



IPMPC

International Pharmaceutical &  
Medical Device Privacy Consortium

2023 YEAR IN  
REVIEW



# Contents

Letter from IPMPC Chair	<b>1</b>
Mission	<b>2</b>
Membership Benefits	<b>3</b>
2023 By the Numbers	<b>4</b>
Insights from Our Members	<b>5</b>
2023 Regional Initiatives	<b>6-9</b>
2023 Initiatives Addressing Important Topics	<b>10</b>
2023 Member Companies	<b>11</b>
2023 Board of Directors	<b>12</b>
Secretariat	<b>13</b>

# Letter from the IPMPC Chair



**Alejandro Gené**  
Chief Privacy Officer  
Bristol Myers Squibb

Dear IPMPC Members and Community,

I am proud to welcome you to the IPMPC's 2023 annual report. In reflecting on the accomplishments of the past year, I recognize and thank all IPMPC members for their collaboration and engagement. In 2023, the consortium held over 100 IPMPC meetings, organized timely webinars on priority topics such as *Navigating India's Digital Personal Data Protection Act* and *Managing the Changing Cookies Requirements in the U.S.*, conducted benchmarking surveys addressing more than 25 different topics, and developed over 35 timely and practical resources, templates, and summaries.

I am particularly grateful that in 2023 IPMPC members had several opportunities to meet and collaborate in-person during conferences and meetings again. The IPMPC Board of Directors gathered in Washington, D.C. in June and in Brussels, Belgium in November to discuss strategic priorities, coordinate advocacy initiatives, and benchmark on timely topics. The U.S. Working Group hosted a practical "Workshop on Patient Assistance Programs in the U.S." in Washington, D.C. The European Working Group held a meeting in Brussels, Belgium to address members' top European data protection issues, review 2023 European data protection developments, and discuss the evolving requirements for further uses of health data. In December 2023, the IPMPC Asia-Pacific Privacy Roundtable brought members together at the Secretariat's office in Shanghai, China for the "IPMPC China Privacy Compliance Workshop."

A great 2023 highlight was the IPMPC Summit on "The Evolving Role of Privacy & Data Compliance in the Digital Era." The full-day Summit facilitated timely, strategic and forward-thinking discussions among global privacy leaders, regulators, and policy experts. The Summit addressed the future of AI regulation, the evolving role of privacy and data protection leaders, and the impact of privacy enhancing technologies (PETs) on data protection compliance. This event provided an engaging day of learning, information sharing, and encouragement and optimism about the evolving roles and responsibilities of privacy leaders in all industries and especially in the life sciences. The 2023 IPMPC Summit also served as a springboard for ideas and topics that will be addressed at forthcoming IPMPC Summits.

Additional key focus areas for the IPMPC in 2023 included new U.S. privacy laws and new requirements for consumer health data in the U.S., the EU-U.S. Data Privacy Framework and international data transfers, and emerging privacy legislation in Latin America and the Asia-Pacific. The IPMPC also played an important role in promoting advocacy efforts through regular coordination with life sciences industry stakeholders. The consortium held a number of joint-meetings with Efpia and MedTech Europe to discuss European data protection considerations, including international data transfers and artificial intelligence. The IPMPC Board of Directors also invited representatives from AdvaMed and BIO to strategic advocacy discussions regarding the evolving U.S. privacy landscape. In 2024, the IPMPC will focus on education and coordination between associations to ensure the life sciences industry speaks with a coherent voice on data protection issues.

The IPMPC continues to be well-positioned to support its members at a unique point in time. The life sciences industry will be navigating an increasingly complex data protection landscape as well as embracing the evolving role of data privacy within a framework of emerging technology, AI, and digital compliance. The IPMPC looks forward to fostering community and bringing members and thought leaders together to share and promote best practices for data protection in the life sciences industry, educate internal and external stakeholders on data protection and the importance of data innovation, and support one another.

