# UCL DPO AND JOINT UCL AND UCLH RESEARCH OFFICE GUIDANCE
# TRANSPARENCY AND PRIVACY NOTICES FOR CLINICAL RESEARCH –COMPLIANCE WITH DATA

**WHAT DOES TRANSPARENCY MEAN?**

Transparency is an overarching principle of GDPR. Transparency means:

- Being clear, honest and open about who we are, how and why we are using research participants' personal data throughout the information lifecycle
- Setting out what personal data you hold on people

**TRANSPARENCY REQUIREMENTS**

Staff must ensure that they tell individuals about how they are using their personal data in a way that is accessible and easy to understand. Notices and information sheets must use clear and plain English.

For personal data that has been collected directly from the research subjects, the Controller is obliged to provide all the information listed in Appendix 1.

Where the personal data is obtained from a third party and there is no direct relationship with the individual, i.e. when collected for secondary analysis, then the Controller must still consider transparency. In such cases it can be even more important to be transparent as people may not know that their personal data is being used.

**Are there any exemptions from the requirement for transparency?**

If the data is obtained from a third party, for example for secondary analysis, then you do not need to provide the data subjects with privacy information in following circumstances

Where an individual already has the information
Where providing the information would be impossible
Where providing the information would require disproportionate effort
Where providing the information would seriously impair the achievement of the research objectives

Where information is collected directly from research participants, the transparency requTJ0 Tw 40.73 0 ?0 Tw 403 6.9 (c)1.2

**Table 1**

| Status of study | High compliance* | Adequate compliance* |
|---|---|---|
| Still recruiting | Full HRA statement or equivalent in a leaflet handed or posted to participants or study specific information on website | Full HRA statement or equivalent in a leaflet handed to participants or on in study specific information on website |
| All protocol required activities concluded for all patients and study sites closed out | Study specific transparency information on website | Study specific transparency information on website |
| End of study notified to HRA | Study specific transparency information on website | generalised information on website |
| Historic datasets | Specific dataset information on website with details of terms of access | generalised information on website |

**APPENDIX 1 Requirements from EU Working Party 29 Guidance**

| **Requirements** | **"Direct" data collection i.e. Face to Face** | **Personal Data NOT obtained directly from the Data Subject** | **COMMENTS** |
|---|---|---|---|
| The identity and contact details of the controller and, where applicable, their representatives | Required | Required | For individual studies, the Data Controller will usually be the sponsor. For the required general statement from the Data Controller, see http://www.ucl.ac.uk/jro/who-are-we/data-protection |
| Contact details for the data protection officer, where applicable | Required | Required | UCL's Data Protection Officer can be contacted on data-protection@ucl.ac.uk. Please do not put the DPO name in here. |
| The purposes and legal basis for the processing | Required | Required | This is also in the general statement |

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