BMEG3103 Big Data in HealthCare 24 October 2024

Privacy and Data Security in Digital Healthcare

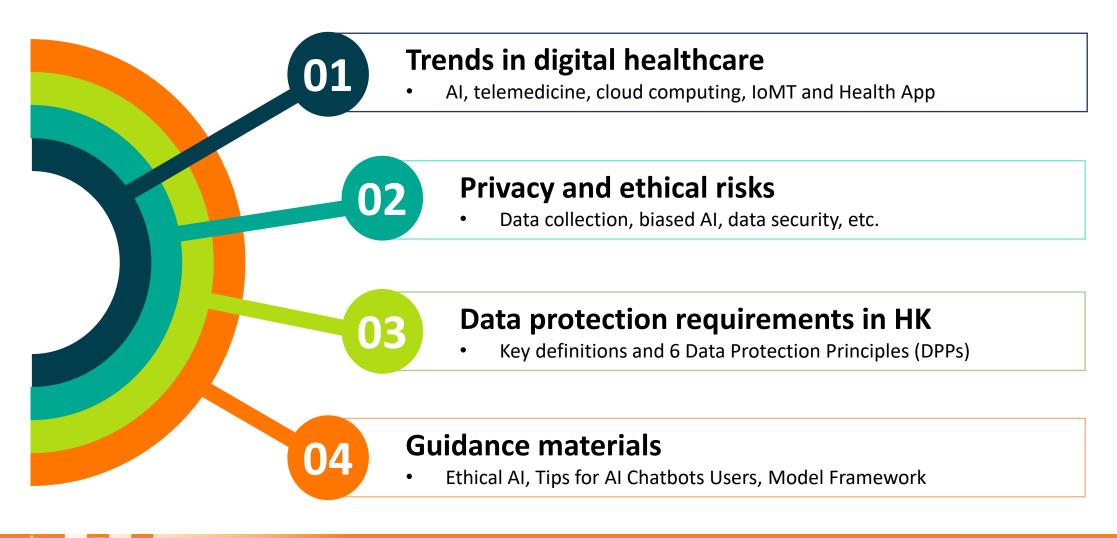
Environment

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Joyce Liu Ag. Senior Legal Counsel & Head of Global Affairs & Research Office of the Privacy Commissioner for Personal Data



Outline



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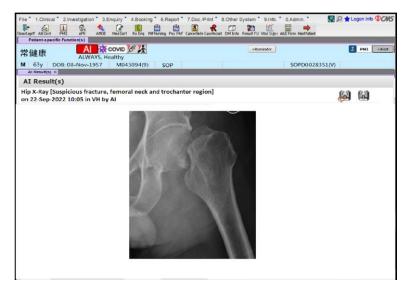
Healthcare and Al

Artificial Intelligence (AI)

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- A family of technologies that mimic human intelligence and involve the use of computer programmes and machines to perform or automate tasks
- Benefits of applying AI in medicine (Venture Beat, 2022):
 - Enable accurate and early diagnosis
 - AI algorithms can <u>extract valuable insights</u> from vast amount of data readings
 - AI technology can <u>identify small details</u> with more precision than humans
 - Can handle repetitive tasks automatically and tirelessly



(Source: HKEJ, 2022)

In HK, the Hospital Authority (HA) cooperated with local universities to develop an AI tool for hip fracture detection. 1 million x-ray films from HA's database were used to train the AI model.

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Application of Al



(Source: Microsoft, 2023)

Microsoft introduced an automated clinical documentation application which generates notes based on the conversations during patient visits using GPT-4.



(Source: HKU, 2023)

HKU developed a diagnostic application, "AI virtual patient" for training medical students, allowing them to virtually simulate interactions with patients during bedside consultations.