# Our Mission



Provide a forum to ensure that the global life sciences industry speaks with one, coherent voice on data privacy issues



Augment member companies' data protection capabilities through the development and sharing of industry best practices



Advance the protection of individual privacy



Anticipate and respond to new challenges affecting the protection of health information



Educate internal and external stakeholders on data protection in the industry and the importance of data innovation

# Privileges of Membership

Access to extensive **privacy-compliance resources** tailored to the needs of the pharmaceutical and medical device industry

**Legal, project management, and logistical support** by the IPMPC Secretariat

**Timely analyses of new privacy laws, court decisions, and pharmaceutical and medical device enforcement actions** impacting business operations

**Updates on global privacy developments** and informative, practical discussions with local counsel from around the world

**Expert insight** into how evolving business models could be impacted by privacy laws

Opportunities to **interact with key regulators**

Regular **interaction and benchmarking with industry colleagues** facing similar challenges

Cost-sharing to **efficiently leverage budget resources**

# By the Numbers



**39**

member companies



**100+**

teleconferences and virtual meetings

**3**



in-person workshops for IPMPC Regional Initiatives: US Working Group, European Working Group, and China Privacy Compliance Roundtable

**2**



new initiatives launched: IPMPC AI Project Team & IPMPC Collaborative Roundtables with MedTech Europe

**2**



submitted responses on regulatory guidance and proposed legislation

**35+**



templates, summaries, and additional resources developed

**12**



comprehensive aggregated benchmarking surveys addressing over **25** different topics

**1,000+**

attendees at IPMPC meetings and roundtables over 2023

Inaugural IPMPC Summit on “The Evolving Role of Privacy & Data Compliance in the Digital Era” with **18** guest presenters and over **60** in-person and virtual individuals attending globally

Second annual IPMPC, MedTech Europe, and Efpia briefing meeting following IAPP Global Data Protection Congress in Brussels

IPMPC Networking Reception during IAPP Global Data Protection Congress in Brussels with over **65** attendees



# Member Insights

"I would highly recommend joining the IPMPC to any company considering it. The resources offered and the engagement with other privacy colleagues are invaluable as organizations navigate the complexities of the privacy landscape. My team and I greatly benefit from the IPMPC's benchmarking on emerging issues, templates and guidance documents on new regulations, webinars on regulatory changes and enforcement actions, opportunities to impact the regulatory environment, and engagement on important topics such as AI and the evolution of privacy as a business enabler."



**Terry-Ann Cooper**

*Associate Vice President, Chief Privacy Officer & Head of Privacy Law*  
Organon

"The IPMPC is one of the best groups I have been involved in during my career! It is well run, provides great resources, and includes outstanding presentations that are immediately impactful. I particularly appreciate that the consortium can expertly address the privacy issues we face every day but also pivot to address emerging topics –for example, the AI working sessions will continue to be an important forum within IPMPC and serve as a bridge during a time when the industry is embracing AI but committing to ethical uses of data."



**Amie Philips Pablo**

*Vice President, Corporate Compliance & Privacy Officer*  
Novo Nordisk

"IPMPC membership provides access to a wealth of collective knowledge and experience in dealing with complex privacy issues, which is invaluable in today's rapidly evolving regulatory landscape. This year, our membership in the IPMPC has been instrumental in keeping my team informed and ahead of the curve on privacy trends, regulatory changes, and enforcement activities. I would highly recommend IPMPC membership to any life sciences company. It provides a unique platform for learning, sharing, and collaborating on critical privacy issues and enables active participation in shaping the future of privacy in our industry. IPMPC also allows life sciences companies to speak with a unique voice on privacy issues, enhances the privacy capabilities of your team through various resources, and demonstrates a commitment to leading privacy practices that are essential in today's global market."



**João Barreiro**

*Chief Privacy Officer (Global)*  
BeiGene

"IPMPC has been an invaluable resource to Incyte during a busy and exciting time. The consortium offers a great balance of globally focused initiatives and discussions while facilitating our ability to keep track of key developments and share practical insights and best practices. Everyone on our team has benefitted from the IPMPC!"



