

ADVICE LEADING TO PUBLIC HEALTH ADVANCEMENT



DECIPHER's RESEARCH ADVISORY GROUP OF  
YOUNG PEOPLE

# Involving children and young people in the conduct and design of research



Llywodraeth Cymru  
Welsh Government



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales

Y RHWYDWAITH  
YMCHWIL  
IECHYD MEWN  
YSGOLION



SCHOOL  
HEALTH  
RESEARCH  
NETWORK

[www.decipher.uk.net](http://www.decipher.uk.net)

DECIPHER DECIPHER

Centre for Development, Evaluation, Complexity  
and Implementation in Public Health Improvement  
A Public Health Research Centre of Excellence

Y Ganolfan Datblygu a Gwerthuso Ymryiadau  
Cymhleth er mwyn Gwella Iechyd y Cyhoedd  
Canolfan Ragoriaeth Ymchwil Iechyd y Cyhoedd

# Welcome



Bethan



Elina



Issy



Peter Gee, Senior Public  
Involvement Officer



Jeremy Segrott, Senior  
Lecturer in Public Health

# Course 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.

10:00am	Welcome, Ice breaker and Expectations
10:20am	Public Involvement – What, why and how?
11:00am	Break
11:10am	Public Health Priorities – Menti.com
11:30am	Case studies: Involving children in intervention development ALPHA involvement in network development
11:45am	Break
11:50am	Planning your own PI Programme
12:15pm	Summary, Evaluation and Close

# Expectations



**Activity Name:** Post-It Storm

**Activity Type:** Development

**Interactive Tool:** Padlet

<https://padlet.com/geep/54sbws7jujng8vxp>

# 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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- Young Persons 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.



# Public Involvement – What, why and how?





# What is Public Involvement?

*INVOLVE defines PI in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.*

*What it is not – PI is not finding participants to be a part of your research*

Involvement	Participation
Where members of the public are actively involved in research projects and in research organisations. E.g. undertaking interviews with research participants.	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.
<b>Engagement</b>	
Public engagement describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit	

# Why undertake Public Involvement

- **Children's Rights** - United Nations Convention on the Rights of the Child Article 12- *“States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”*
- **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.
- **Involvement as a requirement** - National Institute for Health Research (NIHR) *‘Evidence of public involvement will be sought in applications, and comments from reviewers who are members of the public will be requested.’*
- **Outcomes** – What do you want to get out of involvement? What questions do you want answered?

# 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

- 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 14-25 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

- 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.

- 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.



- 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

## Consultation

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

## Collaboration (Coproductioin)

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*

- 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

- Ice Breakers – Funny icebreakers.
- Humour – Try not to 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.

- 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.
- **Payment** – Vouchers or National Institute of Health Research has set national levels for involvement payments.
- **References** – For job and university applications.
- **Volunteering time** – Organisation sign up to Millennium Volunteering scheme lead by Gwirvol can offer volunteering credits – young people receive nationally recognised certificates for 50, 100 and 200 hours.
- **Placements** – Offering placements and additional opportunities. Public Involvement Training – TRIUMPH network.

- 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



- 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, emails, letters and organise Facebook events, for each session.
  - 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)