(Source: CUHK, 2024)

CU Medicine pioneers the introduction of a novel AI system for detection of early gastric cancers during upper GI endoscopy to increase the detection rate of the disease and facilitate endoscopists' training

21 October 2024

The Chinese University of Hong Kong's (CUHK) Faculty of Medicine (CU Medicine) recently became the foothold of the world's first centre to test a novel Al-powered upper gastrointestinal endoscopy system for the detection of gastric cancers. Given the success of Al-assisted colonoscopy, the team believes that the new technology will enhance the accuracy of detecting early gastric cancers and train endoscopists.

CU Medicine has engaged in clinical research in endoscopic and laparoscopic devices since the 1980s and translated novel endoscopic devices and technologies from bench to bedside. It introduced Al-powered colonoscopy detection as early as 2021. Studies proved that the technology not only contributed to a 40% increase in the adenoma detection rate but also improved the training of less experienced physicians.



Mobile App Empowered by Al



(Source: CUHK, 2024)

CUHK developed a depression assessment mobile app which uses AI to analyse the user's multimodal data, including facial expressions, voice, language and subjective mood state, as well as rest-activity statistics, to assist in diagnosing depression.



(Source: HKU, 2024)

HKU developed an AI-powered software that can turn smartphones into stethoscopes. It uses AI to measure heart sounds from the chest and conduct an analysis of whether the user could suffer from heart disease.



Telemedicine

Telemedicine

- The practice of medicine over a distance, in which interventions, diagnoses, therapeutic decisions, and treatment recommendations are based on patient data, documents and other information transmitted through telecommunication systems (World Medical Association, 2018)
- Gained popularity worldwide since the COVID-19 pandemic. Benefits include:
 - Reducing physical contact
 - Alleviating crowdedness in hospitals and clinics
 - Easily accessible and cost-effective



The Hospital Authority (HA) has launched the TeleHealth pilot programme through "HA GO" mobile app.

(Source: HA)



The CUHK Medical Centre also provides telemedicine service. (Source: CUHKMC)

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Cloud computing

Cloud computing

- Cloud computing offers a centralised offsite storage system
- Benefits (Forbes Advisor, 2022):
 - Cost-efficient

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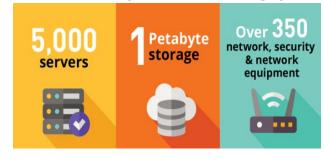
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- Reduce the need for maintaining costly IT infrastructure
- Enable flexible subscription
 - Unlike a physical machine, a cloud storage system can be scaled up and down flexibly
- Facilitate big data analytics
 - Due to the large sets of data available

Contact Tracing



H-Cloud Data Centres: Supporting Healthcare Operations in Singapore



During the COVID-19 pandemic, the US Centers for Disease Control and Prevention (CDC) processed millions of vaccination orders and manage contact tracing data with cloud services.

(Source: CDC, 2023)

The Singapore government has launched the "Healthcare-Cloud" to support the operation of 9 public hospitals. The H-Cloud is expected to help reduce 55% of operational costs by 2025.

(Source: Ihis, 2022)



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Internet of Medical Things

Internet of Medical Things (IoMT)

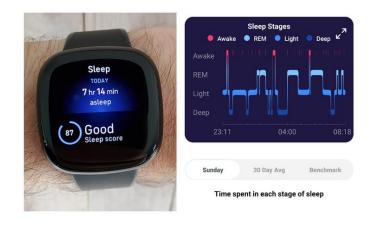
Connection of medical devices to networks and the sharing of data with healthcare applications via Wi-Fi, Bluetooth, and radio-frequency identification (RFID) (Deloitte, 2022)

Improve patients' health outcomes

- Track patients' compliance with physicians' orders
- Allow <u>healthcare staff</u> to <u>access real-time data</u> and <u>make</u> <u>informed decision</u> of treatment options (Digital Health, 2021)
- Improve the management of patients and assets in healthcare facilities
 - Allow healthcare staff to <u>locate patients and available</u> <u>medical equipment</u> in the healthcare premises (Mapsted, 2024)



A wearable that reminds patients to take medications.



