

Module 4-P2: Creating a framework for trustworthy data governance

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1 Introduction

Data has been described as the oxygen that fuels the development of health technology and in turn, the development of new health technologies is facilitating increasingly comprehensive collection, collation and use of personal data.

At the same time, it is almost universally recognised that health data is a particularly sensitive type of personal data (i.e. there are more serious repercussions of health data being leaked than normal types of personal data)

The collection and use of vast amounts of personal health data raises specific ethical and regulatory challenges concerning privacy, data protection and potential for discriminatory practices. As we become increasingly reliant on health technologies (both within the clinical environment and in the personal use of mobile digital health technology) the appropriate curation of health data must be addressed and an appropriate framework of trustworthy data governance developed..

2 Aim

To create a framework for trustworthy data governance, while considering both soft and hard law, and to review guidelines and best-practice approaches to data governance in public health and clinical research.

3 Key PDPA obligations

Accountability		
Collecting personal data:	Care of personal data:	Individual's rights over personal data:
 <p>Notification: Notify individuals of the purposes for collecting and disclosing their personal data</p>	 <p>Accuracy: Ensure that collected personal data is accurate and complete</p>	 <p>Access and Correction: Individuals may request access to their personal data and how it was used or disclosed in the past year, and to correct any error or omission</p>
 <p>Consent: Receive consent from individuals before collecting, using or disclosing their personal data</p>	 <p>Protection: Take reasonable security measures to safeguard personal data</p>	 <p>Data Breach: In the event of a data breach that is significant in harm or scale, notify the PDPC and affected individuals</p>
 <p>Purpose Limitation: Collect, use or disclose personal data only for purposes that are reasonable and appropriate under the given circumstances</p>	 <p>Retention Limitation: Dispose of personal data when it is no longer needed and there is no legal or business purpose for retaining it.</p>	 <p>Data Portability: Individuals may request their personal data to be transferred to another organisation in a commonly used machine-readable format.</p>
	 <p>Transfer Limitation: Transferring personal data overseas is allowed only if the standard of protection of the personal data by the receiver is comparable to the protection under the PDPA.</p>	

Figure 1: Adapted from PDPA Infographic of Data Protection Obligations under the PDPA, accessed at <https://www.pdpc.gov.sg/-/media/Files/PDPC/PDF-Files/Resource-for-Organisation/Data-Protection-Obligations-under-the-PDPA.ashx?la=en>

4 Meeting our obligations

1. SECure system

SECure is the IT platform that FHT uses which has built-in security measures so that researchers may work with data securely

2. Internal policy (Implemented or planning to implement)

A) SEC-wide policies

- Data Protection Policy
- Information Security Policy
- Information Classification Policy
- SEC IT Policy

B) FHT policies

- Data breach incident management plan
- Data access and correction request procedure
- Endpoint security guidelines
- Acceptable Use Policy for SECure
- Data management plans

3. Staff training

SEC PDPA Awareness Session with Deloitte

4. Appointing a Data Protection Officer

Under the PDPA, organisations are required to designate a data protection officer (DPO) to oversee data protection responsibilities and ensure compliance with the PDPA.

5. Data Protection Impact Assessment

Identifying, assessing and addressing personal data protection risks based on the organisation's functions, needs and processes.

