

Submission: “Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper”, Department of Health, Canberra

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Recommendations:

Consistent with the long-term eHealth objectives of the PCEHR it is recommended that consideration be given during this review of “participation arrangements for individuals” and the opt-out trials for:

1. assessment of proposed legislation for a future opt-out system to ensure it does not preclude and in-fact facilitates the ability of participants to approve their willingness to be contacted for observational health research and randomised clinical trials (subject to the usual institutional ethics reviews)
2. a future opt-out system to allow for addition of appropriate fields to the PCEHR to allow participants to nominate their willingness to be contacted by healthcare organisations regarding participation in observational health research and randomised clinical trials (subject to the usual institutional ethics reviews)
3. assessment of proposed legislation for a future opt-out system to allow for a contact interface or mechanism allowing healthcare organisations to directly contact such participants who have volunteered to be considered for inclusion in health research or clinical trials (via the participant’s preference for phone, sms, email or letter contact)
4. assessment of proposed legislation for a future opt-out system to allow for access to aggregated PCEHR data facilitating chronic disease planning and research for nominated diseases by healthcare providers and medical research organisations for specified chronic diseases (e.g. diabetes, cardiovascular disease, arthritis, asthma, mental health, renal disease, dementia)
5. assessment of proposed legislation for a future opt-out system to provide a data transfer interface between PCEHR and PC & mobile device applications developed for patients and health practitioners to support chronic disease care plans and disease management.

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