A sleep tracker.

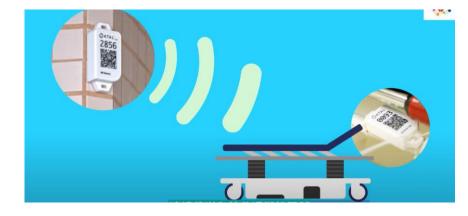


Internet of Medical Things



HA is introducing the use of RFID straps across all 18 Accident and Emergency departments in public hospitals to enhance patient safety. If a high-risk patient wearing the strap attempts to leave the A&E department, an alarm will be triggered to alert the staff.

(Source: HA, 2024)





Queen Elizabeth Hospital has been employing a real time location system to track the location of stretchers for easy management and allocation.

(Source: HA, 2023)

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Health and Wellness App

Health and Wellness App

- Different healthcare services are available in these apps, e.g. (KBI, 2021; Jellyvision, 2022):
 - ➢ Health screening and monitoring
 - Stress management
 - Provision of personalised health advice
- Number of health apps and usage:
 - As of Q2 2024, <u>over 35,000 health apps</u> are available on Apple App Store and Google Play Store respectively (Statista, 2024)
 - In 2023, there were <u>311 million health app users</u> (Business of Apps, 2024)



Pokémon Sleep, a mobile game that functions as a sleep-tracker.



Blua Health, a health app launched by Bupa, incorporates AI to analyze users' health via facial screening.



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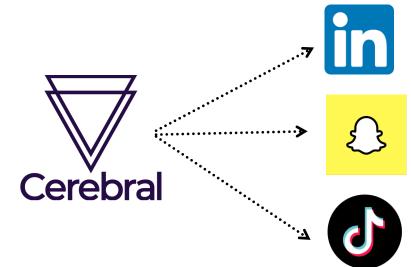




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1) Collection and use of data

- Personal data, including health data, is more valuable than ever
- Health data may be processed, transferred or even used for a new purpose
- In a study of 20,991 health apps (BMJ, 2021):
 - 88% of the apps can collect and potentially share user data
 - 56% of data transmissions go to 3rd parties which include adverts, analytics and other services



In Apr 2024, US Federal Trade Commission proposed a **\$7 million** penalty on online mental health services provider Cerebral for violating 3.2 million customers' privacy by revealing their sensitive mental health conditions to third parties for advertising purposes.

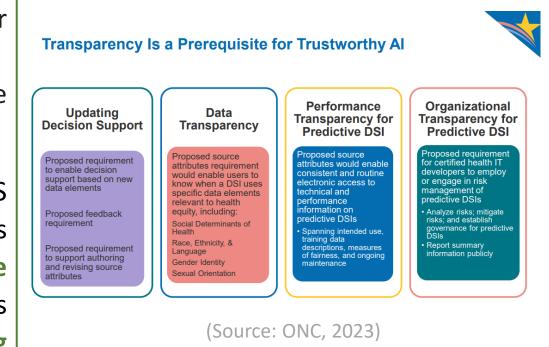
(Source: FTC, 2024)

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2) Lack of transparency

- Al algorithms sometimes evolve beyond our comprehension
- Data processing and decision-making may take place in a "black-box"
- In March 2024, a rule released by the US Department of Health and Human Services became effective. One of its aims is to enhance algorithmic transparency: Al-driven applications are required to let the users review the supporting evidence for unbiased decision-making





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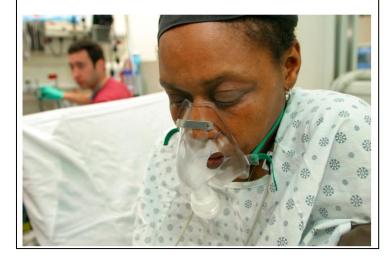
3a) Bias and discrimination — Biased inputs

- Unexpected discrimination may occur if the inputs in the first place are unintentionally biased
- A landmark study on an algorithm used widely by U.S. hospitals found out (Science, 2019):
 - Dark-skinned people were less likely to be referred to personalised care programmes
 - One of the inputs is "medical expense", where poorer dark-skinned people were wrongly classified as "less in need" for care just because they spent less in the past

Millions of black people affected by racial bias in health-care algorithms

Study reveals rampant racism in decision-making software used by US hospitals – and highlights ways to correct it.

