**Data governance guidance for Patient and Public Involvement and Engagement (PPIE) Groups**

Introduction

Data governance is important in any organisation. It refers to the internal standards (data policies) that apply to how data is gathered, stored, processed or disposed of. It governs who can access what kinds of data and what kinds of data are under governance.

Each organisation will have its own data governance policies and guidance. These policies protect the organisation and its data. Everyone in an organisation has the responsibility to treat personal data in accordance with Data Protection Law. Each organisation usually has a clear Data Privacy notice on their website that you can refer to.

In PPIE, we have a need to gather, store and process patient and public data, some of which can be sensitive (including protected characteristics), so it is important we deal with that data correctly.

This document provides guidance on this things to consider when managing PPIE data.

PPIE Group information

When setting up, or growing a PPIE group, you will need to collect some initial information about the group members. A standardised data collection form has been created by the University of Birmingham and has been informed by the National Institute for Health and Care Research (NIHR) which we would encourage you to use. This ensures that data is collected consistently across organisations to enable standardised reporting, particularly to support diversity reporting. It also includes a suggested data privacy notice which is necessary when collecting any personal data as it will explain what the data will be used for and where it will be stored.

What are your responsibilities?

1. When setting up a new PPIE group, you should complete a **Data Protection Impact Assessment (DPIA)**. This is a risk assessment process that you can do yourself by answering a number of questions on a [DPIA template](https://gdpr.eu/wp-content/uploads/2019/03/dpia-template-v1.pdf) *(please note that each organisation may use a different template, this is just an example).* The questions help you to consider your data collection, processing and storage and what to do with the data when the project ends. Support should be available from your organisation’s legal or data governance team.
2. Once you have collected your group information, this will form a database. You may need to record your database on a **Data Asset Register**. This is a record of all databases so should there ever be a data breach, it is easy for the legal team to understand where that database lives and who owns it. This will enable the breach to be dealt with as quickly as possible to limit further damage. Please contact your local data governance or legal team to check what is required.
3. You will need to ensure that your PPIE group database (such as an Excel document) is stored securely and is only accessible to those who absolutely need it. You will need to seek advice from your local data governance or IT team on the most appropriate place to store your data. It is very important that you follow their advice and keep the data secure with the correct access rights in place and that this information isn’t shared with anyone.