

Public Advisory Board Meeting: summary

Date: Tuesday 16 February 2021

Item	Discussion and recommendations
<p>Chair: Angela Coulter</p>	
<p>1. Population Research UK (PRUK)</p> <ul style="list-style-type: none"> a. Public benefit of longitudinal and cohort studies b. Demonstrating trustworthiness of data linkage c. Ongoing public engagement with PRUK 	<p>James Pickett of HDRUK outlined the plans for this new data hub and described the many challenges involved in making data from longitudinal research studies more findable, discoverable and accessible, as well as linking them to a wider range of other types of data to address important research questions. PAB members discussed consent policies and safeguards, harmonisation of meta data, diversity among participants, the importance of clear terminology and transparency, and the need for ongoing public involvement. There was strong support for the goal of maximising use of these data that have often been collected at considerable cost and effort.</p>
<p>2. Developing PPIE training for researchers and contributors</p> <ul style="list-style-type: none"> a. Key learning objectives b. Delivering training c. Good examples to build on 	<p>Sinduja Manohar explained the objective, which is to ensure that HDRUK staff, public contributors and researchers are committed to embedding patient and public involvement throughout health data research and have the skills to achieve this. Discussion focused on training for researchers. PAB members stressed the importance of building confidence in PPIE methods and its value, being clear about what is expected of researchers and why, emphasising the fact that every data point represents a personal experience. Wherever possible research should be fully inclusive and PPIE must be meaningful, not just a box ticking requirement to obtain funding. Suggested learning objectives could include 1) understanding public attitudes to personal data, 2) clear communication, 3) sharing control with public contributors, 4) methods for involving people. Leadership from senior researchers, encouragement from funding bodies, PPIE in PhD programmes, encouragement of reflective practice, mentoring by public contributors, and ongoing monitoring were all felt to be necessary. Members shared various good practice examples both during and after the meeting.</p>