

# *Engaging policymakers in Health Research*

Data Protection Commissioner  
Mrs D.Madhub

# ENHANCING COLLABORATION BETWEEN HEALTH RESEARCHERS AND DATA PROTECTION OFFICERS

As the role of data in health research grows increasingly critical, it is imperative for researchers to engage effectively with Data Protection Officers (DPOs). It is important to foster a productive partnership, ensuring that research endeavors are aligned with data protection regulations and ethical standards.

## Provisions of Data Protection Act 2017 related to research

### 28. Lawful processing

- (1) No person shall process personal data unless –
- (a) the data subject consents to the processing for one or more specified purposes;
  - (b) the processing is necessary –**
    - (i) for the performance of a contract to which the data subject is a party or in order to take steps at the request of the data subject before entering into a contract;
    - (ii) for compliance with any legal obligation to which the controller is subject;
    - (iii) in order to protect the vital interests of the data subject or another person;
    - (iv) for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller;
    - (v) the performance of any task carried out by a public authority;
    - (vi) the exercise, by any person in the public interest, of any other functions of a public nature;
    - (vii) for the legitimate interests pursued by the controller or by a third party to whom the data are disclosed, except if the processing is unwarranted in any particular case having regard to the harm and prejudice to the rights and freedoms or legitimate interests of the data subject; or
    - (viii) for the purpose of historical, statistical or scientific research.**

### 39. Rectification, erasure or restriction of processing

(1) (a) A controller shall, on being informed of the inaccuracy of personal data by a data subject to whom such data pertains, cause the data to be rectified without undue delay.

(b) A right to rectification under paragraph (a) shall include the right of a data subject to have incomplete personal data completed, having regard to the purpose of the processing.

(2) A controller shall erase personal data without undue delay where –

(a) the data are no longer necessary in relation to the purpose for which they were collected or otherwise processed;

(b) the data subject withdraws consent on which the processing is based and where there is no other legal ground for the processing;

(c) the data subject objects to the processing of personal data and there are no overriding legitimate grounds for the processing; or

(d) the personal data have been unlawfully processed.

**39. Rectification,  
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(3) Where the controller has made the personal data public, he shall take all reasonable steps to inform third parties processing such data, that the data subject has requested the erasure of any links to, or copy or replication of, that personal data.

**(4) Subsections (2) and (3) shall not apply where the processing of the personal data is necessary –**

(a) for reasons of public interest in the field of public health;

**(b) for the purpose of historical, statistical or scientific research;**

(c) for compliance with a legal obligation to process the personal data to which the controller is subject or for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller; or

(d) for the establishment, exercise or defence of a legal claim.

## 44. Exceptions and restrictions

- (1) No exception to this Act shall be allowed except where it constitutes a necessary and proportionate measure in a democratic society for –
- (a) subject to subsection (4), the protection of national security, defence or public security;
  - (b) the prevention, investigation, detection or prosecution of an offence, including the execution of a penalty;
  - (c) an objective of general public interest, including an economic or financial interest of the State;
  - (d) the protection of judicial independence and judicial proceedings;
  - (e) the protection of a data subject or the rights and freedoms of others; or
  - (f) issue of any licence, permit or authorization during the COVID-19 period.

**(2) The processing of personal data for the purpose of historical, statistical or scientific research may be exempt from the provisions of this Act where the security and organizational measures specified in section 31 are implemented to protect the rights and freedoms of data subjects involved.**

## Communicating Research Needs and Privacy Concerns between researchers and DPOs

### a) Detail Your Data Requirements:

- i. **Specific Data Needs:** Clearly specify the types of data required and the justification for each data set.
- i. **Data Minimisation:** Emphasize efforts to use only the minimum amount of data necessary for your research.

### b) Address Privacy Concerns:

- i. **Risk Assessment:** Conduct and share DPIA assessments to highlight potential privacy issues and mitigation strategies.
- ii. **Data Anonymisation:** Discuss methods for anonymising or pseudonymising data to protect participants' identities.

### c) Develop Comprehensive Data Management Plans:

- i. **Data Lifecycle:** Outline the entire data lifecycle, including collection, storage, usage and disposal.
- ii. **Access Controls:** Detail access controls and measures to prevent unauthorized data access.