# BREAK





**Activity Name:** Diamond Ranking

**Activity Type:** Interpretation

**Interactive tool:** Menti.com 21 88 74 1



Physical Activity/  
Exercise

Alcohol

Sexual health

Nutrition/Diet

Smoking

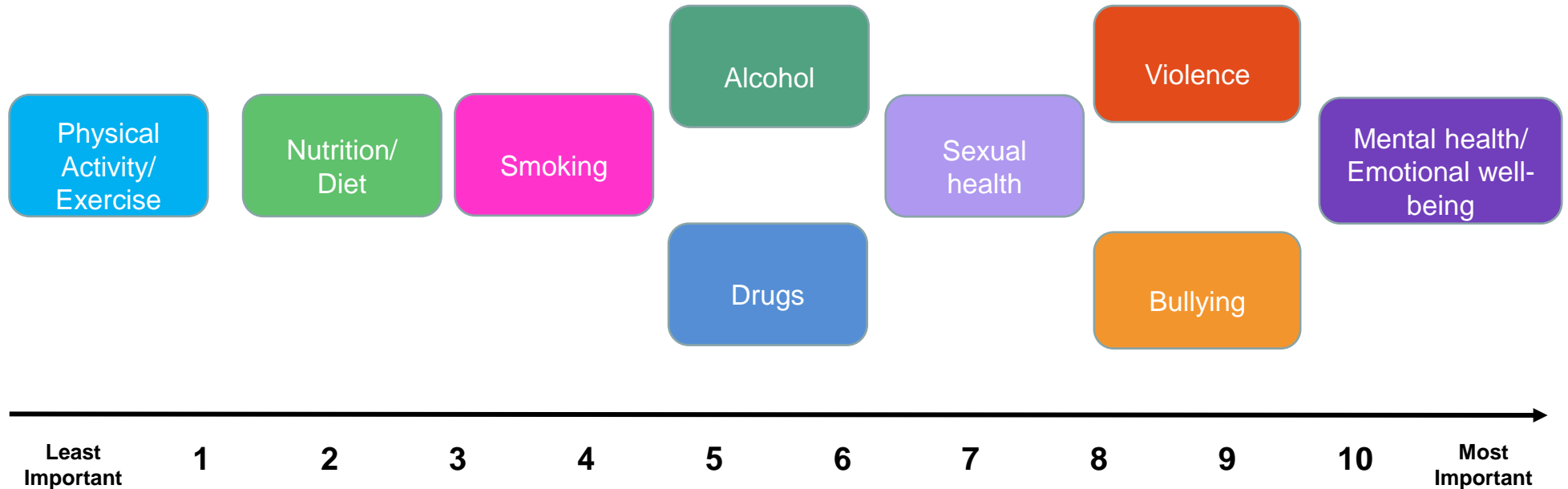
Violence

Bullying

Drugs

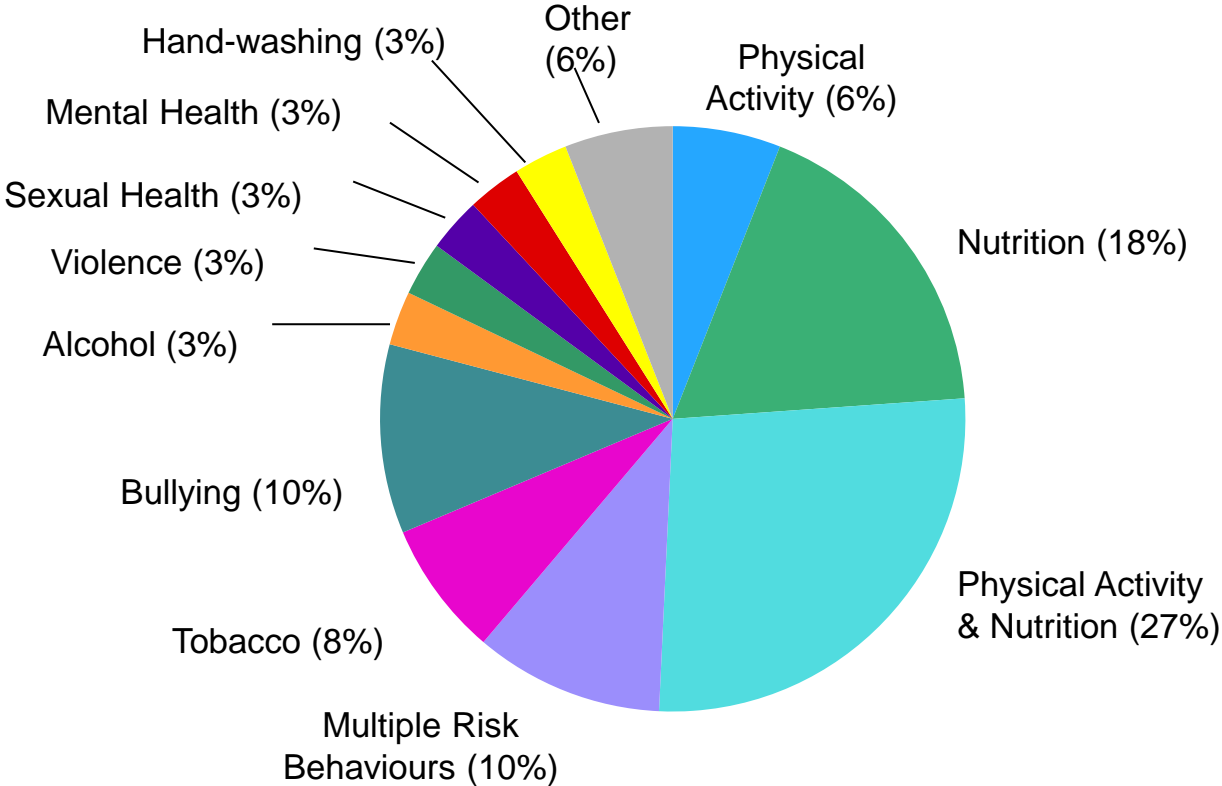
Mental health/  
Emotional well-  
being

