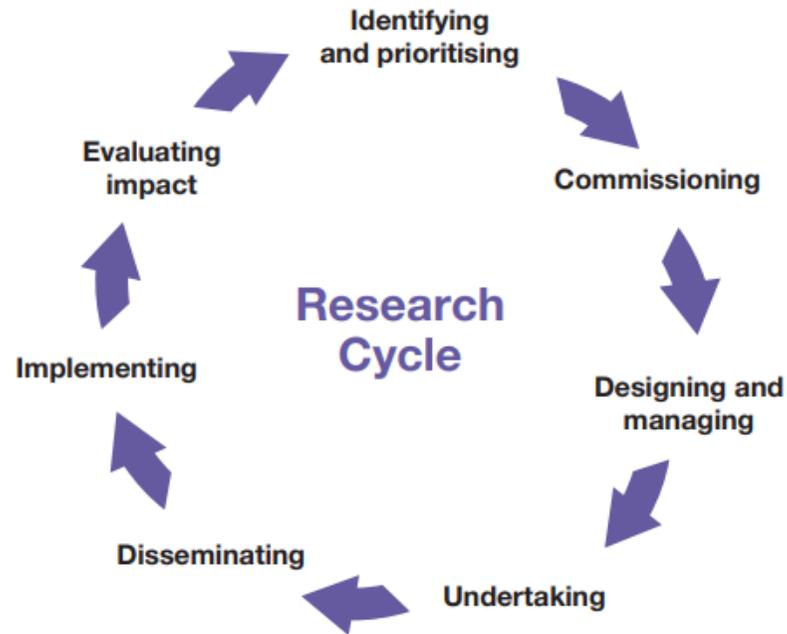
What is Public Involvement?

NHS Health Research Authority (2020) defines PI in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

Involvement	Participation
Where members of the public are actively involved in research projects and in research organisations.	Where people take part in a research study. E.g. People being recruited to a clinical trial or other research study to take part in the research.

Engagement
Public engagement is telling people about your research, why it is important, what it found out and the impact and implications of the results.

Public Involvement & Qualitative research
Public involvement is also different to qualitative research where you are collecting data from patients, service users and carers and finding out their views and opinions, as participants in the study. The distinction is particularly important as you would require ethical approval for participation in a study. HRA (2020)

Public Involvement throughout the research cycle

(Jinks et al 2016)

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Why undertake Public Involvement

- **Increasing research quality** - Public can provide *'knowledge in context'* that increases the relevance, understandability and acceptability of projects.

- **Research Policies** - Research Governance Framework for Health and Social Care Wales; Best Research for Best Health.

- **Research Ethics Committees (RECs)** - can contribute positively to the ethical review process - ask about the plans for public involvement in your research

- **Involvement as a requirement** - Research funders increasingly recommend and require patient and public involvement (PPI) in the design, conduct, and dissemination of health and social care research. Fluerence et al (2015), Canadian institute for health research (2014)'

- **Democratic principles –** People who are affected by research have a right to have a say in it

HCRW Public Involvement Standards

Inclusive Opportunities
- Offer public involvement opportunities that are accessible and that reach people and groups according to research needs
- Research to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs

Governance
- Involve the public in research management, regulation, leadership and decision making
- Public involvement in research governance can help research be more transparent and gain public trust.

Working Together
- Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
- Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected

Support and Learning
- Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.
- Remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.

Impact
- Seek improvement by identifying and sharing the difference that public involvement makes to research
- Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public

Communication
- Use plain language for well-timed and relevant communications, as part of involvement plans and activities
- Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing

Inclusive Opportunities

- Offer public involvement opportunities that are accessible and that reach people and groups according to research needs
- Research to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs

- Make sure you're involving the people affected by and interested in the research involved from the earliest stages.
    - Age – In Welsh policies children are 0-10 year olds and young people are 11-25 year olds. Different activities should be used to work with children and young people.
    - Specific population – Those with a particular medical condition (children with diabetes) or a particular experience (looked after children).
    - Are there already established groups you can access – ALPHA, CASCADE Voices (group of care experienced young people), third sector groups such as Barnardo's that run young carers groups.

- All opportunities to get involved are fair and transparent and reflect equality and diversity

- Remove barriers that prevent people from participating in research, make the service accessible to everyone
    - Websites adapted for visually impaired.
    - Location of meetings
    - Cover consumables – transport and lunch

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Governance

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- Public involvement in research governance can help research be more transparent and gain public trust.