Heidi Ledford



(Source: Nature, 2019)

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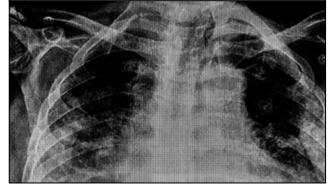


3b) Bias and discrimination — Skewed data

- Al systems rely on training data to acquire their "intelligence"
- If training datasets are skewed and dominated by a particular group, AI systems may be unreliable, esp. when applied to minorities
- In a study of an AI model designed for predicting patients' loss of kidney function (STAT, 2020):
 - > Only 6% of the training data were from female patients
 - The model performed worse when tested on women—the under-represented group



Al systems are worse at diagnosing disease when training data is skewed by sex



(Source: STAT, 2020)



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4) Security of health data

- Health data is "going online", esp.
 with the wide adoption of telemedicine and cloud computing
- Health data stored online may fall prey to hackers
- Among all industries in Australia and UK, the healthcare sector accounts for the largest proportion of data breach incidents

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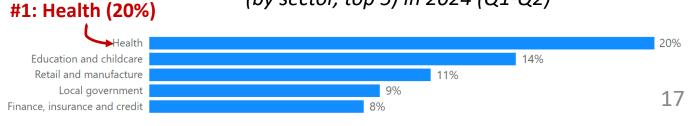
Number of data breach incidents reported in Australia (by sector, top5) in 2024 (Q1-Q2)

#1: Health (19%)

Sector	Number of notifications	Percentage of all notifications received		
Health service providers	102		19%	J
Australian Government	63		12%	
Finance (incl. superannuation)	58		11%	
Education	44		8%	
Retail	29		6%	

(Source: OAIC, 2024)

Proportion of data breach incidents reported in UK (by sector, top 5) in 2024 (Q1-Q2)



(Source: UKICO, 2024)

4) Security of health data

Data Breach Incidents, if found to ** have been caused by inadequate security measures or other violations of the General Data Protection Regulation (GDPR), may result in sanctions by Data Protection Authorities (DPAs)



Data & Security

Centric Health fined €460,000 over 2019 ransomware attack

THE IRISH TIMES

Attack compromised data of about 70,000 Centric patients



<u>Ciara O'Brien</u> Fri Feb 24 2023 - 14:12

G () Y () **!**

Centric Healthcare has been fined €460,000 by the Data Protection Commissioner over a ransomware attack in 2019 that saw patient data encrypted by hackers.

The attack, which restricted access to patient data, hit 11 Primacare GP practices, which Centric Health acquired in 2016. At the time, the practices were being integrated into Centric Health's IT system.

The attack affected the data of 70,000 patients. Of those, 2,500 had their data deleted with no backup available during attempts to mitigate the attack.

Dublin-headquartered Centric offers GP, specialist care and dental services, to more than 400,000 patients throughout the State.



Medical software firm fined €1.5M for leaking data of 490k patients

By Bill Toulas

📰 April 28, 2022 🔯 12:17 PM 💵 1



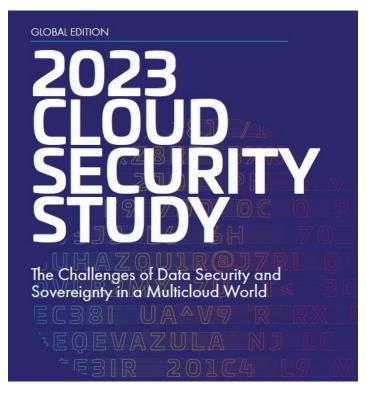
The French data protection authority (CNIL) fined medical software vendor Dedalus Biology with EUR 1.5 million for violating three articles of the GDPR (General Data Protection Regulation).