# ALPHA Public Health Priorities



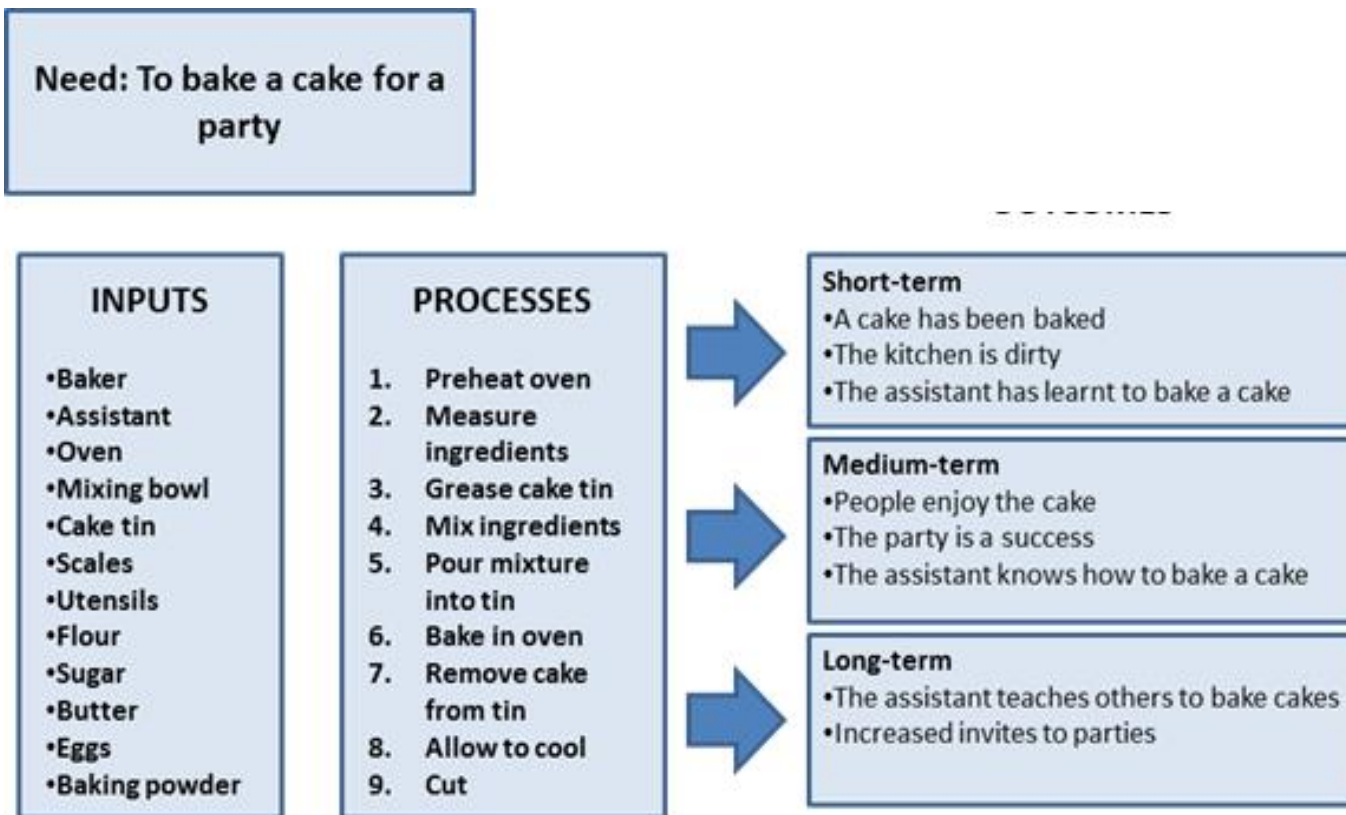


# What do WHO Health Promotion Schools focus on?



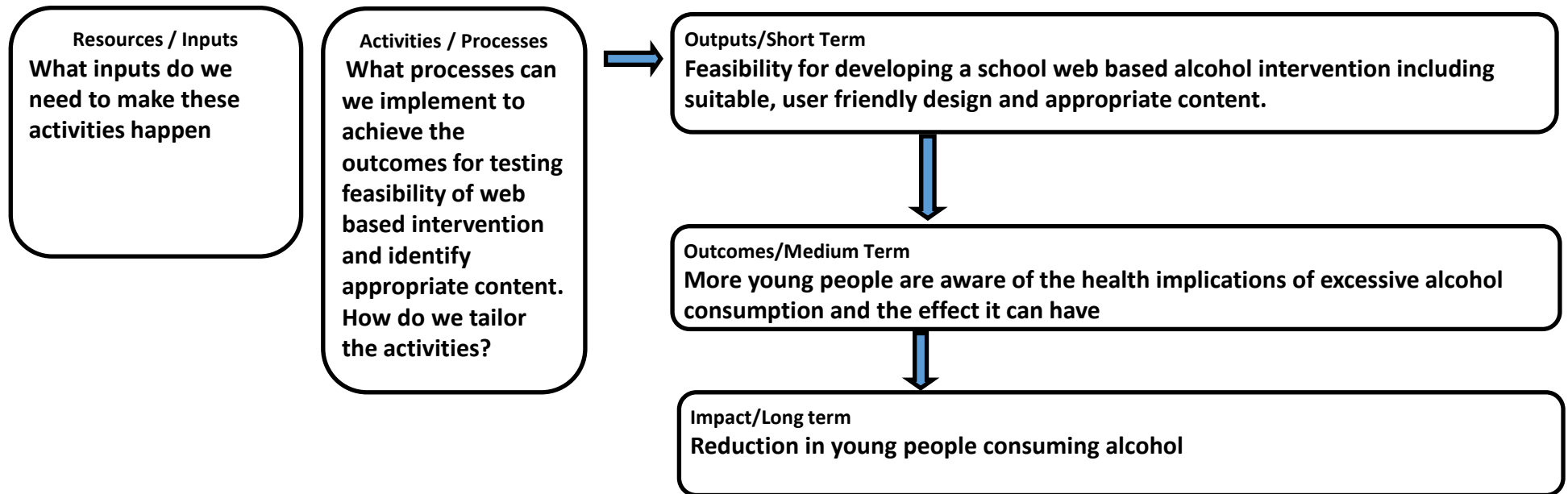


## Activity Name: Bake a Cake logic models



# 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



# 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.



The School Health Research Network (SHRN) and DECIPHer have established a national advisory group of secondary school students to provide consultation and collaboration on public health research.

The National Student Advisory Group (NSAG) is a network of secondary school students who advise our researchers by discussing and debating their views on public health topics and the research SHRN and DECIPHer plan to carry out.

NSAG members will be collaborators and consultants on research - ALPHA on a national scale.



# Logic Model

## Resources / Inputs

Public Involvement Experts

Youth workers

Facilities to run focus groups and workshops

Youth Advisory Group

Close professional relationship with SHRN

Ease of access to large group of students

Knowledge of involvement techniques and engagement workshops

Youth Advisory Group based within south Wales

## Activities / Processes

What we need to do to achieve our outcomes

Stakeholder engagement

Idea exploration

Feasibility testing

Product development

National Student Advisory Group

## Outputs/Short Term

National Group of youth advisors

Improve relationship between researcher and user.

