



FIGIJ PRIVACY AND CONFIDENTIALITY TOOLKIT

1.1 Edition

Published on 20th October 2025

Contents

INTRODUCTION	3
FIGIJ PRIVACY AND CONFIDENTIALITY POLICY	4
APPENDIX 1 FIGIJ CONFERENCE PRESENTER DECLARATION	8
APPENDIX 2 APPLICATION FORM AND PRIVACY DECLARATION FOR CONFERENCE EVENT ORGANISERS AND TECHNICAL SUPPORT STAFF	10
APPENDIX 3 CONFERENCE COMMITTEE PRIVACY DECLARATION (FOR CONFERENCES CO-ENDORSED BY FIGIJ)	11
APPENDIX 4 IFEPAG EXAMINER PRIVACY DECLARATION	14
APPENDIX 5 IFEPAG CANDIDATES PRIVACY DECLARATION	15
APPENDIX 6 TEMPLATE FOR CONSENT FOR PUBLICATION OF A CASE STUDY REPORT OR CASE SERIES (FOR CONFERENCES)	16
APPENDIX 7 TEMPLATE FOR CONSENT FOR PUBLICATION OF A CASE STUDY REPORT FOR CASE CORNER	18
APPENDIX 8 CASE CORNER ACCESS AND PRIVACY DECLARATION	20

INTRODUCTION

This toolkit, developed by the FIGIJ Board and Chairs, is intended to guide FIGIJ members, (and affiliated societies seeking FIGIJ endorsement), of FIGIJ's privacy and confidentiality principles and code of conduct with respect to sharing of health data. Members of FIGIJ hold a fundamental ethical obligation to safeguard patient information and uphold trust. We trust that our members and affiliates of good-standing already adhere to local health privacy laws and will support and declare their adherence to the FIGIJ privacy and confidentiality policy when sharing or receiving health data under the FIGIJ banner. Feedback or ratification of this document by member societies is enthusiastically welcomed. Modification requires FIGIJ Board approval. Please contact the secretary-general or your local FIGIJ Board member (<https://figij.org/about/current-board/>) for further discussion.



INTERNATIONAL FEDERATION OF PAEDIATRIC AND ADOLESCENT GYNAECOLOGY

FEDERATION INTERNATIONALE DE GYNECOLOGIE INFANTILE ET JUVENILE

FEDERACION INTERNACIONAL DE GINECOLOGIA INFANTIL Y JUVENIL

FIGIJ PRIVACY AND CONFIDENTIALITY POLICY

Document v7 2025 10 20

Last Approval date 15/9/2025

The International Federation of Paediatric and Adolescent Gynaecology (FIGIJ) strives to improve the reproductive health of young people by improving clinical care, research and education in Pediatric and Adolescent Gynecology (PAG).

FIGIJ brings together PAG experts from all corners of the globe to educate those who serve this population and build a community of practice. FIGIJ is committed to ensuring the organisation complies with relevant privacy, confidentiality and security legislation – to protect our clients, our members and our professional body. To facilitate this, individuals are required to understand their obligations and responsibilities when becoming a FIGIJ member.

In medical education, privacy and confidentiality are paramount, both ethically and legally. **Confidentiality** refers to the protection of patient information discussed between a person and their healthcare practitioners. **Privacy**, relates to the protection of identifiable personal information, including health information. **Direct identifiers** are unique to a person and can be used to identify them with a high degree of certainty. They include Name, Address, Phone number, Social Security number, Driver's license number, Email address, Passport number, Medical record number, Credit card number. **Indirect identifiers** may not directly identify someone on their own, but can be combined with other information to identify an individual. Examples include: Date of birth, Place of birth, Gender, Race or ethnicity, Occupation, Postcode, Age, IP address, Employment information, General information that could be combined with other data points to reveal an individual (such as unique medical history combined with location of treatment).

Key Principles of Privacy and Confidentiality in Medical Education:

Ethical Obligations: Healthcare professionals have a strong ethical duty to protect patient information and maintain patient trust. This includes protecting information about other individuals, such as family members.

