Bills Committee on Electronic Health Record Sharing System Bill

List of follow-up actions arising from the discussion at the meeting on 31 March 2015

The Administration was requested to -

- (a) in respect of clauses 10 and 22, which provided for the suspension of a healthcare recipient ("HCR") and a healthcare provider ("HCP") by the Commissioner for the Electronic Health Record ("the Commissioner") under the circumstances specified, consider specifying in the Bill a time limit on how long the suspension could last;
- (b) advise the relevant ordinances under which the use of data and information contained in an electronic health record ("eHR") kept in the Electronic Health Record Sharing System ("eHRSS") would be permitted as provided for in clause 29;
- (c) in respect of clauses 30, 31 and 32 concerning the procedures for applying for use of identifiable data of an HCR contained in an eHR for carrying out research, or preparing statistics, that were relevant to public health or public safety,
 - (i) advise whether a separate set of guidelines setting out the detailed criteria for the Electronic Health Record Research Board in consideration of an application for using such identifiable data for research or statistics purpose under clause 31 would be formulated and if so, provide a copy of the draft guidelines for consideration by the Bills Committee when available;
 - (ii) advise whether views of patient groups for rare diseases on the use of identifiable data of HCRs contained in eHRSS for research and statistics purposes had been gauged;
 - (iii) provide for members' reference information on the number and examples of health and medical research in tertiary institutions and public healthcare sector which involved data collection on the health records of identifiable data subjects;
 - (iv) provide for members' reference copies of the guidelines of the Hospital Authority ("HA"), the Research Grants Council under the University Grants Committee and the tertiary institutions relating to

the use of identifiable data of data subjects for health and medical research purpose, in particular information on whether the data subjects concerned had to give separate consent to the use of their data for the research being carried out; and

- (v) advise whether there had been any complaints lodged against the data users, such as HA, for providing identifiable data of the data subjects for health and medical research purpose without obtaining separate consent from the data subjects concerned;
- (d) provide a response to address the concern raised by Professor John Bacon-Shone in his submission dated 18 March 2015 (Appendix VII to LC Paper No. CB(2)1145/14-15(03)) about the re-identification risk of the non-identifiable data of a HCR contained in an eHR being used for research or statistics purpose; and
- (e) advise the respective circumstances under which the Commissioner and the HCP would be exposed to legal liability in the use of data or information contained in eHRSS, particularly where the activity or service was performed outside Hong Kong by the HCP for the HCR.

Council Business Division 2
<u>Legislative Council Secretariat</u>
10 April 2015