Young people feel listened to, valued and meaningfully engaged

Young people in the YAG feel their involvement is important and valued

Young people feel their involvement makes a difference

Adult stakeholders feel more confident in the value and practice of engaging with young people

Adults feel prepared to work outside their comfort zone

Network members feel connected

Network members feel inspired to submit funding applications

Adult stakeholders learn about different ways to involve young people in their work.

Adult stakeholders learn about youth public mental health from the perspective of young people.

Young stakeholders learn about youth public mental health from practitioner, policy maker & academics' perspectives

## Outcomes/Medium Term

Larger pool of young people to consult with

More researchers consulting with young people on their research studies.

Increases the research quality

Improves participation in research studies – now information is more user friendly

Research is more focused on young people's interest and concerns.

Increase diversity in research, making it easier to work with 'harder to reach' groups.

## Impact/Long term

More people engaged in research, not just Public Health – citizen science

Young people more educated and informed about Public Health research

Platform for young people to have a say in matters that directly impact them.

Potential to increase the number of research being undertaken on youth Public Health.

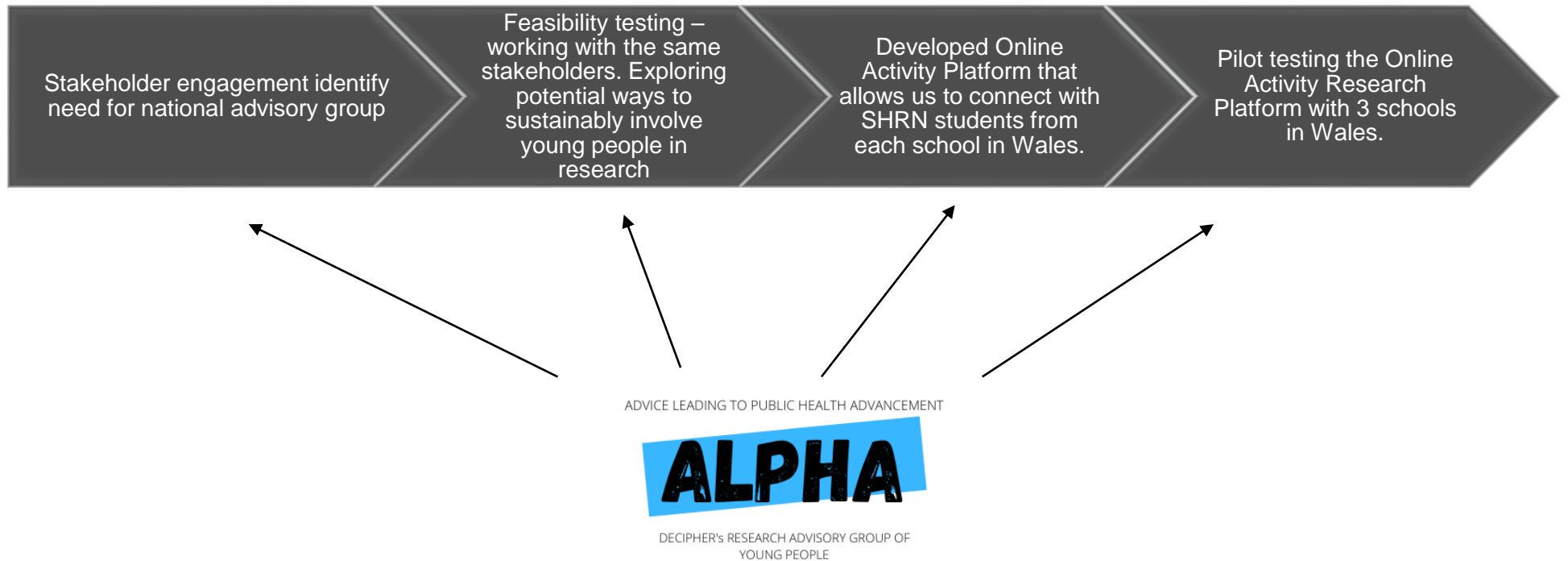
Potential to reduce the prevalence of disease

Expand to other areas of research

DECIPHer forefront of youth involvement in research.