- Members of ALPHA are involved in the Public Involvement Steering Group (PISG) who provide strategic direction for PI within DECIPHer

- PI charter jointly produced with ALPHA members. The Charter is used to illustrate out commitment to the Participation Standards

- Make sure there is visible and accountable responsibility for PI throughout. Have one person dedicated to PI or responsible for PI. It should not be tokenistic, this approach will lead to building better relationships and trust with members of the public

- Are there realistic resources in place? Young people are provided their spare time to help and support our research, they should be rewarded accordingly, this could be in the way of vouchers, references, or training. One way to know how to do this is ask them directly.

www.decipher.uk.net

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- Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected

Consultation

Involves children and young people being asked for their views about research as a one-off activity.

Collaboration (Coproduction)

Involves children and young people advising during several stages of the research cycle.

User Led

Involves children and young people as equal partners throughout the research cycle which includes developing the idea, and collecting and analysing data

INVOLVE 2012. *Briefing notes for researchers: public involvement in NHS, public health and social care research*

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— Ice Breakers – Funny icebreakers.

— Humour – Try not too be too serious.

— Don't try to be cool - Acknowledge that you are a grown up and don't try and 'get down with the kids'.

— Don't patronise - Try not to be condescending.

— Pitch it at the right level - Explain your research like you are talking to a friend that is not a researcher

— Capacity Building Activities – Where we train/upskill young people.

— Development Activities – Young people to articulate their own ideas.

— Review/Discussion Activities – We take an idea to young people to scrutinise and refine.

— Pilot/Evaluation Activities – Run through a questionnaire or intervention session with young people as if they were participants and gain their feedback.

— Interpretation Activities – Young people given research study findings to interpret.

— Evaluation Activities – Young people evaluate how well we have involved them.

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Support and Learning

- Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.
- Remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research.

- **Capacity building training** – We all need the right information to make informed decisions. What do your public need to understand before being involved?

- **Ask them** - What do the members of the public want/need?

- **Knowledge/skill development** – Lessons that can be linked to curriculum and gaining informal accreditations.

- **Payment** – Vouchers or National Institute of Health Research has set national levels for involvement payments.

- **References** – For job and university applications.

- **Volunteering time** – Time Credits or a in house system to award and recognise young people for their participation.

- **Placements** – Offering placements and additional opportunities. Public Involvement Training – TRIUMPH network.

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Impact

- Seek improvement by identifying and sharing the difference that public involvement makes to research
- Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public

- **Close the loop** Summary of activity sessions can be produced (written? Infographic?) to show what the public said. Also researchers should return to the group to say how you have used their ideas, and if you have not been able to explain why. Give contact details so that children and young people can contact you if they do not agree with summary.

- What difference does Public involvement make to the research. How to evaluate?

- **Ways to do this** - Using 'You said, we did' tables.

- **Timely feedback** – This can be difficult due to

lengthy research bid processes.

Initial – 6month – 1year

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Communication

- Use plain language for well-timed and relevant communications, as part of involvement plans and activities
- Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing

- In collaboration with members of the public develop communication plans for the involvement activities.

- In DECIPHer we inform ALPHA members of the research topic at least 2 weeks prior to the sessions. (Rights based approach)

- Inclusive and flexible communication methods.

  - Provide more than one approach for communicating. We send out text, Whatsapp and emails. Find out what your group's preferred method is.

  - Additional communication follow a formal approach – don't want to overburden the young people, we normally email young people.

  - Provide more than one method for feeding back on research – group discussions as well as one to one workings. Online use zoom, surveys, mentimeter, padlets (get creative)

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School settings

- When undertaking PI work **in** schools
- Important setting – a place where many young people spend much of their lives
- Consider issues of agency and power
- Who controls who takes part and how they are selected?
- Do young people have the ability to decide whether they want to be involved?
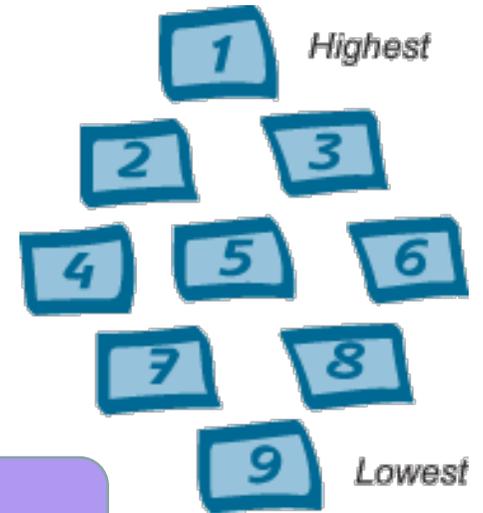
BREAK