**Amy Anderson**

*Global Privacy Officer, Associate Vice President*  
Incyte

"I am a big fan of the IPMPC. The consortium is filling a gap that is not filled elsewhere. The weekly discussions on U.S. privacy laws in 2023 were effective, strategic, and immediately helpful to all members. Without the IPMPC it is hard to imagine how companies would have kept up with the avalanche of developments. IPMPC will continue to serve an important role because it meets the life sciences industry where it is, understands the unique challenges faced by privacy leaders in this industry, and strives to provide practical and thoughtful solutions and resources that are immediately useful."



**Xavier Jean**

*VP Chief Privacy Officer*  
Sanofi

"IPMPC membership enables our team to serve our business stakeholders more effectively. We are called upon to make strategic decisions and provide timely and practical guidance. IPMPC resources – whether benchmarking reports, live discussions, or toolkits and templates – are unique; they are focused on our industry's challenges and reflect the collaborative and sophisticated insights of industry thought leaders. This is extremely valuable for us and we cannot find this elsewhere!"



**Erin Geygan**

*Senior Counsel – Privacy*  
Johnson & Johnson

# European Working Group



**Efstathia Gkika**  
*European Working Group*  
Co-Chair  
Baxter



**Luca Nevano**  
*European Working Group*  
Co-Chair  
Becton Dickinson

## 2023 Accomplishments:

- Monitored privacy developments in Europe and provided summaries of key changes, including developments in regards to the EU-U.S. Data Privacy Framework, EU AI Act, European Health Data Space, Cyber Resilience Act, European Court of Justice key rulings, and guidance and enforcement actions by European data protection authorities
- Provided opportunities for live benchmarking discussions, including concerning website analytics and cookie-less solutions, the ethical use of artificial intelligence, and the interplay of the EU Whistleblowing Directive and data protection requirements
- Developed IPMPC Checklist for EU-U.S. Data Privacy Framework Implementation
- Organized IPMPC meeting in Brussels to discuss evolving requirements for further uses of health data
- Organized joint-meeting with Efpia and MedTech Europe members in Brussels to debrief from IAPP Data Protection Congress and share progress on respective initiatives



**Felix Czwikla**  
*Privacy Counsel, EMEA*  
Becton Dickinson

"The IPMPC European Working Group provides an important forum for IPMPC members to discuss evolving European data protection and compliance developments. In particular, in 2023 the European Working Group met in-person in Brussels for a workshop focused on further uses of health data in Europe. This opportunity to engage in practical discussions and review case studies on a key issue for the life sciences industry was of great value to IPMPC members. As Co-Chair of the European Working Group in 2024, I am looking forward to continuing to bring together IPMPC members to discuss new developments and benchmark on practical compliance considerations."

# U.S. Working Group



**Charlie Blanchard**  
*US Working Group*  
Co-Chair  
Amgen



**Katie Fierek**  
*US Working Group*  
Co-Chair  
Eli Lilly & Company

## 2023 Accomplishments:

- Monitored privacy developments in the U.S. at the state and federal level and provided summaries of key changes, including in relation to new consumer health state privacy laws, state privacy legislation and regulations, genetic and biometric privacy legislation, enforcement actions by the Federal Trade Commission (FTC), and pixel litigation
- Provided opportunities for live benchmarking discussions on priority topics, including around the implications of FTC enforcement actions, managing changing requirements around the use of online trackers, and compliance with requirements to obtain opt-in for uses and disclosures of sensitive data
- Organized webinars on: FTC BetterHelp Enforcement, FTC GoodRx Overview & FAQs, Marketing Practices & Health Information Privacy, Sensitive Data Consent Requirements, and Use of Pixels and Similar Tools on Health Websites and Apps in the U.S.
- Organized workshop in Washington, D.C. on privacy requirements for U.S. patient assistance programs, with over 60 in-person and virtual attendees
- Created and regularly updated the 2023 IPMPC State Privacy Legislation Tracker
- Updated and expanded IPMPC State Privacy Compliance Toolkit resources for compliance with new privacy laws and consumer health data laws
- Submitted Comments on the FTC's proposed changes to its Health Breach Notification Rule
- Submitted Comments on the proposed rules implementing the Colorado Privacy Act



**Joanna Levin**  
*Assistant General Counsel*  
Pfizer

"2023 marked another year with a lot of changes in the U.S. privacy landscape. The IPMPC's U.S.-focused initiatives were an incredibly helpful resource to my team and me. The timely tracking of privacy legislation combined with thoughtful summaries, practical tools and templates, and benchmarking discussions helped us navigate the evolving requirements and obtain helpful insights from our peers in the industry. The IPMPC's industry benchmarking, both formal and informal, and the collaborative and generous nature of the group are key differentiators for us."