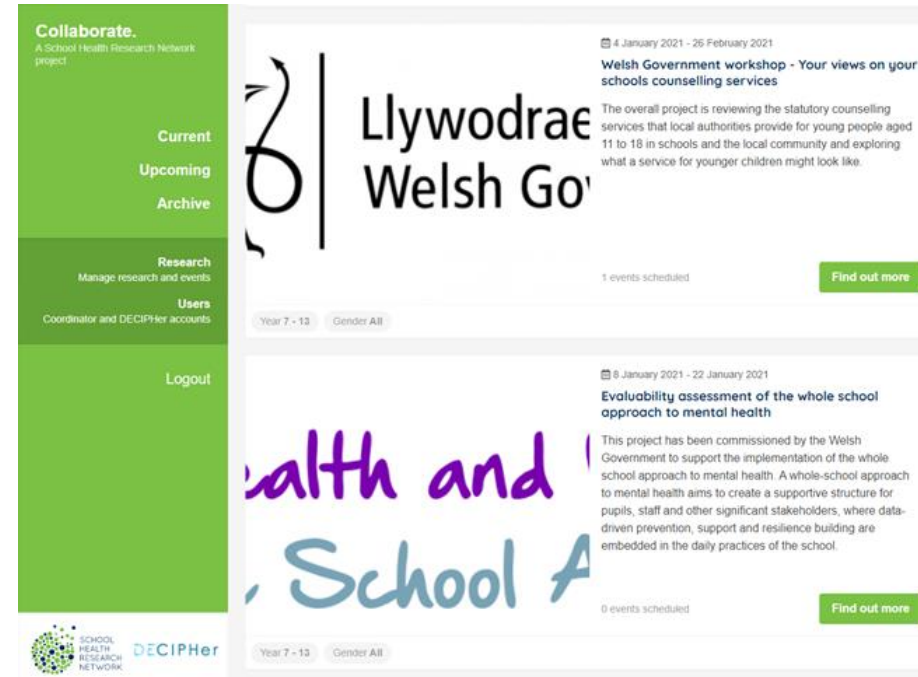


# Activities/processes - Co-producing the National Student Advisory Group timeline



# Online Research Activity Platform (ORAP)

- Connect with a large number of SHRN students
- Fast turn around of raw data – everything is documented digitally
- Secure log in system
- Monitor students activity – time & work commitment
- Forums and group discussions
- Central point for showcasing youth involvement activities
- Upload documents to the platform for SHRN students
  - Questionnaires
  - Participant Information Sheets
  - Study materials



The screenshot displays the ORAP platform interface. On the left is a green sidebar menu with the following options: 'Collaborate. A School Health Research Network project', 'Current', 'Upcoming', 'Archive', 'Research Manage research and events', 'Users Coordinator and DECIPHER accounts', and 'Logout'. The main content area shows two event listings. The first listing is for a 'Welsh Government workshop - Your views on your schools counselling services' held from 4 January 2021 to 26 February 2021. It features a treble clef graphic and the text 'Llywodraeth Welsh Go'. Below the title, it states '1 events scheduled' and includes a 'Find out more' button. The second listing is for an 'Evaluability assessment of the whole school approach to mental health' held from 8 January 2021 to 22 January 2021. It features a graphic with the text 'Health and School A'. Below the title, it states '0 events scheduled' and includes a 'Find out more' button. At the bottom of the sidebar, there is a logo for 'SCHOOL HEALTH RESEARCH NETWORK' and 'DECIPHER'.

# BREAK





# Planning your own public involvement

- We have a logic model which will help you plan your own public involvement activity.
- Jeremy, Pete and ALPHA members will answer any questions you have.
- At the end of this session we will have a few minutes for feedback and to ask questions.





Go to [www.menti.com](https://www.menti.com) and enter the code 21 88 74 1

# Thank you

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