Dedalus Biology provides services to thousands of medical laboratories in the country and the fine is for exposing sensitive details of of 491,939 patients from 28 laboratories.

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5) Loss of control due to outsourcing

- Technical support services are often **outsourced** to boost efficiency. Examples of outsourcing include:
 - Saving patients' health data to **cloud storage**
 - Providing telemedicine consultations via videoconferencing apps
- In a survey of nearly 3,000 IT and security professionals across 18 countries (Thales, 2023):
 - 39% of businesses have experienced a data breach in their cloud environment last year



(Source: Thales, 2023)

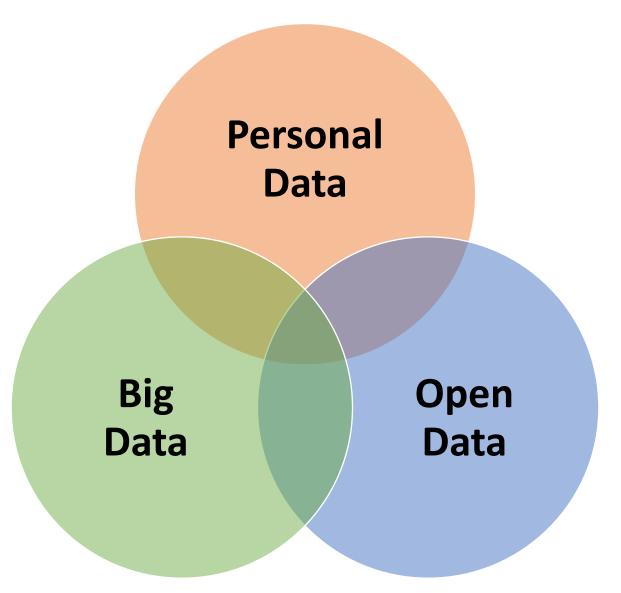


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What is personal data?

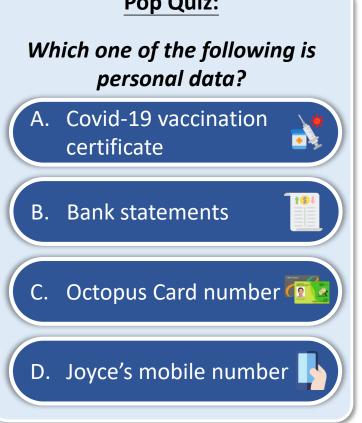
According to Section 2(1) of the Personal Data (Privacy) Ordinance, personal data means any data — Pop Quiz:

Relating directly or indirectly to a **living individual**;

 $\overline{\mathbf{Q}}$

Practicable for the **identity** of the individual to be directly or indirectly **ascertained**; and

In a form in which access to or processing of is practicable







Who are involved?

Personal Data (Privacy) Ordinance:

The individual who is the **subject** of the data

A person who, either alone or jointly or in common with other persons, controls the collection, holding, processing or use of the data;

Data subject

Data user

A person who –

- a) Processes personal data
 on behalf of another
 person; and
- b) Does not process the data for any of his/her own purposes

Data processor

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General requirements of personal data protection

6 Data Protection Principles (DPPs):

Represent the core requirements of the Personal Data (Privacy) Ordinance (PDPO)

Cover the entire lifecycle of personal data, from collection, holding, processing, use to deletion

Data users must comply with the DPPs



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DPP1—Purpose and manner of collection of personal data

- Must be collected for a lawful purpose directly related to a function or activity of the data user
- The means of collection must be lawful and fair
- The data is adequate but not excessive in relation to the purpose of collection
- All practicable steps shall be taken to notify the data subjects whether it is obligatory to supply the personal data , the purpose of data collection, and the classes of persons to whom the data may be transferred, etc.