Legal Requirements: Privacy and confidentiality are also legally protected, with laws regulating how personal information, including health information, is collected and handled.

Patient Rights: Patients have the right to access and control their health information, and they should be informed about how their information will be used and shared.

Information Sharing: Information can be shared with other healthcare professionals for education purposes, but only with the patient's consent or if legally required.

Data Security: Healthcare providers must ensure that patient information is stored and transmitted securely to prevent unauthorized access and disclosure.

Consent and Permissions: Consent is required before any health information is disclosed or shared, unless there is a legal exception.

Digital Communications: Healthcare providers must use digital communications (e.g., email, text messages, group chats, zoom or teams) in a way that is consistent with their ethical and legal obligations to protect patient confidentiality and privacy.

Data Breach Response: In line with requirements for healthcare organizations FIGIJ has a data breach response plan in place to manage and respond to any unauthorized access or disclosure of patient information.

GENERAL PRINCIPLES

- 1) **FIGIJ educational conference/meeting/webinar presenters** (members, invited guests, contractors, volunteers and students) are personally responsible for maintaining health privacy, and
 - 1.1 must sign a privacy agreement indicating
 - 1.1.1 that they are responsible for maintaining the privacy, confidentiality and security of health information,
 - 1.1.2 that they have received written consent from the patient for case reports and case series,
 - 1.1.3 that they have received written consent or a human research ethics approved waiver of consent for presentation of surveys or cohorts.
 - 1.2 All data must remove direct identifiers (personally identifiable information) including name, social security number (SSN), email address, medical record number (MRN), other account numbers linked to the patients, biometric data: (unique physical characteristics, such as fingerprints or facial scans), full-face photographs. Facial images with only the eyes blacked out are not acceptable.
 - 1.3 Patient consent is required for the use of indirect identifiers (such as date of birth, gender, postcode, occupation, unique medical diagnosis, approximate location or treating centre) if this information is not presented as grouped deidentified data. Someone aware of the patient may be able to identify them through indirect identifiers when combined with other data.
- 2) **Any FIGIJ member wishing to upload materials onto the internet** (public or password protected) relating to FIGIJ educational activities must
 - 2.1 sign and adhere to the FIGIJ privacy and confidentiality agreement (***which will be kept with FIGIJ***) and receive the appropriate written consent from the patient/guardian (***that should be filed in the local patient medical record***). FIGIJ highly recommends that a copy of the consent form be filed in a secure locked location within the institution (eg institutional password protected network drive, computer, or locked cupboard; and a copy provided to the family). It is the presenters responsibility to be able to access this information if required. The patient/guardian consent form should include information about the extent of information to be shared, where it will be shared, the audience who has access and duration of access, who is responsible for publishing the information and the date that the child once 18 years or over may wish the content to be removed; that duplication and dissemination of the content can occur once online.
 - 2.2 Not use the FIGIJ logo or reference FIGIJ without Board approval.
- 3) **FIGIJ meeting organisers and technical support at educational meetings:** must provide
 - 3.1 written agreement stating that the presentations (power point or video material) cannot be shared unofficially with attendees or online and
 - 3.2 will be destroyed after the conference, unless official arrangements have been made (see below).
- 4) **FIGIJ conference committee will**
 - 4.1 provide written agreement that they will abide by the FIGIJ privacy and confidentiality policy

- 4.2 will be responsible for reviewing abstracts and ensuring appropriate privacy and confidentiality agreements have been received.
- 4.3 Apart from abstracts, educational materials (slide presentations, videos) will not be retained by organisers longer than six months after the conference.

5) IFEPAG candidates and examiners:

- 5.1 Candidates and examiners are responsible for sharing transmission and storage of health data and will sign and adhere to the FIGIJ privacy and confidentiality agreement (**which will be kept with the Director of IFEPAG**)
- 5.2 Direct identifiers including hospital UR numbers will not be reported outside the health centre setting. Candidates may record the hospital ID in their own records within the institution and have a supervisor verify that the cases are genuine on their submission. If needed by IFEPAG examiners, these can still be re-identifiable by local institutional members to ascertain details about the case.
- 5.3 Only the IFEPAG committee and examiners will have access to the case reports. They will not be published or shared outside of IFEPAG and will be destroyed after the examination.

