



**PiCC**<sup>®</sup>  
UNITED

## **Bylaws of PiCC United Stichting**

Version 1.0, May 2026

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## 1 ROLE OF THE BYLAWS (revised)

### 1.1 Role of the Bylaws

These Bylaws are an internal governance document of PiCC United Stichting.

They supplement the Deed of Incorporation and describe the governance framework, internal organisation, and decision-making arrangements of the Foundation.

The Bylaws shall at all times be interpreted and applied in a manner consistent with the Deed of Incorporation and applicable Dutch Civil Law (Burgerlijk Wetboek, Boek 2). In the event of any inconsistency, the Deed of Incorporation and mandatory law shall prevail.

### 1.2 Bylaw ownership and maintenance (revised)

The Bylaws are adopted, owned, and maintained by the Board of PiCC United Stichting.

The Board may amend, revise, or rescind these Bylaws by formal Board resolution.

The Board shall review the Bylaws annually, to ensure that they remain fit for purpose and aligned with the Foundation's mission, governance needs, and legal obligations.

The Board may, at its discretion, consult advisory bodies or community representatives when considering amendments to the Bylaws, provided that such consultation does not confer decision-making authority or legal rights.

### 1.3 1.1 Definitions

In these Bylaws, unless the context requires otherwise, the following terms shall have the meanings set out below:

**Board** means the Board of PiCC United Stichting (Raad van Bestuur), being the sole governing body of the Foundation.

**Director (Bestuurder)** means a natural person appointed as a member of the Board in accordance with the Deed of Incorporation and these Bylaws, and who holds collective responsibility for the governance, strategy, and legal oversight of the Foundation under Dutch law.

**Bylaws** means these bylaws of PiCC United Stichting, as amended from time to time by resolution of the Board.

**Deed of Incorporation** means the notarial deed establishing PiCC United Stichting, including its articles of association (statuten), as amended from time to time.

**Foundation** means PiCC United Stichting, a foundation (stichting) incorporated under and governed by the laws of the Netherlands.

**Special Resolution** means a resolution adopted by a qualified majority of at least two-thirds (2/3) of the votes cast by the Board, where such majority is expressly required under these Bylaws.

## 2 About PiCC United

### 2.1 Name of the Foundation

The legal name of the foundation is **PiCC United Stichting**.

The Foundation may operate and communicate under the name is PiCC United (Patient Involvement and Collaboration Community United).

### 2.2 Purpose and Mission

The purpose of PiCC United Stichting is to serve the public interest by promoting and strengthening meaningful patient involvement and engagement in research, healthcare, policy development, and society.

The Foundation aims to improve accessibility, inclusivity, and diversity in patient involvement by supporting individuals and communities who may otherwise face barriers to participation.

In pursuing its purpose, the Foundation operates on a non-profit basis and does not seek to generate profits for distribution to founders, Directors (Bestuurders), or any other private persons.

The Board shall determine the strategy, activities, and methods through which the purpose of the Foundation is pursued, in accordance with applicable law and the Deed of Incorporation.

### 2.3 Alignment with the United Nations Sustainable Development Goals

The activities of PiCC United Stichting are informed by and broadly aligned with relevant objectives of the United Nations Sustainable Development Goals (SDGs), in particular those relating to health and well-being, reduced inequalities, and partnerships.

This alignment serves as a guiding reference and does not create legal obligations or limit the discretion of the Board in determining the Foundation's strategy, priorities, or activities.

### 2.4 Language

The working language of the Foundation is English.

Where required for legal filings, registration, or communication with authorities in the **Netherlands**, the Foundation may use the Dutch language.

## 2.5 Registered Office

The statutory seat (statutaire zetel) of the Foundation is in The Hague ('s-Gravenhage), the Netherlands.

The Board shall determine and may change the registered office address of the Foundation within the Netherlands by Board resolution.

## 2.6 Financial Year

The financial year of the Foundation shall run from 1 January to 31 December.

## 2.7 Banking

The Board is responsible for establishing and maintaining one or more bank accounts in the name of the Foundation with financial institutions deemed appropriate by the Board.

The Board shall determine by Board resolution which Directors or authorised representatives may operate the Foundation's bank accounts, including signing authority, approval limits, and dual approval requirements.