# Asia-Pacific Roundtable



**Agatha O'Malley**  
*Asia-Pacific Roundtable  
Co-Chair*  
Otsuka

## Asia-Pacific Roundtable 2023 Accomplishments:

- Organized quarterly Asia-Pacific Roundtable meetings to discuss new privacy legislation in the Asia-Pacific region and support benchmarking discussions on priority topics of interest
- Webinar on Privacy Developments in South Korea - Presentation by Bae, Kim & Lee on the amendments to PIPA
- Webinar on India's Digital Personal Data Protection Bill - Presentation by AZB & Partners on the new data protection bill in India
- Updated Asia-Pacific Privacy Legislation Landscape Tracking Chart



**Viola Pan**  
*Asia-Pacific Roundtable  
Co-Chair*  
Organon

## China Privacy Compliance Roundtable 2023 Accomplishments:

- Hosted IPMPC China Privacy Compliance Workshop at the IPMPC Secretariat's Shanghai office with participation from 8 guest speakers and over 40 in-person and virtual attendees
- Organized 5 China Privacy Compliance Roundtable Meetings to address the Proposed New Rules for Cross-Border Data Transfers, Measures on the Standard Contract for the Cross-border Transfer of Personal Information, and key benchmarking topics, including Cross-border data transfer security assessments, Personal Information Protection Impact Assessments (PIPIAs), Data localization, Responding to data subject requests, Personal Information deletion, Reporting Requirements, and Records of data processing procedure
- Conducted benchmarking survey and created aggregated report on key compliance considerations in China



**Violet Shan**  
*Data Privacy Manager  
and Data Protection  
Officer, APAC*  
Cook Medical

"The IPMPC's APAC initiatives have been instrumental in building a platform for mutual communications among industry privacy leaders. Presentations on privacy developments in the region and benchmarking on industry privacy practices not only provide participants with insights but also facilitate the exchange of experiences. Understanding the state of compliance in our industry and where we stand at a given point in time can help boost confidence in dealing with uncertainty in an evolving regulatory landscape. In particular, I found great joy and value in the IPMPC's China Privacy Compliance Workshop held in Shanghai this past December. It's a great feeling to connect with industry peers in real life. Handshaking shortened the social distance and smiling to others created more interactions. Speaking, presenting and sharing with others in a cozy conference room created an atmosphere of cooperation, thus reinforcing our initial need to learn from each other and improve ourselves. I am very grateful to the IPMPC and look forward to the next in-person meeting this year."

# Latin America Roundtable



**Arturo Cuellar**  
*Latin America Roundtable*  
*Co-Chair*  
Fresenius Medical Care



**Teresa Patraquim da Conceição**  
*Latin America Roundtable*  
*Co-Chair*  
Novartis

## 2023 Accomplishments:

- Organized roundtable meeting series with local counsel from several different countries to address privacy developments in Latin America:
  - Latin America Roundtable on Current Latin America Privacy Landscape & What to Look Out For in 2024: The IPMPC invited local counsel from several Latin American countries to participate in a panel session to assess the current privacy landscape in the region and highlight priority countries and topics to watch in 2024. Invited firms included Santamarina y Steta, Marval, O'Farrel & Mairal, and Machado Meyer.
  - Latin America Roundtable on Privacy Developments in Argentina: The IPMPC organized presentations from three local law firms in Argentina, Beccar Varela, Marval, O'Farrel & Mairal, and ECIJA, to provide an overview of the history of the regulation of data privacy in Argentina, the proposed personal data protection bill, and priority privacy topics relevant to the pharmaceutical and medical device industry.
  - Latin America Roundtable on Privacy Developments in Brazil: The IPMPC organized presentations from three local law firms, Machado Meyer, Rabelo Maurer, and Pinheiro Neto Avogados, to provide an overview of the history of the LGPD, LGPD guidance relevant to the pharmaceutical and medical device industries, and key compliance considerations.