6) CASE CORNER

- 6.1 Cases may be used for educational purposes after parent/guardian consent. The consent form will outline the extent of information being shared, who it will be shared with and how it will be transmitted, stored and for how long. The consent form **should be filed in the local patient medical record and on the local password protected departmental computer or network drive of the treating institution for three years**. The patient/guardian consent form should include information about the extent of information to be shared, where it will be shared, the audience who has access and duration of access, who is responsible for publishing the information and the date.
- 6.2 Approval will be required by the Resources committee, prior to uploading into Case Corner
- 6.3 Cases will be deleted from the FIGIJ Case Corner site within nine years.
- 6.4 FIGIJ members wishing to access Case Corner will need to be verified members (email verification of FIGIJ from Head of Department or PAG secretariat or local societal subscription) and will need to sign a privacy agreement. Members are not permitted to download cases from the website.

7) Endorsement of PAG and other Society conferences: FIGIJ remains committed to supporting member societies for medical education and professional development. Where a society seeks endorsement of FIGIJ and use of the FIGIJ logo to promote a conference or educational event

- 7.1 Approval by the Board is required.
- 7.2 The applicant should provide
- o Conference name year and location
 - o Organising society
 - o Conference Chair name, affiliation, email
 - o Aims and learning objectives
 - o Audience
 - o Name and affiliations of Conference Organising committee
 - o The Conference Program (titles of talks with speakers and affiliations)
 - o Conflicts of interest and funding sources
- 7.3 While FIGIJ cannot be responsible for all content presented at external conferences, FIGIJ will require a signed declaration from the conference chair that the presenters organisers and technical support will abide by the principles of the FIGIJ Privacy and confidentiality agreement.

8) Storage:

- 8.1 For conference presentations, consent forms will be stored in the patient medical record (this is the responsibility of the treating clinician/presenter sharing information about the case). FIGIJ highly recommends that a copy of the consent form be filed in a secure locked location

within the institution (eg institutional password protected network drive, computer, or locked cupboard; and a copy provided to the family).

- 8.2 Presenter /technical support/committee declarations will be stored with the conference committee/chair then handed over to the Secretary General of FIGIJ for uploading in the FIGIJ google drive.

9 In the event of a report of data breach or scientific fraud

- 9.1 The Secretary-General and President will be notified
- 9.2 Further reported to executive (VP, Treasurer) and senior Board members (past president and Chair of By-laws)
- 9.3 Contact author to request removal of offending materials.
- 9.4 FIGIJ will try to verify extent of involvement and how breach occurred and its extent
- 9.5 Report will be sent to Board and reporting person
- 9.6 If fraud or breach has occurred then FIGIJ has the right to temporarily suspend membership until formal report undertaken by relevant regulatory body.
- 9.7 If external: encourage reporter to report to medical governance body with our full cooperation
- 9.8 Notify Professional Society of person potentially responsible for breach
- 9.9 Consider legal advice. Legal jurisdiction FIGIJ: official address is USA, but has global membership.

10) Related Documents

1. FIGIJ privacy declaration for presenters
2. FIGIJ privacy declaration for event organisers and technical support staff
3. FIGIJ privacy declaration for PAG conference committees
4. IFEPAG examiner declarations
5. IFEPAG candidate declarations
6. FIGIJ patient/guardian example template for consent for presentation at meetings/webinars
7. FIGIJ patient/guardian consent template for Case Corner
8. FIGIJ privacy declaration for health provider access to Case Corner
9. FIGIJ updated Statutes and By-laws (<https://figij.org/about/mission/>)



APPENDIX 1 FIGIJ CONFERENCE PRESENTER DECLARATION

Document V2 2025 08 01
Approved on 15/9/2025

Dear Colleagues

We appreciate your help in partnering with FIGIJ to create a protected space to learn, teach and engage in scientific discourse free from commercial bias and respectful of patients/study participants. As trusted authorities, we are committed to protection of health information. We ask that you please review FIGIJ's privacy and confidentiality policy then complete this declaration within seven days.