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DPP1—Purpose and manner of collection of personal data

Example of Collection of Personal Data by Unfair means:

- A private doctor recorded the conversations between himself and his patients without the patients' knowledge
- Contravention of DPP1
- The doctor undertook to cease the act of recording and confirmed that all the audio records had been deleted

What should be done?

To comply with DPP1, hospitals or clinics should provide patients with a "Personal Information Collection Statement" (PICS) setting out the purpose of collection, the classes of persons to whom the data may be transferred, etc

Example from "Application of Generative AI":

"Microsoft introduced an automated clinical documentation application which generates notes based on the conversations during patient visits using GPT-4.

If it involves recording the conversations, which probably include the personal data of patients, the patients should be notified beforehand.

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DPP2—Accuracy and duration of retention of personal data

- Data users should take all practicable steps to ensure:
 - > the accuracy of the personal data
 - the personal data is not kept longer than is necessary for the fulfilment of the purpose for which the data is used
- If a data processor is engaged to process personal data, the data user must adopt contractual or other means to prevent the personal data from being kept longer than is necessary





DPP3—Use of personal data

 Personal data shall not, without the prescribed consent of the data subject, be used for a new purpose.

"<u>New purpose</u>" means any purpose which is <u>unrelated to the</u> <u>original purpose or its directly related purpose</u> when the data is collected

Under certain circumstances, a relevant person in relation to a data subject may, on his or her behalf, give the prescribed consent required for using the data subject's personal data for a new purpose.





DPP3—Use of personal data

- However, under section 62 "Statistics and research" of the PD(P)O, personal data is <u>exempt</u> from the provisions of DPP3 where —
 - (a) The data is to be used for <u>preparing statistics</u> or carrying out <u>research</u>;
 - (b) The data is not to be used for any other purpose; and
 - (c) The resulting statistics or results of the research are not made available in a form which <u>identifies the</u> data subjects or any of them





醫院管理局與科技園正式開放數據平台 支援科學園創科企業進行科研 (28 March 2024)



……醫管局與科技園公司公布,雙方於香港科學園內設置的 「數據實驗室」正式開放給科學園內合資格的創科企業,申 請使用醫管局的醫療數據作科研及開發用途……

……醫管局已在可供查閱的數據中, **刪去可辨認病人身分的** 資料。數據並不會離開醫管局, 無法下載、複製或存 取。…… (Source: GovHK, 2024)

Pop Quiz:

Would section 62 exemption apply in this case?



Tips:

- Is the data to be used for preparing statistics or carrying out research?
- 2. What is personal data? Are these information personal data?

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DPP4—Security of personal data

- Data users should take all practicable steps to ensure the personal data that they hold is protected against unauthorised or accidental access, processing, erasure, loss or use
- Adequate protection must be given to the storage, processing and transfer of personal data
- If a data processor is engaged, the data user must adopt contractual or other means to prevent unauthorised accidental access, processing, erasure, loss or use of the data transferred to the data processor for processing



DPP4—Security of personal data

Practicable steps

Data users should consider:

- 1) the kind of data and the harm that could result from data security incidents;
- 2) the physical location where the data is stored;
- 3) any security measures incorporated into any equipment in which the data is stored;
- 4) any measures taken for ensuring the integrity, prudence and competence of persons having access to the data; and
- 5) any measures taken for ensuring secure transmission of the data.