## 2.8 Borrowing Powers

The Foundation shall not engage in borrowing as a primary means of financing its activities.

The Board may, only where strictly necessary and in furtherance of the Foundation's purpose, resolve to enter into borrowing arrangements or assume financial obligations, provided that such arrangements are prudent, proportionate, and do not jeopardise the financial sustainability or independence of the Foundation.

Any decision to borrow shall be taken by formal Board resolution.

## 2.9 Financial Responsibility

The Board shall ensure that the financial affairs of the Foundation are managed in a prudent and responsible manner, in accordance with applicable Dutch law and generally accepted principles of non-profit financial governance.

The Board shall take appropriate action if the financial position of the Foundation gives rise to material risk.

## 3 Structure and Governance Overview

PiCC United Stichting is governed by its Board (Raad van Bestuur), which holds full legal responsibility for the governance, strategy, and oversight of the Foundation.

The Board may establish advisory bodies, committees, working groups, or other supporting structures to assist in the execution of the Foundation's purpose and

activities. Such bodies shall operate under mandates approved by the Board and shall not have independent decision-making authority or legal status.

The Board may delegate operational tasks and responsibilities to Directors (Bestuurders), external partners, or appointed representatives, provided that such delegation does not transfer the Board's collective legal responsibility.

## **4 PiCC United Board (Raad van Bestuur)**

The Foundation shall be governed by a Board (Raad van Bestuur), which is the sole governing body of PiCC United Stichting.

The Board holds collective responsibility for the governance, strategy, financial management, and legal compliance of the Foundation and acts in the best interest of the Foundation and its public-benefit purpose.

Directors (Bestuurders) shall perform their duties in accordance with applicable Dutch law, the Deed of Incorporation, and these Bylaws.

### **4.1 Responsibilities of the Board**

The Board shall act collectively and is jointly responsible for the governance, strategic direction, financial oversight, and legal compliance of the Foundation.

Each Director (Bestuurder) shall perform their duties in good faith, with due care and diligence, and in the best interest of the Foundation and its public-benefit purpose.

The Board may allocate specific roles, tasks, or areas of focus among its Directors or delegate operational responsibilities to Directors, committees, or external parties, provided that such delegation does not transfer the Board's collective legal responsibility.

### **4.2 Composition of the Board**

The Board shall consist of at least two (2) and no more than seven (7) Directors (Bestuurders). As a matter of governance policy, the Board intends to maintain at least three (3) Directors whenever practicable.

The Board may appoint from among its members a Chair and such other internal functions as the Board considers appropriate. The allocation of such functions shall not affect the collective responsibility of the Board or the equal legal position of each Director.

All Directors shall have equal rights and obligations under Dutch law and these Bylaws.

#### **4.2.1 Chair and President**

The Board may appoint from among its Directors a Chair and, where deemed appropriate, a President.

The Chair and President shall perform such internal coordinating or representative functions as determined by the Board. The allocation of these functions shall not affect the collective responsibility of the Board, nor confer any additional legal authority, voting rights, or supervisory powers beyond those of other Directors.

#### 4.2.2 Other Directors

The Board may include Directors other than the Chair and President.

All Directors shall have equal rights and obligations and shall participate collectively in the governance and decision-making of the Foundation.

The Board may allocate internal functions or areas of responsibility among its Directors as it considers appropriate, without affecting the collective responsibility of the Board.

### 4.3 Appointment and Reappointment

Directors (Bestuurders) shall be appointed by resolution of the Board.

Appointments may be made for an indefinite or fixed term, as determined by the Board at the time of appointment.

A Director may be reappointed by resolution of the Board, provided that the Director continues to meet the eligibility requirements set out in these Bylaws.

#### 4.3.1 Resignation and Removal

A Director may resign at any time by providing written notice to the Board.

The Board may remove a Director by resolution, with due regard to applicable Dutch law and principles of reasonableness and fairness.

A Director shall automatically cease to hold office if the Director:

- becomes legally incapable or bankrupt;
- is disqualified from holding office under Dutch law; or
- no longer meets the eligibility requirements set out in these Bylaws.