1. I have read and will abide by FIGIJ's privacy and confidentiality policy
 yes

2. I have disclosed all financial relationships with private entities to the conference organisers
 yes

3. Content for this activity including presentation of therapeutic options is balanced, evidence-based and commercially unbiased.
 yes

4. I am responsible for maintaining the privacy, confidentiality and security of the health information I will be presenting.
 yes

5. Please confirm one of the following
 I have received written consent from patients/participants for presentation of case reports and case series
Or
 I have received written consent or a human research ethics approved waiver of consent for presentation of original research data

6. I will remove all patient identifiers from my presentation materials.
 yes

7. I will not use identifiable photographs without patient permission. I will not use full-face photographs, facial images with only the eyes blacked out or fingerprints.
 - yes

8. I will provide educational content in advance as requested
 - yes

9. I will not upload patient-related materials on the internet (direct or indirect identifiers) without appropriate written consent from the patient/guardian. The consent form will include information about i) the extent of information to be shared; ii) where it will be shared; iii) the audience who has access; iv) duration of access; v) who is responsible for publishing the information and the date; vi) that the child once 18 years or over may wish the content to be removed; vii) that duplication and dissemination of the content can occur once online.
 - yes

10. I will not use the FIGIJ logo without FIGIJ Board approval
 - yes

11. If AI is used to generate the presentation I will acknowledge the AI tool utilised, the prompts I used and how I used the output, on my disclosure slide.
 - yes

I attest that the above information is correct (please sign below)

Signature and date	
Name	
Role	
Institution	
Professional Society	
Address	
Email	
Phone	



INTERNATIONAL FEDERATION OF PAEDIATRIC AND ADOLESCENT GYNAECOLOGY

FEDERATION INTERNATIONALE DE GYNECOLOGIE INFANTILE ET JUVENILE

FEDERACION INTERNACIONAL DE GINECOLOGIA INFANTIL Y JUVENIL

APPENDIX 2 APPLICATION FORM AND PRIVACY DECLARATION FOR CONFERENCE EVENT ORGANISERS AND TECHNICAL SUPPORT STAFF

Document V2 2025 08 01

Approved on 15/9/2025

Dear Colleagues

We appreciate your help in partnering with FIGIJ to create a protected space to learn, teach and engage in scientific discourse free from commercial bias and respectful of patients/study participants. As trusted authorities, we are committed to protection of health information. We ask that you please review FIGIJ's privacy and confidentiality policy then complete this form within 7 days of receiving it.

Conference name, year and location	
------------------------------------	--

PRIVACY DECLARATION

1. I have read and agree to abide with FIGIJ's privacy and confidentiality policy
 yes
2. I will not share abstracts and presentations (powerpoint or video material) unofficially or online without the presenters consent
 yes
3. I will destroy scientific content after the conference as per arrangements with conference organisers
 Yes
4. I will not use or share the FIGIJ logo without FIGIJ Board approval
 yes

I attest that the above information is correct (please sign below)

Signature and date	
Name	
Affiliation	
Address	
Email	
Phone	



INTERNATIONAL FEDERATION OF PAEDIATRIC AND ADOLESCENT GYNAECOLOGY

FEDERATION INTERNATIONALE DE GYNECOLOGIE INFANTILE ET JUVENILE

FEDERACION INTERNACIONAL DE GINECOLOGIA INFANTIL Y JUVENIL

APPENDIX 3 CONFERENCE COMMITTEE PRIVACY DECLARATION (FOR CONFERENCES CO-ENDORSED BY FIGIJ)

Document V3 2025 08 04

Approved on 15/9/2025

Dear Colleagues

We appreciate your help in partnering with FIGIJ to create a protected space to learn, teach and engage in scientific discourse free from commercial bias and respectful of patients/study participants. As trusted authorities, we are committed to protection of health information. We ask that you please review FIGIJ's privacy and confidentiality policy then return this completed form within seven days.