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Activity Name: Diamond Ranking
Activity Type: Interpretation
Interactive tool: Menti.com

Highest
1
2   3
4   5   6
7   8
9
Lowest

Physical Activity/ Exercise
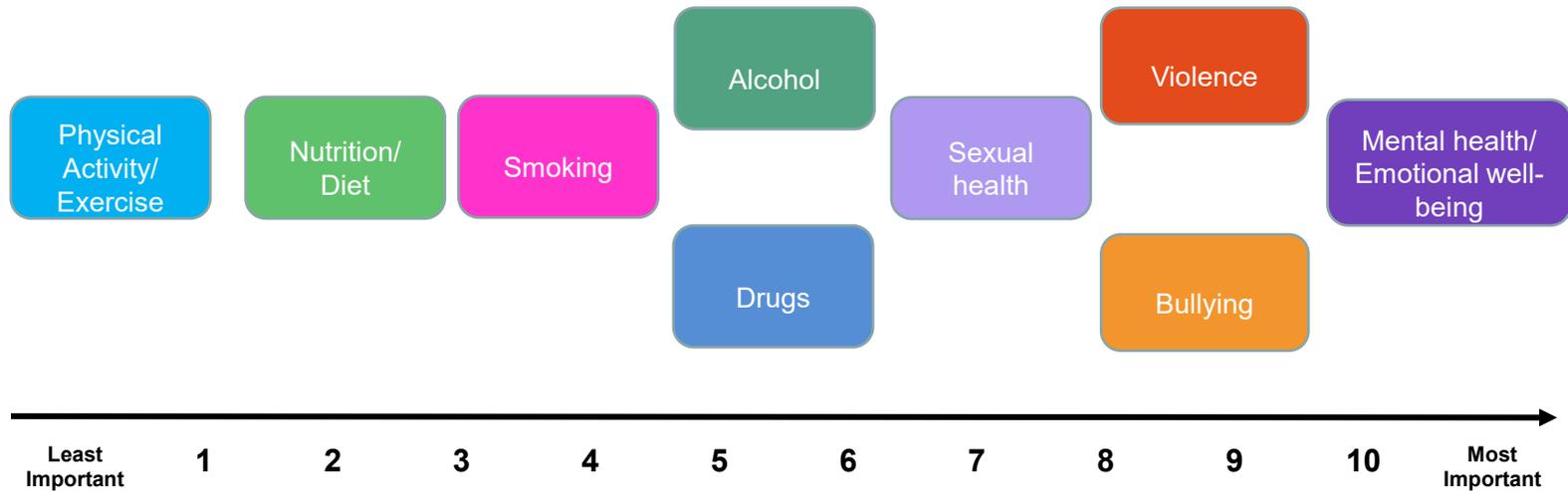
Alcohol

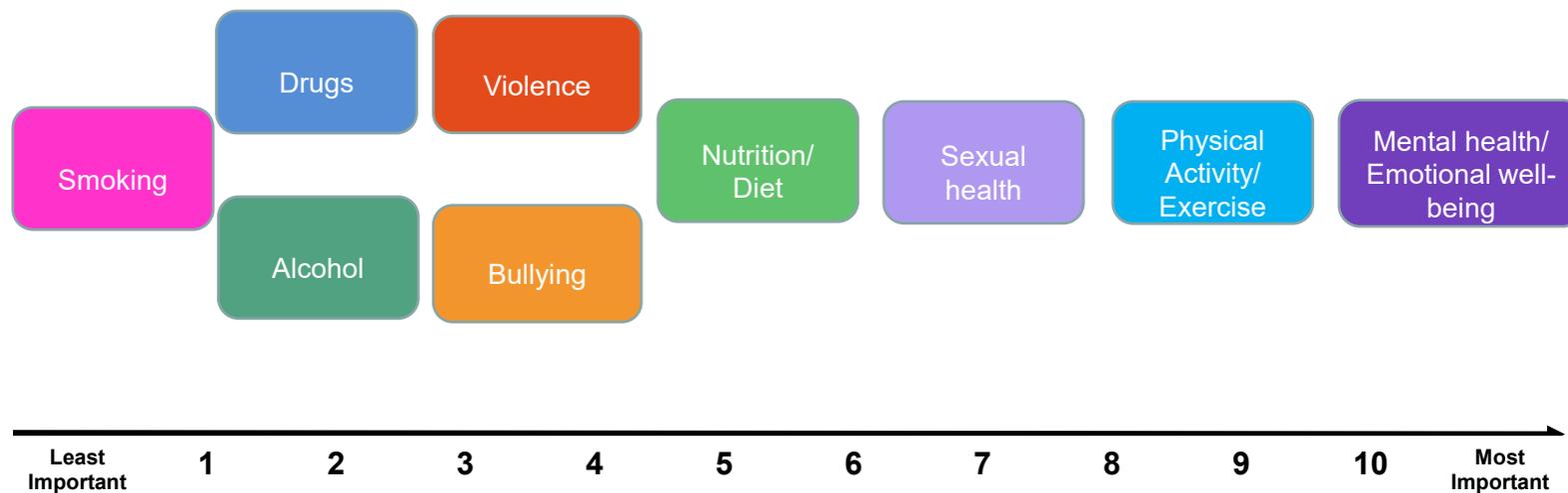Sexual health

Nutrition/Diet

Smoking

Violence

Bullying

Drugs

Mental health/ Emotional well-being

ALPHA Public Health Priorities before COVID 19

ALPHA Public Health Priorities - since COVID19 restrictions

School Health Research Network (SHRN)

What do WHO Health