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Examples of data breaches which involved loss of patient data for research purpose



懷疑失竊的辦公室範圍需以密碼進出,亦設有獨立門鎖。醫院已就事件報答,並翻查閉路電視片段展開調查。醫院 已透過早期事故通報系統向醫院管理局總辦事處報告事件,並已通知個人資料私隱專員公署跟進。

TOPick向院方查詢,院方表示涉事病人為外科病人。醫院亦就事件向影響的病人致歉,將通知受影響病人解釋事件,預計將於下周內完成通知工作。院方稱,失竊事件沒有影響醫院的臨床服務,亦不會對有關病人的治療構成影



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DPP5—Information to be generally available Transparency

Data users must provide information on:

- 1) the policies and practices in relation to personal data;
- 2) the kind of personal data held; and
- 3) the main purposes for which the personal data is or is to be used.





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DPP6—Access to personal data

Data subject's rights

- A data subject must be given access to his personal data and the right to request corrections where the data is inaccurate.
- A data user must comply with a data access/correction request within 40 days after receipt of the request. (Sections 19 and 23 of the PDPO)



私隱專員鍾麗玲發現,考評局就查閱資料而徵收的費用,均低於直接有關及必須的成 本,包括員工薪酬開支、電腦操作時間費及其他開支,當中並不包括「打印機的操作和 保養費用」及「紙張及文具費用」。鍾麗玲認為,考評局徵收的相關費用沒有超乎適 度,沒有違反《私隱條例》的規定。











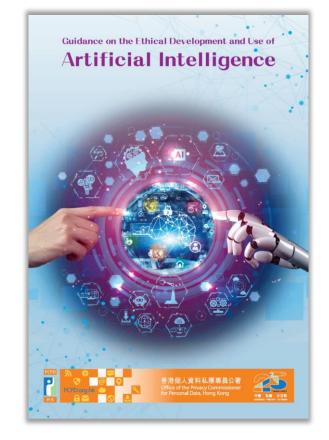
PCPD's Guidance Materials on Artificial Intelligence





Objectives

- To facilitate the healthy development and use of Al in Hong Kong
- To provide guidance to enable organisations to develop and use AI in compliance with the requirements of the PDPO and in an ethical manner
- To facilitate Hong Kong's development into an innovation-and-technology hub and a world-class smart city



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3 Data Stewardship Values



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7 Ethical Principles for AI



- **1. ACCOUNTABILITY**
- Organisations should:
- Be <u>responsible</u> for their actions
- Be able to provide <u>sound</u> justifications for the actions



2. HUMAN OVERSIGHT

- The <u>level of human</u> <u>involvement</u> should:
- Be <u>proportionate to the</u> <u>risks and impact of using AI</u>





7 Ethical Principles for AI



3. TRANSPARENCY & INTERPRETABILITY

Organisations should:

- <u>Disclose</u> their use of AI and the relevant <u>data privacy policies</u>
- Improve the <u>interpretability of</u> automated decisions



4. DATA PRIVACY

Organisations should:

 Put <u>effective</u> data <u>governance</u> in place to protect personal data privacy



7 Ethical Principles for AI



5. FAIRNESS

Organisations should:

 Treat individuals in a reasonably equal manner, <u>without</u> <u>unjust bias or</u> <u>unlawful</u> discrimination



6. BENEFICIAL AI

The use of AI should:

- <u>Provide benefits</u> to stakeholders
- <u>Minimise harm</u> to stakeholders



7. RELIABILITY, ROBUSTNESS & SECURITY

AI systems should:

- Operate <u>reliably</u>
- Be <u>resilient</u> to errors
- Be <u>protected against</u> <u>attacks</u>



