Meaningful stakeholder engagement

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Webinar ground rules

- The host will introduce presenters
- Please mute your microphone throughout the webinar
- Email questions to LDT@phe.gov.uk
- The host will select questions to ask the presenters during the questions sessions
- If we are unable to answer all of your questions we will respond after the webinar
- Slides are presented as overview, not in depth explanation. For more information go to https://tinyurl.com/ihalarchive
Nothing About Us Without Us
Our First Advisory Group

- The first Advisory Group was in the East of England and met twice a year
- People who were part of the group were also on national and/or regional groups
- The plan was to get the observatory talked about in regional and national groups
- This didn’t happen well as the regional forum stopped meeting
Our Second Advisory Group

- The second Advisory Group was set up when we moved into PHE and meets 3 times a year
- The groups that run it are Changing Our Lives, Inclusion East and Inclusion North
- The groups take it turn to host and run the meeting
- The groups are paid for their input to the meetings
- We have self-advocate members with a wide range of needs and family carers
- The group continue to inform and influence the work of the observatory
- Representatives at our annual steering group
- Work in a more proactive way now
- We invite other organisations along to some meetings
Examples of their input

Helping us plan the work programme in terms of suggestions on the topics for:

- Secondary analysis
- Systematic reviews
- Reasonable adjustment guides

When our website was transitioned they offered advice around our user needs

A while ago we asked their opinion on our easy-read information

We work with individual members or their groups on specific events

They provided advice for how wider parts of PHE can engage with people with learning disabilities
Reflections

What has worked well:
- Increasing the number of meetings a year
- Wider representation from across the country
- Consistency of members
- The group getting to know each other better
- More frequent contact from us and updates

What could be better:
- We have had turnover of group members
- Representation from children
- Getting the optimum size
Cross PHE opportunities

- Opportunity for all teams to engage with people with a learning disability
- The public health context and a recap of the equality objectives
- The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) – what it is and how it works
- The Valuing People Alliance (member of the above)
- How a cross-PHE advisory function works
- Next steps
The public health context

- People with learning disabilities continue to die younger than the general population and experience significant health inequalities.
- Many of these deaths are preventable.
- Public Health England (PHE) has both a statutory duty and a **remit** set out by the government to work towards reducing health inequalities.
- PHE has a dedicated learning disability observatory and learning disability lead nurse within its nursing directorate.
- Work is also undertaken across PHE programmes to try to reduce the inequalities experienced by this group, such as in screening programmes.
- PHE has committed to take specific actions as part of its **Equality Objectives**.
PHE’s learning disability equality objectives

• Routinely produce and evaluate information on aspects of health and care for people with learning disabilities in forms appropriate for health and social care professionals, family carers and people with learning disabilities. This will be provided in booklets, web pages, webinars, face to face events and videos

• Continue to collect and report place-based data and information relating to health and the wider determinants of health of people with a learning disability to support local planning

• Continue to work to improve the availability and reporting of data relating to the health and healthcare of people with a learning disability
What is the Health and Wellbeing Alliance?

The Voluntary Community and Social Enterprise (VCSE) Health and Wellbeing Alliance (HW Alliance) has been established to:

• Facilitate integrated working between the voluntary and statutory sectors
• Support a two way flow of information between communities, the VCSE sector and policy leads
• Amplify the voice of the VCSE sector and people with lived experience to inform national policy
• Facilitate co-produced solutions to promote equality and reduce health inequalities

The HW Alliance is jointly managed by the Department of Health (DH), Public Health England (PHE) and NHS England and is made up of 21 VCSE Members that represent communities who share protected characteristics or that experience health inequalities.

Funded for core and additional work
The Valuing People Alliance

'A partnership between:

The British institute of learning disabilities

Learning Disability England

The National Development Team for Inclusion

The Valuing People Alliance is the only member of the H&W Alliance that focuses only on people with learning disabilities.

NDTi is currently part of the learning disabilities team in PHE
How could the wider advisory function work?

Current advisory group can draw on wider membership of self-advocacy and family carer groups to source people with relevant experience/knowledge of issue requiring advice

Time/travel expenses can be funded from core work budget

Need to know what issues PHE requires advice on – to increase accessibility to programmes and reduce inequalities

We need enough notice to find appropriate individuals

Ways of providing advice could include attending meetings/workshops, taking part in teleconferences and webinars (families – not so good for people with learning disabilities), commenting on documents

http://phenet.phe.gov.uk/Services/public-involvement/Pages/Learning-disability-involvement.aspx
Case study

• The VPA were approached by the maternity programme manager.

• They wanted to ensure that the Improving Prevention and Population Health workstream of the national maternity transformation programme incorporated the views of women and their partners with learning disabilities during the perinatal period.

• The VPA worked with the programme manager to develop some accessible questions and sent these out through the advisory group. The request was met by a group of mums with learning disabilities, ‘the Geordie Mums’, who provided responses to Anna’s questions.

• This was turned around quickly and the work programme was able to incorporate the responses into their outputs.
PHE’s public involvement team

✓ Advise on where public involvement adds value and how to plan for it
✓ Manage PHE’s People’s Panel
✓ Set up and run focus groups
✓ Recruit lay people to committees or working groups
✓ Provide advice on engaging with specific groups such as young people through the NHS Youth Forum
✓ Support scientists wanting to take part in outreach work such as British Science Week
People’s Panel activity

- 15 members sit on 8 committees and working groups
- Consultations
- Completing surveys

25 in 2017/18 so far, including:
  - Antenatal screening
  - Smokefree NHS
  - Operation Cygnus
  - School entry vision screening
  - Nuclear incidents
  - Reproductive health
  - Cancer registration
  - UTIs

We are setting up a Focus Group Facilitation Network
Children and young people
Questions
Thank you!

Archived website: https://tinyurl.com/ihalarchive

Community of interest Knowledge Hub group – email LDT@phe.gov.uk for an invitation to join

LDT@phe.gov.uk

@ihal_talk

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