SHRN ADOPTED STUDIES

- Physical Activity / Exercise
- Nutrition/Diet
- Bullying
- alcohol
- Smoking
- Drugs
- Sexual health
- Violence
- Mental health/Emotion wellbeing
- Other
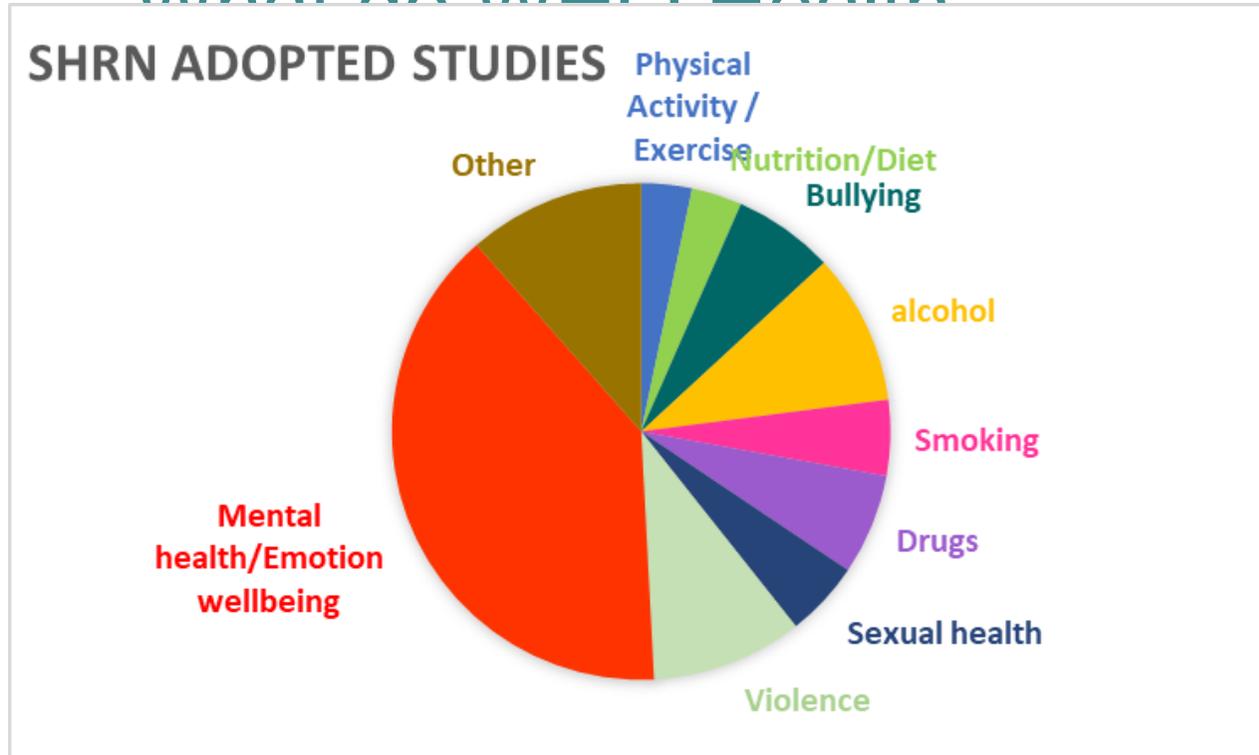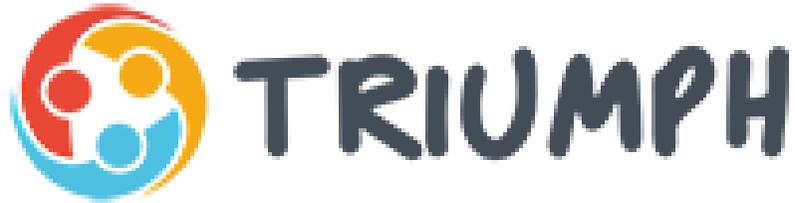
TRIUMPH

Transdisciplinary Research for the Improvement of Youth Mental Public Health (TRIUMPH) Network

It aims to bring together young people with academics, health practitioners, and policy-makers to find new ways to improve youth mental health and wellbeing, especially among those where need is greatest.

