



PHE Board meeting

Title of meeting	PHE Board meeting
Date	Wednesday 20 July 2016
Presenters	Iain Mallett, Head of Public Involvement Jonathan Tritter, Chair of PHE's Public Involvement Advisory Group
Title of paper	Public Involvement briefing paper

1. PURPOSE OF THE PAPER

- 1.1 To provide the Board with an update on the activities of the Public Involvement Programme and the People's Panel with specific reference to exploring ways of engaging with young people.

2. RECOMMENDATIONS

- 2.1 The Board is asked to:
 - a) **NOTE** the range of public involvement activities and the support the People's Panel has provided to PHE in the last year.
 - b) **AGREE** the direction and further development of a model for engaging and involving young people in the work of PHE.

3. BACKGROUND

- 3.1 Last June (2015) the Board received its first update on PHE's public involvement activities which included an explanation of the role and recruitment of the People's Panel (details of the model can be found in Appendix 1).
- 3.2 At the November meeting the Board received the results of the second annual public opinion survey also in attendance were young people as part of Takeover Day. At that meeting the Board then asked the public involvement team to explore ways of engaging with young people with a view to develop a model possibly along the lines of the People's Panel by the end of the next year (2016).

4. PUBLIC INVOLVEMENT ACTIVITIES UNDERTAKEN BY THE PEOPLE'S PANEL

- 4.1 The People's Panel have continued to make a significant contribution to the work of PHE in the development of its plans, priorities and communications activities. The membership continues to grow with each public opinion survey which invites respondents to work with PHE and as a result 1,645 people are now part of the panel.
- 4.2 Since 2015, 193 members of the panel have taken part in PHE's public involvement activities. There have been 15 discussion groups and a consultation workshop as part of

the Tailored Review is due to take place at the end of this month (29 July). A seminar hosted by PHE's Equality Forum which looked at the theme of young people and personal resilience included the active participation of members of the People's Panel which was held at a school in the West Midlands. The next seminar is planned for September to explore the role of religion and faith in health and wellbeing.

4.3 In the spring of this year (2016) a series of workshops were run in London, Birmingham and Manchester to encourage more panel members to sign up to the highest level participation (level 3) thereby making themselves available to join PHE working groups and committees. In response to our workshop invitations 36 members of the panel attended the workshops and 17 have subsequently joined working groups and committees following an induction and training event in May. Adding to the previous year's recruits we now have a pool of 22 volunteers at level 3.

4.4 **Public involvement activities by level for the last 12 months**

Level 1 activities have included surveys and questionnaires on the following subjects:

- a) Guidance on ownership and use of materials for microbiology services clinical governance
- b) Scientist training programme, applied epidemiology new curriculum review
- c) Tailored Review

4.5 Level 2 activities have included focus groups and workshops on the following subjects (focus groups are usually composed of a general cross-section of diversity unless a specific group is required):

- a) **Flu vaccination programme** – vaccine uptake
- b) **Overheating in homes** – public information provision
- c) **Palliative care and end of life** – data collection (two sets of focus groups)
- d) **New-born blood spot screening programme** – positive result information (two sets of focus group)
- e) **Major incident health registers** – collection of public and patient information
- f) **Prostate cancer screening** – response to screening invitations
- g) **Science Hub** - public information
- h) **Urinary Tract Infections (UTIs)** - factsheets and advice (two sets of focus group)

4.6 Further focus groups are planned this year in the following subject areas:

- a) **Cancer screening** – to explore the possible cause of poor up-take in BaME communities
- b) **National Travel Health Network and Centre (NaTHNaC) website** – to review of the updated and redesigned travel health advice website
- c) **E-bug** - to collect feedback on the health education resource for 4-18 year olds about microbes, antibiotic resistance, and infection control
- d) **Pandemic flu communications** - a post exercise focus group to evaluate the public information produced by the players.
- e) **Urinary Tract Infections (UTIs)** – patient information and advice

4.7 Level 3 activities undertaken include People's Panel membership of the following groups:

- a) National Institute for Health Research (NIHR) Health Protection Research Unit (HRPU) in Gastrointestinal Infections External Advisory Panel (EAP)
- b) NIHR HPRU in Immunisation Advisory Board