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Self-assessment Checklist

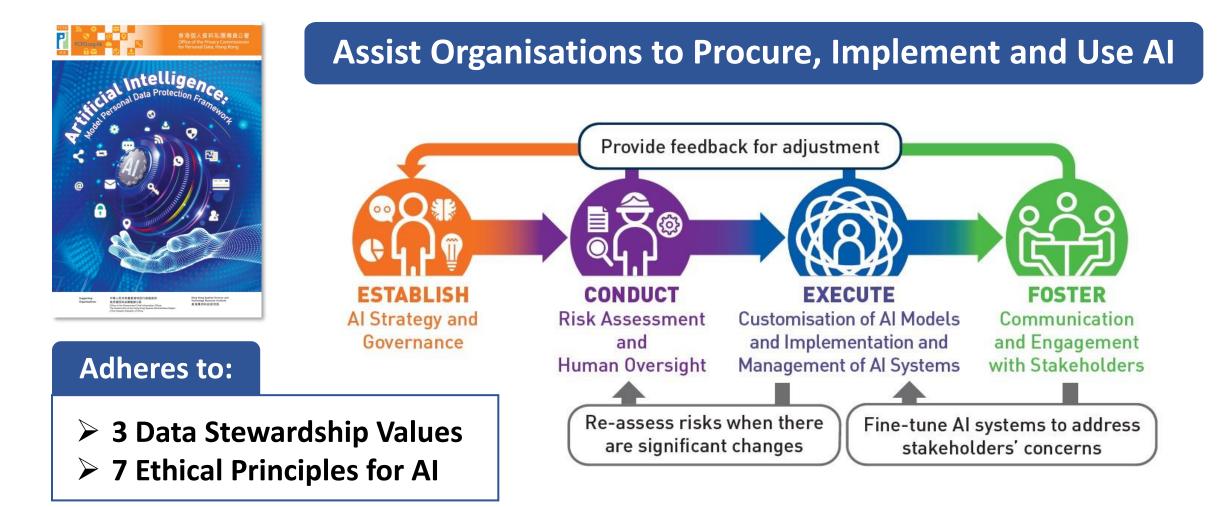
- The checklist contains self-assessment questions on the 4 major business processes
- Practical suggestions made by the Guidance are also incorporated

APPENDIX A - Self-assessment Checklis			
AT 3	Question	Answer (Yes/No)	Further actions required
1	Has your organisation formulated an AI strategy before the development and use of AI?		
2	Did your organisation set up internal policies and procedures specific to the ethical design, development and use of AI?		
3	Did your organisation establish an Al governance committee (or a similar body) that would oversee the life cycle of the Al system, from its development, use to termination?		
4	Does the Al governance committee (or a similar body) have: • Members from different disciplines and departments to collaborate in Al development and use? • A C-level executive (or management in a similar role) to oversee its operation?		
5	Did your organisation set out clear roles and responsibilities for the personnel involved in the development and use of AI?		
6	Has your organisation set aside adequate resources in terms of finance and manpower for the development and use of AI?		
7	Has your organisation provided training to the personnel involved in the development and use of Al that is relevant to their respective roles?		
8	Has your organisation arranged regular awareness-raising exercises to the use of AI with all relevant personnel?		



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Model Personal Data Protection Framework



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10 Tips for Users of AI Chatbots

Before Registration / Use When Interacting with AI Chatbots Safe and Responsible Use of AI Chatbots



A) Before Registration / Use:

- 1. Read the Privacy Policy, the Terms of Use and other relevant data handling policies
- 2. Beware of **fake apps** and **phishing websites** posing as known AI chatbots
- 3. Adjust the settings to **opt-out of sharing chat history** (if available)





10 Tips for Users of AI Chatbots

Before Registration / Use When Interacting with AI Chatbots Safe and Responsible Use of AI Chatbots



B) When Interacting with AI Chatbots:

- 4. Refrain from sharing your own personal data and others' personal data
- 5. Submit a correction or removal request, if necessary
- 6. Guard against cybersecurity threats
- 7. Delete outdated conversations from chat history





10 Tips for Users of AI Chatbots

Before Registration / Use When Interacting with AI Chatbots Safe and Responsible Use of AI Chatbots



C) Safe and Responsible Use of AI Chatbots:

- 8. Be **cautious about using the information** provided by AI chatbots
- 9. Refrain from sharing confidential information and files
- 10. **Teachers / parents should provide guidance** to students when they are interacting with AI chatbots



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Thank you!



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