Conference Details	
Conference Chair Role Institutional Affiliation Email Phone	
Conference Name location date	
Society Name	

Conference Committee	
Name Role Institutional Affiliation Email	Copy and paste more rows as required or provide program brochure

Speakers	
Name Role Institutional Affiliation Short Bio Title of talk	Copy and paste more rows as required or provide program brochure

Conference style	
Face to face, online, hybrid?	
Commercial interests to declare	
Is there a request to use the FIGIJ logo and on what materials?	
Will conference materials be shared beyond the conference itself?	

PRIVACY DECLARATION BY CONFERENCE COMMITTEE

1. The conference committee, have read and will abide by the principles of the FIGIJ's privacy and confidentiality policy
 - Yes

2. The conference committee will only use the FIGIJ logo in instances where it is approved by the FIGIJ Board.
 - Yes

3. FIGIJ is not responsible for maintaining the privacy, confidentiality and security of the health information that is being presented.
 - Agree

I attest that the above information is correct (all conference committee members please sign below, add rows as required)

Name of Conference Committee Member	Signature	Date

FIGIJ INTERNAL USE

Approved by FIGIJ Board

- yes
- no

Date

Are modifications required

- yes
- no



APPENDIX 4 IFEPAG EXAMINER PRIVACY DECLARATION

Document V2 2025 08 01

Approved on 15/9/2025

Dear Colleagues

We appreciate your help in partnering with FIGIJ to create a protected space to learn, teach and engage in scientific discourse free from commercial bias and respectful of patients/study participants. As trusted authorities, we are committed to protection of health information. We ask that you please review [FIGIJ's privacy and confidentiality policy](#) then provide the completed form within seven days.

I have read and will abide by the principles of the FIGIJ's privacy and confidentiality policy

- Yes

Signature	
Name	
Date	
Date and place of exam	



APPENDIX 5 IFEPAG CANDIDATES PRIVACY DECLARATION

Document V2 2025 10 20
 Last Approved on 2025 09 15

Dear IFEPAG Candidates

We appreciate your help in partnering with FIGIJ to create a protected space to learn, teach and engage in scientific discourse free from commercial bias and respectful of patients/study participants. As trusted authorities, we are committed to protection of health information. We ask that you please review [FIGIJ's privacy and confidentiality policy](#) then provide the completed form during the application of the IFEPAG examination.

I have read and will abide by the principles of the FIGIJ's privacy and confidentiality policy

- Yes

Signature	
Name	
Date	
Date and place of exam	



INTERNATIONAL FEDERATION OF PAEDIATRIC AND ADOLESCENT GYNAECOLOGY

FEDERATION INTERNATIONALE DE GYNECOLOGIE INFANTILE ET JUVENILE

FEDERACION INTERNACIONAL DE GINECOLOGIA INFANTIL Y JUVENIL

APPENDIX 6 TEMPLATE FOR CONSENT FOR PUBLICATION OF A CASE STUDY REPORT OR CASE SERIES (FOR CONFERENCES)

Document V2 2025 08 01

Approved on 15/9/2025

Dear (name)

I am asking your permission to use and share (name's) medical information for the purposes of medical education for a case study report.

What is a case study report?

A Case Study Report is a description and explanation of a person's medical condition and treatment. Scientists and doctors like to publish these as they can be used to teach other health professionals. Reports are intended to be published or presented in ways aimed mainly at health providers (e.g. in a medical journal, thesis, or at a conference), although they are usually publicly available.

Where could this case study report be published?

This Case Report will be for (choose one: presentation at the [insert name, location and date of conference];).

Who can access the Case Study Report?

The information will be presented to other health providers at the conference who are bound by confidentiality. A summary of the information may be published in a conference proceeding or abstract in a journal, but only with your consent.

Will people who read the Case Study Report know who it is about?

The report will be presented without including information that can identify (you/your child). Thus it will not include name date of birth, hospital number, social security number etc). Only information already recorded in the medical record that was part of routine care, will be used. You may review the medical information before you consent to share this. Rarely it is possible someone who knows you well - may identify you/them.