TRIUMPH believes that young people should be involved in all of the work that we do; if young people aren't involved in these conversations then a part of the jigsaw puzzle is missing.

Recruit a youth advisory group (YAG) to support the strategic development of the network.

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TRIUMPH Youth Partner Organisations

VOYPIC
Voice of Young People in Care

ALPHA
Advice Leading to Public Health Advancement

YEA
Young Edinburgh Action

Free2B Alliance
LGBTQ+ Equality through inclusion

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Adapting parenting interventions for online delivery

- Worked with parents and young people during development of funding application

- Included:

    - Consultation with parents at community centre

    - Speaking to parents who had attended an online parenting group

    - Meeting with DECIPHer parents' advisory group

    - ALPHA session

What do you think?

- Is it a good idea to do this research?

- What do you think about running a parenting group using video chat (Whatsapp, Zoom)?

- How can we explain our research clearly?

- What things are important? Have we missed anything?

- How do we involve children in the research?

Reducing Excessive Alcohol Consumption and Harm (REACH). Intervention Development

Situation:

- substantial proportion of YP drink F-50% M-66%.

- YP lack awareness around drinking – effects of different types & volumes.

- Previous studies identified small positive effects of an school web-based intervention.

- Researcher required the views and opinions of ALPHA to help develop content for the web-based intervention and feasibility

Feasibility

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Feasibility of school-based web intervention

1. Develop a Website not App.
   - Young People skim read Apps but take more notice of websites on computers.
   - Schools becoming more stringent on mobile use – banning or having mobile free zones.
   - Schools are using computer rooms, students won't become distracted by other websites.
   - Develop something similar to Kahoots – game based learning platform that teachers can see who's using.

2. Website would be limited outside of lessons, some may use it but those among the targeted population probably would not.

3. Scope to include additional subjects, including drugs and smoking. Give a more serious tone.

Design and Information included in website.

1.Content – relatable:

- Real life, relevant case studies from young people.
- Physiological information relating to alcohol. The short, medium and long term effect on the body.
- Risks, misconceptions and dangers relating to alcohol.
- Economic disadvantages of drinking

2.Activities – best approaches:

- Online learning modules
- Interactive Video Drama
- Short simple multiple choice quizzes
- Testimonies from recovered alcoholics and pictures

3.Layout – suitability:

- Vibrant and relatable, reaching the targeting population
- Keep scientific explanations and information to a minimum – keep it simple
- Concise, user friendly and easy to use.

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Planning your own public involvement

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Impacts of learning from home on young people's mental health

Project objectives

- Identify key challenges experienced by young people

- Explore the support they received from schools

- Identify young people's needs as schools reopened

Methods

- Mixed methods

- Survey and qualitative interviews / focus groups

Impacts of learning from home on young people's mental health

Your task (in groups)

- You are about to write the funding application for this project idea

- At what points in the application process **and** the actual study could you undertake public involvement?

- What would you do and why?

- What things might need to be thought about (resources, challenges)?

1. **Study aims and design**
- Importance of topic, which questions to address
- Study design and selection of methods

2. **Study conduct**
- Recruitment and retention strategies
- Content of information sheets and consent forms
- Content, presentation and structure of data collection tools

3. **Data analysis**
- Providing input on initial analysis and findings
- Identifying importance / meaning for young people

4. **Dissemination**
- Contributing to lay summaries
- Informing how results shape policy/practice

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What next?

- More information about our research and public involvement on our website – DECIPHer | Public Health Research Centre of Excellence

- Updates from ALPHA group via Twitter - @ALPHA_DECIPHer

- DECIPHer training course on public involvement

- UK Public Involvement Standards - UK Standards for Public Involvement | Health Care Research Wales (healthandcareresearchwales.org)

- Please get in touch with us if you have further questions!

- segrottj@cardiff.ac.uk / JonesS206@cardiff.ac.uk

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Evaluation

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