- c) Revalidation Steering Group for public health doctors and other medical practitioners
- d) Steering Committee for UK Standards for Microbiology Investigations (SMIs)
- e) Understanding the role of human behaviour in modelling the spread of infectious diseases
- f) Identifying and examining determinants of vaccine uptake from healthcare and public perspectives
- g) PHE Research, Translation and Innovation Strategy Implementation Group (PHE RTI SIG)
- h) Virology Working Group
- i) Bacteriology Working Group
- j) National User Manual Template Working Group
- k) Investigation into the effects of radiation on the development of heart disease

4.8 Examples of the People's Panel shaping communications:

- a) **Encouraging risk reduction during pandemics** – by participating in working groups and focus groups the panel helped to explain why factual information and campaigns to raise awareness of the risks from pandemics alone are not enough to make the public take up offers of vaccination and think about infection control. Based on the panel's insights we can develop communications materials based on the knowledge that the public are more likely to follow health protection advice if the risks to their immediate family and community are highlighted and not just themselves as individuals.
- b) **Infographic development** – through feedback from successive focus groups which explored the graphical representation of facts, figures and advice PHE has an emerging visual language which has currency with the public.
- c) **Improving the quality of information to mothers** – by reviewing a range of information materials for mothers the panel has helped produce a yield of revised leaflets and booklets for expectant mothers and after the birth of their child.
- d) **Giving young people a say in PHE** – building on the work of the children and young people's seminar and Takeover Day by the end of the year PHE will have a draft model of engagement to provide a conduit for young people to get involved in the work of PHE.

Feedback from the People's Panel

- 4.9 One way we measure the value of the People's Panel's involvement in the work of PHE is to ask its members for their feedback on the effectiveness of their participation in working groups, committees and focus groups. Overall responses from participants continue to be positive and nevertheless they have made some suggestions for improvements. Some examples of their comments are as follows:

'A complex subject, with no definitive conclusions, was well discussed and received with much contribution from attendees.'

'A very good session, pleased to have attended. I have learnt a lot.'

'Today's focus group covered a lot of very sensitive issues relating to human beings most vulnerable stage of life [end of life]. It was handled extremely sensitively and professionally.'

'Started well and continued in a lively and progressive manner but got bogged down in superfluous detail and air of exasperation.'

'My involvement was well accepted and enabled them to look at the wider picture of what they were doing and why.'

'The Chair and the rest of the committee were very positive about having me there and allowing me to contribute. They were also very willing to take my ideas on board.'

'The research being discussed was well beyond my understanding, but it was interesting to talk to the students about their work and how they were getting on.'

5. EXPLORING A MODEL OF ENGAGEMENT WITH YOUNG PEOPLE

5.1 In response to the Board's challenge to involve young people in the work of PHE, the public involvement team and the children and young people's leads from the Health and Wellbeing and the Nursing Directorates worked with the charity Brook, who organised Takeover Day, to develop a model of engagement.

5.2 While there are a number of models for engaging with young people the decision was made to involve young people from the beginning before initiating a PHE model. As a result a workshop was organised with the support of Brook to ask young people what method of engagement they thought would be most effective and likely to achieve their support and commitment and what key public health issues were important.

5.3 The workshop had the following aims:

- a) work with young people to explore ideas for their engagement which could be shared with the Board
- b) help the participants to understand what PHE does and what input it might want from young people
- c) identify what might motivate and inspire young people to continue their engagement with PHE
- d) highlight barriers and opportunities for young people to get involved in the work of PHE

5.4 The workshop took place on Saturday 9 July at Coinstreet Community Centre, London with 26 young people who ranged in age from 14 to 24 years. They came from across England (regions represented included London, the North, the South East, the East of England, the West Midlands and the South West) and from a diverse range of socio/economic groups and communities including BaME and LGBT. The young people were recruited by Brook, Addaction, Street Games, CLIC Sargent and Interchange CIC and from PHE's Equality Forum.

6. FEEDBACK FROM THE YOUNG PEOPLE

6.1 Individually the young people who took part in the workshop made the following comments:

'Young people should play a focal role in creating change. Adults might make it happen but young people are the spark which sets off the change.'

