



DRAFT PUBLIC CONSULTATION QUESTIONS FOR REVIEW OF NATIONAL STATEMENT SECTION 4

Thank you for the opportunity to comment on the Draft Public Consultation for Review of the National Statement on Ethical Conduct in Human Research. The Public Service Research Group at UNSW Canberra has a strong track record of research into public services in Australia and overseas, covering various aspects of public sector management, delivery of public services and user experiences. Our researchers focus on a range of population groups and public service programs across different service and sector contexts, including the Australian Public Service, the National Disability Insurance Scheme, Aboriginal health services, and women's services.

Many of the proposed changes contained in the draft document are minor, we therefore confine our comments to issues of terminology and associated ethics processes raised in Section 4.

We agree with the principle that vulnerability exists on a continuum and is context-specific. Vulnerability is, as the document points out, not a binary state nor a fixed characteristic of individuals or groups but is a matter of degree. A group of individuals, for example young people or people with disabilities, is not *necessarily* more vulnerable to harms than others and should not therefore be excluded from research on the basis of these characteristics alone. Such a focus encourages labelling as pointed out in the document.

Following from recent published research (Have 2015; Walker 2018) however, we prefer the terminology of marginalisation over vulnerability. Vulnerability tends to focus on the characteristics of individuals at the expense of sufficient attention to the social connections that shape human life, and experiences of exclusion and discrimination. Marginalisation, as a term, better highlights the social and systemic factors

with its two axes of risk – increasing likelihood and increasing severity of harm –in Chapter 4.1 particularly useful. The matrix does not provide much guidance to researchers on how to use the framework to determine levels of risk nor determine strategies required to ameliorate

