

Public Advisory Board Meeting Agenda

Date: Thursday 10 December 2020

Item	Discussion and recommendations
<p>1. Data access committees</p> <ul style="list-style-type: none"> a. Developing a 'best practice' standard for patient-public information and involvement in data access request decision-making b. What specific questions / criteria should be considered by data access committees to ensure that patient/public interests are addressed? 	<p>Discussed possible best practice standard and recommendations for data access committees, focusing in particular on patient/public information needs and involvement. Before making specific recommendations, PAB members require more information about how this is currently handled by data controllers. Agreed to survey data controllers to learn more about their current procedures vis a vis public information and involvement, prior to developing a set of recommendations. This should also help to inform the design of the data access request form on the Gateway.</p>
<p>2. Data and Connectivity</p> <ul style="list-style-type: none"> a. Overview of Covid-19 National Core Studies and the Data and Connectivity programme that supports the other five studies and is led by HDR UK b. Developing ongoing PPIE in the Data and Connectivity programme 	<p>Sophie Morris described the COVID-19 National Core Studies programme. Margaret Rogers is a member of the Data and Connectivity advisory group and Judy Slape leads on PPIE for the whole programme. PAB members asked for wording on 'legal barriers to data sharing' in Sophie's presentation to be changed. Members were concerned that PPIE is not seen as an essential requirement by all research funders and has not been included in the list of evaluation criteria for the National Core Studies up to now. PAB members called for this to be included in the next round.</p>