What PHE can do for young people

'[PHE] should help us to share our views and experiences so that someone important hears us to make sure that change happens and becomes an actual reality.'

'Make sure there is fairness [equity] in services so young people get the same as adults for example in mental health services.'

'We [young people] are not one group we need more than one strategy to tackle issues that face us...Don't lump us together we are as diverse as you, maybe more.'

Towards a model of engagement

'They [young people's mediators] could help take control in People's Panel meetings so we aren't overwhelmed. They could help collect the young people's ideas and express them to the adult members.'

'If you want us to influence the top people you need to train us to challenge them as we don't have the experience.'

'It can be hard to make the commitment [to join a national panel] so sometimes let us meet locally and feed up to the Board. Not everyone wants to travel.'

'Advertise and promote it [the Young People's Panel] but it must be a campaign designed by young people...maybe with wrist bands. Have PHE open days at schools so you can get the parents and schools on board especially if it's educational'

'Don't make your Young People's Board boring with men in suits and long reports...keep it simple, no jargon, dress like us.'

'Make your meetings accessible at times and places that work for young people'

'Tell us what you have done, how we made a difference. 'You said, we did' or something to motive us to get involved and stay involved.'

'Digital is good, like a website that young people can use to share issues and problems and get advice without having to say who they are. But run by young people who won't talk down to us.'

Next steps

'Run some more workshops like this to tell us what you will do next and what you want to learn from us.'

'Make us (the young people who volunteer) into ambassadors, may be run internships or apprenticeships.'

7. TOPLINE FINDINGS FROM THE YOUNG PEOPLE'S WORKSHOP

7.1 Overall it was the view of the workshop participants that the approach to engaging with adults through the People's Panel is inappropriate for young people. It was clear that

young people have the capacity to understand public health issues and have an interest and a desire to engage with PHE to make a difference.

- 7.2 **Remember the local and regional** - it can be hard for young people to find the time to travel to London, therefore whatever model we develop should include an opportunity for young people to engage locally and feed up nationally.
- 7.3 **Education is a good route for engagement** - but it is acknowledged that with increasing school autonomy we can no longer expect all schools to come on board simply by engaging with the local authorities. Also we must not forget many young people are not in mainstream education and those that fall into this group often come from marginalised communities.
- 7.4 **Digital is key** - there was an interest in e-communications as a way of engaging with young people especially via social media but with caveats as some young people do not use social media for a range of reasons such as online bullying and the platforms change regularly. And therefore if a digital platform is developed it needs to be led and run by young people.
- 7.5 **Meeting in person is vital** – it was important to meet face to face especially for discussions about the further development of the young people's panel. They were not particularly concerned about venues as long as they were accessible and safe.
- 7.6 **Incentives for taking part** - the biggest incentive was being listened to and made to feel valued although they felt participants should receive recognition specifying transferrable skills which could go on a CV or educational portfolio including certificates and if the commitment was significant there should be opportunities to join a PHE involvement apprenticeship.
- 7.7 **Resources** - to make engagement work PHE needs to provide money to pay for public involvement activities with young people such as venues, staff to ensure child protection, incentive payments and the possible development and maintenance of a social media platform.
- 7.8 **Mental health is key** - while the young people understood that they could make a contribution to a wide range of public health issues they would expect to be involved in mental health matters as a priority because it is the single most important area of public health for them.
- 7.9 **Young People are diverse** - in the same way that adults fall into many groups young people are not a homogenous group either and that any approach to engagement with them should recognise their differences whether by socioeconomic status, region/locality, LGBT, BaME, disability, religious, homelessness etc.
- 7.10 **Work collaboratively** - wherever possible public engagement should be developed working together with young people from the start.
- 7.11 **Highlight success** - PHE should raise awareness and promote successful engagement with young people perhaps running an awards scheme with prizes for the best and most innovative examples from around the country.

