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International Children's Palliative Care Network (ICPCN)

Policy No: ICPCN25 Data Protection Policy

Date Drafted	April 2018
Date Revised	August 2021
Date Approved by the Board	August 2021
Review Date:	May 2023

1. Introduction

- ICPCN is committed to processing data in accordance with its responsibilities under the GDPR (General Data Protection Regulation)
- As a membership organisation ICPCN holds the following personal data:
 - Its membership list.
 - Individuals completing training programmes, either through the e-learning courses or face-to-face training.
 - Specific groups such as the African Children's Palliative Care Network.
 - Participants in research projects.
 - Participants attending the ICPCN conference and other meetings.
 - International Database of CPC services on the website.
- This policy will help ensure that ICPCN handles data sensitively and in line with the GDPR.

2. Definitions

- Charity – means the ICPCN, a registered charity in England and Wales and a registered public benefit organisation in South Africa
- GDPR – General Data Protection Regulation
- POPI – Protection of Public Information
- Responsible person – Julia Downing, Chief Executive
- Register of Systems – a register of all systems or contexts in which personal data is processed by the Charity.

3. Data Protection Principles

Article 5 of the GDPR requires that personal data shall be:

- Processed lawfully, fairly and in a transparent manner in relation to individuals.
- Collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall not be considered to be incompatible with the initial purposes.
- Adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.
- Accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that

personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay.

- Kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods insofar as the personal data will be processed solely for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes subject to implementation of the appropriate technical and organisational measures required by the GDPR in order to safeguard the rights and freedoms of individuals; and
- Processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures.”

4. General Provisions

- This policy applies to all personal data processed by the Charity.
- The Responsible Person shall take responsibility for the Charity’s ongoing compliance with this policy.
- This policy shall be reviewed at least annually.
- The Charity shall register with the Information Commissioner’s Office as an organisation that processes personal data.
- All ICPCN staff will be trained on the GDPR to ensure safe handling of data.

5. Lawful, Fair and Transparent Processing

- To ensure its processing of data is lawful, fair and transparent, the Charity shall maintain a Register of Systems.
- The Register of Systems shall be reviewed at least annually.
- Individuals have the right to access their personal data and any such requests made to the charity shall be dealt with in a timely manner.

6. Lawful Purposes

- All data processed by the charity must be done on one of the following lawful bases: consent, contract, legal obligation, vital interests, public task or legitimate interests ([see ICO guidance for more information](#)).
- The Charity shall note the appropriate lawful basis in the Register of Systems.
- Where consent is relied upon as a lawful basis for processing data, evidence of opt-in consent shall be kept with the personal data.
- Where communications are sent to individuals based on their consent, the option for the individual to revoke their consent should be clearly available and systems should be in place to ensure such revocation is reflected accurately in the Charity’s systems.
- A privacy policy will be put up on ICPCN’s websites i.e:
 - The main charity website – www.icpcn.org
 - The elearning website – www.elearnicpcn.org
 - The Pain App - on the appropriate App stores e.g. Google Play Store
 - The conference website – www.icpcnconference.org – as required

7. Data Minimisation

- The Charity shall ensure that personal data are adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed.
- ICPCN will tell people what they are doing with their data, and who will have access to it. NB No data

from ICPCN will be shared with another organisation without the consent of the individuals involved.

8. Accuracy

- The Charity shall take reasonable steps to ensure personal data is accurate.
- Where necessary for the lawful basis on which data is processed, steps shall be put in place to ensure that personal data is kept up to date.

9. Archiving/ Removal

- To ensure that personal data is kept for no longer than necessary, the Charity shall put in place an archiving policy for each area in which personal data is processed and review this process annually.
- The archiving policy shall consider what data should/must be retained, for how long, and why.

10. Security

- The Charity shall ensure that personal data is stored securely using modern software that is kept-up-to-date and password protected.
- Access to personal data shall be limited to personnel who need access and appropriate security should be in place to avoid unauthorised sharing of information.
- When personal data is deleted this should be done safely such that the data is irrecoverable.
- Appropriate back-up and disaster recovery solutions shall be in place.

11. Breach

- In the event of a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure of, or access to, personal data, the Charity shall promptly assess the risk to people's rights and freedoms and if appropriate report this breach to the ICO ([more information on the ICO website](#)).

Policy approved by the Board and accepted by the Chief Executive of the ICPCN.



Chair of the ICPCN Board
Lynda Gould



Chief Executive of ICPCN
Julia Downing









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Final Audit Report

2021-09-08

Created:	2021-09-08
By:	Barbara Steel (admin@icpcn.org)
Status:	Signed
Transaction ID:	CBJCHBCAABAAge7IOTuniXiaVcpzD3FmBbf0V5yJkTt

"ICPCN25 Data Protection Policy - August 2021" History

-  Document created by Barbara Steel (admin@icpcn.org)
2021-09-08 - 10:10:09 AM GMT- IP address: 90.252.29.219
-  Document emailed to Prof Julia Downing (julia.downing@icpcn.org) for signature
2021-09-08 - 10:11:35 AM GMT
-  Email viewed by Prof Julia Downing (julia.downing@icpcn.org)
2021-09-08 - 10:23:52 AM GMT- IP address: 31.54.173.20
-  Document e-signed by Prof Julia Downing (julia.downing@icpcn.org)
Signature Date: 2021-09-08 - 10:24:40 AM GMT - Time Source: server- IP address: 31.54.173.20
-  Document emailed to Lynda C Gould (lyn@butterflyhospice.org) for signature
2021-09-08 - 10:24:42 AM GMT
-  Email viewed by Lynda C Gould (lyn@butterflyhospice.org)
2021-09-08 - 11:56:48 AM GMT- IP address: 94.5.45.230
-  Document e-signed by Lynda C Gould (lyn@butterflyhospice.org)
Signature Date: 2021-09-08 - 12:19:09 PM GMT - Time Source: server- IP address: 94.5.45.230- Signature captured from device with phone number XXXXXXXX7161
-  Agreement completed.
2021-09-08 - 12:19:09 PM GMT