

Public Advisory Board Meeting: Summary	
Date: 20 April 2021	
Item	Discussion and recommendations
Chair: Angela Coulter	
<p>Ways of working and priorities for the coming year</p> <ul style="list-style-type: none"> • Maximising PAB's role and impact • Priorities for 2021/2 	<p>HDR UK staff are often asked for advice on PPIE in health data science by other organisations. Demonstrating the impact of PAB is one way to help showcase the importance of PPIE.</p> <p>The expansion of HDR UK has meant that PAB's role now feels somewhat less strategic than previously and less plugged in to organisational decision-making.</p> <p>There has been an increase in PPIE activities across the organisation and much positive change, but there is still work to be done to strengthen the commitment of those in senior positions.</p> <p>We should be more ambitious about influencing funders, data controllers and research leaders, some of whom do not give sufficient priority to public involvement.</p> <p>It is important to remember that HDR UK can advise and influence but is not usually in a position to require people to do things differently.</p> <p>ACTION: Agreed to organise an away day in May to discuss PAB's role and ways of working and agree priorities for the coming year. Members of ExCo to be invited.</p>
<p>Data access committee processes</p>	<p>Following the data access committee processes survey that was sent to HDR UK Alliance members earlier this year, Alice Dowden presented her report on the findings. Responses were very varied with evidence of some good practice, but many organisations are at a very early stage of involving patients and public in their committee procedures. There is an opportunity for PAB to make recommendations that build on the good examples and support those members who are just starting out with data access committees and registers, with the aim of encouraging consistency among Alliance members. Our recommendations should cover both who is involved and the criteria they adopt for approving requests.</p> <p>ACTION: PAB will draft a paper for the July Alliance Board meeting plus follow-up actions to be planned later.</p>