**Arturo Cuellar**  
*Privacy Lead Latin*  
*America and Global*  
*Support Functions*  
Fresenius Medical Care

"I am grateful for the practical and timely presentations and discussions organized by the IPMPC Latin America Roundtable in 2023. The IPMPC invited local counsel from different jurisdictions to share insights on new developments in the region and keep IPMPC members apprised of changing compliance requirements. Participating in the roundtable meetings allows IPMPC members to gain a better understanding of how privacy regulations and guidance are evolving in Latin America. Furthermore, the practical benchmarking discussions provide a unique opportunity to address top-of-mind issues specific to the life sciences industry. I am looking forward to participating in roundtable meetings in 2024. I am especially keen in looking into best practices when integrating the different regulatory frameworks in the region into global privacy programs. Also, I am interested in keeping up to date on how countries in Latin America continue to address emerging technologies such as artificial intelligence and the Internet of Things (IoT)."



# 2023 Initiatives Addressing Important Topics

## IPMPC AI Project Team

The IPMPC launched the AI Project Team in 2023 to provide a forum for members to explore issues related to AI-governance and develop IPMPC tools to help member companies' AI governance programs. The Project Team conducted a benchmarking survey and created a report on AI Governance & Risk Management and developed Vendor Contract AI Template Clauses.

## IPMPC & MedTech Europe Collaborative Medical Device Roundtable

Beginning in Fall 2023, the IPMPC Medical Device Roundtable launched a series of joint-discussions with MedTech Europe to focus on privacy issues for medical device and medtech companies and identify benchmarking questions and discussion topics.

## IPMPC Privacy Stewardship & Privacy Programs Project Team

IPMPC members organized a meeting to benchmark on priority topics for Data Privacy Day 2024, while also developing a IPMPC crowdsourcing resource.

## International Data Transfers Project Team

Organized 3 meetings to provide IPMPC members with an opportunity for open benchmarking in response to important international data transfer developments, including the Irish Data Protection Commission's Decision Against Meta and the EU Commission's Adequacy Decision concerning the EU-U.S. Data Privacy Framework.

### ROUNDTABLE

## Changing Requirements for Cookies & Websites in the U.S.

This roundtable, facilitated by Nick Apruzzi (Incyte), Sara Berkson (Vertex), and Joanna Levin (Pfizer) provided an opportunity for members to review U.S. privacy requirements and relevant enforcement and guidance related to the use of online tracking technologies in the health industry, to discuss respective health privacy requirements on the state level in California, Colorado, Washington and Connecticut, and to benchmark on best practices.

### ROUNDTABLE

## Informed Consent Management: Good Practices & Lessons Learned

This roundtable, facilitated by Amy Anderson (Incyte), Alejandro Gené (Bristol Myers Squibb), and Amie Phillips Pablo (Novo Nordisk), reviewed ICF requirements and guidance and provided an opportunity for members to engage in an open benchmarking discussion on ICF management.

# Member Companies

Abbott Laboratories  
AbbVie  
Adaptive Biotechnologies  
Amgen  
Amicus Therapeutics  
Astellas Pharma  
AstraZeneca  
Baxter  
Becton, Dickinson and Company  
BeiGene  
BioMarin  
Boehringer-Ingelheim  
Bristol Myers Squibb  
Cochlear Limited  
Cook Medical  
Eli Lilly and Company  
Fresenius Medical Care  
Genentech/Roche  
Gilead Sciences  
GSK  
Idorsia  
Incyte  
Jazz Pharmaceuticals  
Johnson & Johnson  
Karl Storz  
Kyowa Kirin  
Moderna  
Novartis  
Novo Nordisk  
Organon and Company  
Otsuka Pharmaceutical Company  
Pfizer  
Regeneron Pharmaceuticals  
Sanofi  
Seagen  
Stryker  
Sunovion Pharmaceuticals  
Takeda Pharmaceutical Company  
Vertex Pharmaceuticals

