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Data Linkage Framework for Statistics & Research Consultation

The Information Commissioner's Office (ICO) is pleased to take this opportunity to respond to the above consultation in respect of its role as regulator for, inter alia, the Data Protection Act 1998.

Having representation on the Data Linkage Steering Group and the Operations Group, the ICO welcomes the proposed establishment of a formal framework for data linkage for statistics and research in Scotland. Data linkage research is not new. However, the added value of a more formal and structured data linkage strategy is only just being realised, building on the success of projects such as the ScotXed programme for education and the health, social care and housing projects. The ICO welcomes the comprehensive discourse provided in the consultation document in respect of the proposal, and particularly welcomes the articulation of the many benefits to be had from a more formal framework being established.

However, although issues of privacy and control are discussed throughout the document the proposed framework provides a level of confidence in respect of privacy assurance and control mechanisms not articulated as a specific, stand-alone benefit. Establishing a formal framework, which the proposed National Data Linkage Centre will use to co-ordinate linkage projects, will have the potential to offer greater privacy assurance and control compared to the current disparate setup. Indeed, the ICO believes that the general privacy architecture underpinning the Framework is very well thought out in terms of safeguards and strikes the balance well between availability of information and privacy protection. Of particular note is the 'trusted third party' type role that ISD will play.

The challenges or barriers which may exist at the moment to more data linkage research are well documented in the consultation. It is hoped that the public and stakeholder engagement afforded by the consultation process will assist in addressing these matters, providing assurances where necessary. As might be expected, the ICO's preference is that anonymised data be used where possible, rather than personally identifiable data, even where this is consented. Perhaps assurances in respect of the imperative towards anonymisation post linkage could be made more forcefully, as well as adherence to the forthcoming ICO Anonymisation Code of Practice. In addition, the incorporation of periodic privacy reviews through, for example pen-testing type approaches, to assess re-identification risk, would all go some way in bolstering public and researcher confidence in the process.

The Guiding Principles are very welcome by the ICO in providing baseline standards for processing specific to data linkage research, and reference to various external Codes of Practice, including the ICO's Data Sharing Code of Practice and the Scottish Government's Identity Management and Privacy Principles, is refreshing. However, as with all high level Principles, such as the eight Data Protection Principles, the issue is how they are actually implemented at the front line of processing. In this regard, the roles of the Privacy Advisory Committee and the National Data Linkage Centre will be invaluable, especially in the early days of the Framework.

The ICO particularly welcomes the proposed establishment of a Privacy Advisory Service (PAS) and believes that this will be of fundamental importance in realising the benefits of privacy assurance and control mechanisms for the research community. As the consultation document highlights, data custodians are often paralysed by their insecurities concerning the balancing of privacy and purposeful research which can result in less robust and significant outcomes. Being able to avail themselves of the PAS should allow a more confident approach which should lead to better and more meaningful outcomes.

The value of the proposed National Data Linkage Centre (the Centre) is self-evident: the important networking information and opportunities researchers will gain by discovering other projects/researchers in similar or complementary areas, will be invaluable. The Centre has the potential to be the linchpin in facilitating good practice and introducing an element of control regarding research activity and the ICO believes that its development is fundamental to the safe and secure fulfilment of the open data agenda. As such, the ICO would welcome opportunity to provide input into the development of both the Privacy



Advisory Service and the National Data Linkage Centre as each are carried forward.

With best wishes,

Dr Ken Macdonald
Assistant Commissioner Scotland & Northern Ireland

Enc: Respondent Information Form