### d) Ethical Considerations:

- i. **Informed Consent:** Ensure that informed consent procedures are robust and transparent, detailing how data will be used and protected.
- ii. **Participant Rights:** Respect and uphold the rights of research participants, providing them with clear information on data usage and their rights.

## Effective Communication with Data Protection Officers

### a) Establish Clear Lines of Communication:

- i. **Meetings:** Schedule meetings at the start of your project to discuss goals, data needs and privacy considerations.
- ii. **Designated Contact Points:** Identify primary contacts within both teams to streamline communication and avoid misunderstandings.

### b) Transparent Information Sharing:

- i. **Research Objectives:** Clearly articulate your research objectives and how data will be used, stored and protected.
- ii. **Data Flow Diagrams:** Provide visual aids like data flow diagrams to illustrate how data will be handled throughout the project.

### c) Use Plain Language:

- i. **Avoid Jargon:** Simplify technical language to ensure mutual understanding. Not all DPOs may have a background in health research.
- ii. **Summarize Key Points:** Provide executive summaries for complex documents and research plans.

## Tips for Building a Strong Working Relationship

### **Collaborative Planning:**

**Joint Development:** Involve DPOs in the planning stages to co-create data handling protocols and ensure compliance from the outset.

**Feedback Loops:** Implement feedback mechanisms where DPOs can review and suggest improvements to data management practices.

### **Continuous Education:**

**Training Sessions:** Organize joint training sessions on data protection regulations, ethical considerations, and the latest best practices.

**Stay Informed:** Both parties should stay updated on evolving privacy laws and technological advancements affecting data protection.

Effective collaboration between health researchers and Data Protection Officers is essential for the successful and ethical conduct of research. By establishing clear communication, fostering mutual respect, and addressing privacy concerns proactively, researchers can ensure that their projects comply with data protection regulations while advancing scientific knowledge.

# ENGAGEMENT STRATEGIES FOR POLICYMAKERS AND STAKEHOLDERS

To advance health research while upholding robust data protection standards, it is vital for researchers to engage strategically with policymakers and stakeholders. The following guidelines aim to enhance advocacy efforts, foster collaboration, and integrate research findings into health policies effectively.

## Approaches to Advocating for Research-Friendly Data Protection Policies

### a) Highlighting the Value of Research:

- i. **Evidence-Based Advocacy:** Present robust evidence and case studies demonstrating the societal and health benefits of your research.
- i. **Impact Reports:** Develop impact reports that clearly show how research contributes to public health improvements and policy development.

### c) Building Awareness and Trust:

- i. **Transparency:** Be transparent about research methods, data usage, and protection measures to build trust and demonstrate ethical commitment.

### b) Proposing Balanced Solutions:

- i. **Policy Proposals:** Draft policy proposals that balance the need for data accessibility in research with stringent data protection measures.
- ii. **Risk-Benefit Analysis:** Provide thorough risk-benefit analyses to illustrate how research benefits outweigh potential privacy risks subject to adequate protections being in place. Useful tools are data protection impact assessments, anonymisations and pseudonymisation techniques.

**Building Partnerships with Policymakers to facilitate the integration of research findings into health policies while ensuring data protection**

**a) Creating Collaborative Frameworks:**

**Memorandums of Understanding (MoUs):**

Establish MoUs with government agencies and policymakers to formalise collaborative efforts and shared goals.

**Joint Research Initiatives:** Develop joint research initiatives that include policymakers as partners to ensure alignment with public health priorities and policy frameworks.

**b) Ensuring Ethical Compliance:**

**Ethical Guidelines:** Work with policymakers to develop ethical guidelines that facilitate research while protecting data privacy.

**Compliance Frameworks:** Develop and promote compliance frameworks that align with both research objectives and data protection regulations.

### **Conclusion**

Effective engagement with policymakers and stakeholders is crucial for advancing health research and ensuring robust data protection. By fostering open communication, advocating for balanced policies, and building strong partnerships, researchers can integrate their findings into health policies while safeguarding data privacy. These strategies will help create a collaborative environment where health research can thrive and contribute meaningfully to public health improvements.

**Thank you**