Can I withdraw consent

Your decision is voluntary and will not affect (your/names) medical care. You may withdraw consent at any time before the case study report is published. If it is already published in conference proceedings or an abstract, you cannot withdraw consent.

A copy of this consent form will be filed in the medical record, another copy will be saved by your clinical team at (your hospital name) under the custodianship of (name of person holding consent), and a third copy will be provided to you.

CONSENT

I have read and understood this consent form, and have been provided with a copy for my records	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I consent for (my/names) medical information to be used for presentation at (name of conference year location).	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I consent for (my/names) medical information to be published in an abstract or conference proceedings.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Signature		
Name	Date	
Witness Signature		
Witness name	Date	



INTERNATIONAL FEDERATION OF PAEDIATRIC AND ADOLESCENT GYNAECOLOGY

FEDERATION INTERNATIONALE DE GYNECOLOGIE INFANTILE ET JUVENILE

FEDERACION INTERNACIONAL DE GINECOLOGIA INFANTIL Y JUVENIL

APPENDIX 7 TEMPLATE FOR CONSENT FOR PUBLICATION OF A CASE STUDY REPORT FOR CASE CORNER

Document V2 2025 08 01

Approved on 15/9/2025

Dear (name)

I am asking your permission to use and share (name's) medical information for the purposes of medical education for a case study report.

What is a case study report?

A Case Study Report is a description and explanation of a person's medical condition and treatment. Scientists and doctors like to publish these as they can be used to teach other health professionals.

Where could this case study report be published?

This Case Report will be for publication on a password protected website of the International Federation of Paediatric and Adolescent Gynaecology. It will be removed after nine years.

Who can access the Case Study Report?

The information will be presented to other health providers in the society who are bound by confidentiality. They can only access it with a password.

Will people who read the Case Study Report know who it is about?

The report will be presented without including information that can identify (you/your child). Thus it will not include name date of birth, hospital number, social security number etc). Only information already recorded in the medical record that was part of routine care, will be used. You may review the medical information before you consent to share this. Rarely it is possible that someone who knows you well - may identify you/them.

Can I withdraw consent

Your decision is voluntary and will not affect (your/names) medical care. You may withdraw consent at any time and the information will be destroyed. A copy of this consent form will be filed in the medical record, another copy will be saved by your clinical team at (your hospital name) under the custodianship of (name of person holding consent), and a third copy will be provided to you.

CONSENT

I have read and understood this consent form, and have been provided with a copy for my records

Yes

No

I consent for [\(my/names\)](#) medical information to be used for publication in Case Corner on the secure International Federation of Paediatric and Adolescent Gynaecology website.

Yes

No

Signature

Name

Date

Witness Signature

Witness name

Date



APPENDIX 8 CASE CORNER ACCESS AND PRIVACY DECLARATION

Document version v2 2025 08 01
 Approved on 15/9/2025

Dear Colleagues

We appreciate your help in partnering with FIGIJ to create a protected space to learn, teach and engage in scientific discourse free from commercial bias and respectful of patients/study participants. As trusted authorities, we are committed to protection of health information. We ask that you please review [FIGIJ's privacy and confidentiality policy](#), and complete this form within 7 days.

Name	
Role	
Institution	
Email	
Member society of FIGIJ	
Individual member or Societal membership	
Please provide email verification of your membership (subscription) or email verification from your Head of Department or PAG society secretariat verifying membership	

PRIVACY DECLARATION

1. I am a FIGIJ member and have verified this by individual subscription of FIGIJ or of my PAG society, or email verification from my Head of Department (HOD) or PAG society secretariat (attached).
 - Yes
2. I have read and agree to abide by the principles of the FIGIJ's privacy and confidentiality policy
 - Yes
3. I agree not to download clinical cases from Case Corner onto my personal devices.
 - Yes

I attest that the above information is correct (please sign below)

Signature of applicant	
Name and date	

FIGIJ INTERNAL USE

Approved by Resources Committee

- yes
- no

Date