#### 4.3.2 Eligibility

To be eligible for appointment as a Director, an individual must:

- be at least eighteen (18) years of age;
- have legal capacity to act;
- not be prohibited by law from acting as a Director; and
- support the purpose and public-benefit objectives of the Foundation.
- have no prohibited conflicts of interest. Non-prohibited conflicts of interest may be permitted, provided they are declared, managed transparently, and handled in accordance with the Foundation's conflict of interest policy.

The Board may establish additional eligibility criteria through internal policies, provided such criteria are consistent with applicable law and these Bylaws.

### 4.3.3 Conflict of Interest

A Director shall not participate in deliberation or decision-making on matters in which the Director has a direct or indirect personal interest that conflicts with the interests of the Foundation.

The existence of a conflict of interest shall be disclosed to the Board in a timely manner and recorded in the minutes of the relevant meeting.

Decisions involving a conflict of interest shall be taken in accordance with applicable Dutch law and principles of good governance.

### 4.3.4 Founding Directors

The Foundation recognises **Lisbeth Oxholm Snede** and **Jenny Royle** as Founding Directors of PiCC United Stichting.

The Founding Directors were appointed at the establishment of the Foundation in recognition of their initiating role, long-term commitment, and responsibility for the development of the Foundation's purpose and governance.

A Founding Director may resign at any time by providing written notice to the Board.

A Founding Director may be removed only in accordance with Dutch law and by a Board resolution adopted with due regard to the special role and contribution of the Founding Director.

### 4.3.5 Agents and Representation

(see document article of association).

## 4.4 Board meetings and decision-making

### 4.4.1 Board meetings

The Board shall meet as often as necessary to perform its duties and at least twice per calendar year.

Board meetings may be convened by the chairperson or by any board member with reasonable notice to all board members.

Board meetings may be held in person, by telephone or electronically, provided that all participants can communicate with each other simultaneously.

### 4.4.2 Quorum

A quorum shall be present when a majority of the Directors in office are present or represented at a Board meeting.

If a quorum is not present, no binding resolutions may be adopted.

### 4.4.3 Decision-Making

The decisions of the Board of Directors are adopted by a simple majority of the votes cast, unless the Deed of Incorporation, these Bylaws, or applicable Dutch law require a higher majority.

Each member of the Board of Directors has one vote. In the event of a tie, the proposal is considered not adopted.

### 4.4.4 Written Resolutions

The Board may adopt resolutions in writing, without holding a meeting, provided that all Directors have been given the opportunity to express their views and all Directors consent to the adoption of the resolution in this manner.

Written resolutions shall have the same legal effect as resolutions adopted at a duly convened Board meeting.

### 4.4.5 Minutes

Minutes shall be kept of all Board meetings and resolutions, whether adopted at a meeting or in writing.

The minutes shall record the resolutions adopted and, where relevant, any declared conflicts of interest. The minutes shall be approved by the Board and retained by the Foundation.

## 4.5 Representation and Authority

The Foundation shall be represented by the Board acting collectively.

The Board may, by resolution, authorise one or more Directors (Bestuurders) to represent the Foundation individually or jointly, within the scope and limits determined by the Board.

The Board may also grant powers of attorney to agents or authorised representatives in accordance with Section 4.3.6, subject to such conditions and limitations as the Board may determine.

Any limitation on the authority to represent the Foundation shall only be effective internally and shall not affect third parties acting in good faith, unless such limitation is legally binding under applicable law.

## 4.6 Operational Role Areas

### 4.6.1 President & Chair

Joint responsibility (President + Chair):

- Ensure that PiCC United stays on course in terms of its purpose, values and non-profit framework
- Overall oversight of governance, compliance and ethics
- Ensuring that the board functions effectively and responsibly

- Acting as a 'safety net' if the organisation grows rapidly or faces difficult decisions

President – typical focus:

- External representation (strategic partnerships, international collaborations, foundations)
- Overall strategic development and new initiatives
- Coherence between community, projects and vision
- Ambassador for PiCC United in international forums

Chair – typical focus:

- Structure, processes and quality of board work
- Meeting facilitation and clarity of decision-making
- Ensuring correct documentation, basis for decision-making and follow-up
- Sparring partner for the President and board members

Important: In your model, the President and Chair are **not 'above' the board**, but have **extended responsibility for continuity and stability**, especially in the early years.