8. RECOMMENDATIONS

- 8.1 The Board is asked to support the continued development of a PHE model for engagement with young people based on the following actions with an update at its November meeting.
- 8.1.1 Run a workshop in October to explore a draft model for a Young People’s Panel and scope out the specification for a digital platform run by young people.
- 8.1.2 Investigate multiple routes for recruiting members of PHE’s Young People’s Panel with a range of partners.
- 8.1.3 Develop a provisional model for a PHE Young People’s Panel including recruitment, development, involvement activities and measurement of impact.
- 8.1.4 Provide proposals to pilot the draft model in one or two local authority areas in England.
- 8.1.5 Finalise a PHE Young People’s Panel for systematically and sustainably engaging with young people in England.
- 8.2 **Provisional Plan for Development and Piloting of PHE Young People’s Panel**

Objective	Timing	Activity	Deliverables
8.1.1	Oct 2016	Workshop with Young People	<ul style="list-style-type: none"> Explore draft model of Young People’s Panel Agree an approach to a digital platform as part of the Young People’s Panel
8.1.2	Oct 2016	Engagement with organisations that engage with young people	<ul style="list-style-type: none"> Agree an approach to recruiting young people to join a PHE Young People’s Panel
8.1.3	Nov 2016	Board Report	<ul style="list-style-type: none"> A provisional model of a PHE Young People’s Panel Plan for implementation pilot including evaluation including resource implications
8.1.4	Jan 2017	Work with two local authorities and PHE Centre/s to agree a pilots site/s	<ul style="list-style-type: none"> Identify resource implications of one year pilot
8.1.5	March 2017 – March 2018	Implementation of a pilot of PHE’s Young People’s Panel	<ul style="list-style-type: none"> Report and evaluation of pilot/s and recommendations for a revised model of a PHE Young People’s Panel including resource implications

Iain Mallett and Jonathan Tritter
July 2016

APPENDIX 1: PHE'S PUBLIC INVOLVEMENT MODEL

When the National Executive agreed the Public Involvement Strategy it made a commitment to embed public involvement in the 'way we do things'. This included the expectation that everyone in PHE would have a responsibility to ensure the public's voice is heard and valued. PHE aims to involve and engage with people in a way that empowers and reflects the value it places on the time they give by contributing their knowledge, skills and experience.

The benefits of public involvement

Public involvement when it is effective can help PHE to understand what people think specifically what they would like it to do, the programmes and services it should provide and the way they should be provided. Specifically the public can help PHE to:

- a) Provide better public health advice and services because they will be evaluated by the people who benefit from them.
- b) Strengthen research applications by demonstrating public involvement is part of the research process to funding bodies.
- c) Provide a stronger focus on equality and inequalities by helping PHE to meet the regulatory requirements for public involvement under the duties of the Equality Act.
- d) Achieve PHE's priorities and ambitions by embedding people and communities in the narrative on prevention, early intervention and the wider social determinants of health.

The People's Panel

In 2013 PHE produced its first public involvement strategy which outlined its approach to public involvement and the cornerstone of the strategy was to begin a process to understand public attitudes to health protection and wellbeing as well as awareness of the agency and its work.

- a) In 2014 Ipsos MORI was commissioned to test public opinion via a national survey and the results informed the corporate communications strategy. A second public opinion took place in 2015 with the intention of it becoming an annual survey. A third survey is due to be conducted in September this year which will report to the findings to the Board in November.
- b) The strategy outlined the governance arrangements for the Public Involvement Advisory Group (chaired by Professor Jonathan Titter) and defined its role as a 'critical friend' for public engagement activities.

One of the survey questions asks respondents if they would be happy for PHE to contact them again to continue collecting their views on public health matters. As result of this recruitment process PHE has one of the largest health consumer panels of its kind with a membership of 1,645 people. This database of contacts has created a People's Panel which offers a unique and valuable insight into public health issues by revealing what the public feels is important and especially how they understand and respond to health information.

The members of the People's Panel are offered three levels of involvement:

- Level 1: They receive updates, newsletters, occasional surveys and invitations to events.
(all 1,645 members)
- Level 2: They receive everything from level 1 plus invitations to take part in one-off focus groups, workshops and consultation events (250)
- Level 3: They receive everything from level 2 plus the offer to join Public Health England working groups and committees (22)

Currently we hold the following information on panel members: their contact details (telephone numbers, home address and if they have one their email) gender and age. Approximately a third of the panel have completed equality monitoring forms detailing their ethnicity, disability, belief or no belief, sexual orientation and occupation.