# Board of Directors



**Alejandro Gené**

*Chair of IPMPC*  
Bristol Myers Squibb



**Charlie Blanchard**

*Vice Chair of IPMPC*  
Amgen

## Planning Committee

Theresa Niland *Astellas*

João Barreiro *BeiGene*

Megan Charlesworth *Cook Medical*

Laura Donahue *Eli Lilly*

Amie Philips Pablo *Novo Nordisk*

Joanna Levin *Pfizer*

Gloria Greco *Stryker*

### **Abbott Laboratories**

Jacob Springer

### **AbbVie**

Eric Berman  
Fran Wiet

### **Adaptive Biotechnologies**

Alea Garbagnati  
Joanna Winn

### **Amgen**

Charlie Blanchard  
Emily Mason

### **Astellas Pharma**

Theresa Niland  
Antonios Roussos

### **AstraZeneca**

Amy Papili  
Laura Marchant

### **Baxter**

Efstathia Gkika  
Mary Deligianni

### **Becton, Dickinson and Company**

Luca Nevano

### **BeiGene**

João Barreiro

### **Boehringer-Ingelheim**

Catherine Williams

### **Bristol Myers Squibb**

Luis Vilarin

### **Cook Medical**

Megan Charlesworth

### **Eli Lilly and Company**

Laura Donahue  
Audrey Mills

### **Fresenius Medical Care**

Bobby Rao  
Dorene Stupski

### **Genentech/Roche**

Kimberly Gold  
Florian Zabel

### **Gilead Sciences**

Danielle Manner

### **GSK**

Catherine Baena  
Jesús Herranz

### **Incyte**

Amy Anderson

### **Jazz Pharmaceuticals**

Rachel Ralston  
Jessica Vialle

### **Johnson & Johnson**

Ivelisse Clausell  
Winston Khoo

### **Karl Storz**

Erica Yen  
Reginald McKee

### **Kyowa Kirin**

Catherine Clemons  
Chad McManamy

### **Moderna**

Zoe Philippides  
Marcus Sinha

### **Novartis**

Ashley Bashore  
Franziska Janorschke

### **Novo Nordisk**

Amie Philips Pablo

### **Organon and Company**

Terry-Ann Cooper  
Kelly Tyler

### **Otsuka Pharmaceutical Company**

David McKinney  
Agatha O'Malley

### **Pfizer**

Patrice Ettinger  
Joanna Levin

### **Regeneron Pharmaceuticals**

Ericka Watson

### **Sanofi**

Xavier Jean

### **Seagen**

Elizabeth Smith

### **Stryker**

Gloria Greco  
Melissa Van Buhler

### **Takeda Pharmaceutical Company**

Rachel Chapman  
Nick Tyler

### **Vertex Pharmaceuticals**

Sara Berkson  
Michael Bullard

# Secretariat

For more information and to stay up to date on IPMPC activities, visit [ipmpc.org](http://ipmpc.org) and follow the IPMPC's [LinkedIn Page](#).



## In Support of the IPMPC, the Secretariat:

Prepares legal analyses and drafts compliance and training tools and materials

Coordinates regular industry benchmarking

Facilitates dialogue, consensus-building, and governance

Manages outreach and legislative contacts

Organizes teleconferences, meetings, and workshops

Prepares meeting agendas, summaries, and presentations

Serves as antitrust counsel

The law firm of Faegre Drinker Biddle & Reath LLP serves as Legal Counsel and Secretariat to the IPMPC. Composed of attorneys, scientists, and project managers, the Consortia Management Team forms and supports life sciences industry collaborations that help companies throughout the world address complex topics of mutual interest. For more than 25 years, the team's work with these collaborations has focused on issues impacting the pharmaceutical and medical device industries.

## IPMPC Membership Inquiries

Membership in the IPMPC is open to research-based medical device and pharmaceutical companies. Because membership is at the company level, members enjoy unlimited participation on IPMPC working groups and IPMPC educational webinars.

For questions about the IPMPC's priorities, progress, or membership, please email [info@ipmpc.org](mailto:info@ipmpc.org) or contact:



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