#### 4.6.2 Other board members (3–7 in total)

All board members:

- Have joint legal responsibility
- Make decisions collectively
- Work on a voluntary basis (with the possibility of FMV for specific tasks)

In addition, each member has a **primary area of responsibility** that matches the five pillars in the figure 📌

#### 4.6.3 The five operational priority areas – with role descriptions

#### 4.6.4 Partnerships

Board role: Partner manager

Responsibilities:

- Maintain and develop strategic partnerships
- Ensure alignment between PiCC United and external actors
- Overview of MoUs, forms of cooperation and relationships
- Ensure that partnerships strengthen – and do not dilute – PiCC United's purpose

Typical profile:

- Strong network
- Understands cross-sector collaboration
- Good at relationships and managing expectations

#### 4.6.5 Involvement Support

Board role: Patient & community manager

Responsibilities

- Overview of support for small patient groups and individuals
- Ensure that the 'low threshold' approach actually works
- Follow up on feedback from community and advisory groups
- Ensure that the patient perspective is present in decisions

Typical profile:

- Patient representative or strong experience with patient environments
- Empathetic, structured and value-driven

#### 4.6.6 Project Delivery

Board role: Project and contract manager

Responsibilities:

- Overview of ongoing projects
- Ensure that there are clear frameworks, contracts and roles
- Monitor deliverables, quality and learning
- Escalate risks or challenges to the board

Typical profile:

- Project management experience
- Understands governance, contracts and collaboration
- Structured and realistic

#### 4.6.7 Outreach & Education

Board role: Communications and knowledge manager

Responsibilities

- Overview of webinars, events, materials and knowledge
- Ensuring quality, ethics and consistency in messaging
- Support visibility and awareness
- Connection between knowledge, practice and community

Typical profile:

- Strong communication skills
- Experience with teaching, communication or advocacy
- Sees connections and can 'translate' complex knowledge

#### 4.6.8 Operational Sustainability

Board role: Head of Operations & Sustainability

## Responsibilities

- Financial overview and responsible operations
- Follow-up on budget, liquidity and funding mix
- Effective processes, systems and compliance
- Continuous improvement of the 'engine room'

## Typical profile

- Financial or organisational insight
- Focus on sustainability and risk
- Able to think long term

## 5 Financial Matters

### 5.1 Non-Profit Nature

The Foundation operates on a non-profit basis.

No profits or surpluses shall be distributed to Directors (Bestuurders), founders, or any other private persons. All income and assets of the Foundation shall be applied solely towards the achievement of the Foundation's purpose.

### 5.2 Remuneration of Directors

Directors shall not receive any remuneration for their role as Director.

Directors may be reimbursed for reasonable expenses incurred in the performance of their duties, provided that such expenses are:

- directly related to the activities of the Foundation; and
- supported by appropriate documentation.

Reimbursement of expenses shall be determined in accordance with internal policies adopted by the Board.

### 5.3 Payments for Services

Nothing in these Bylaws shall prevent a Director or a person affiliated with a Director from providing professional services to the Foundation, provided that:

- such services are demonstrably necessary for the Foundation's activities;
- the terms are fair, reasonable, and at arm's length;
- any actual or potential conflict of interest is disclosed and managed in accordance with these Bylaws; and
- the relevant Director does not participate in the decision-making process relating to such services.

## 5.4 Financial Administration

The Board shall ensure that the Foundation maintains proper financial records and accounts in accordance with applicable Dutch law and generally accepted accounting principles for non-profit organisations.

The financial administration shall provide a clear and accurate overview of the Foundation's financial position at all times.

## 5.5 Annual Accounts and Reporting

The Board shall prepare annual accounts after the end of each financial year.

The annual accounts shall be approved by the Board and made available in accordance with applicable legal requirements.

Where required by law or deemed appropriate by the Board, the annual accounts may be reviewed or audited by an independent external party.

## 5.6 Advisory structures – separate from the board

### 5.6.1 Strategic Supporter's Advisory Circle

Purpose

- Input, sparring and perspectives
- Cross-sector dialogue (patients, academia, ethics, regulators, etc.)

Important:

- No voting rights
- No legal or financial decision-making power
- Advisory, inspirational, learning role

The board's responsibility:

- Listen
- Document input
- Show how input is used (or why it is not used)

### 5.6.2 Strategic Sponsor's Advisory Board

Purpose:

- Dialogue with sponsors
- Transparency and mutual understanding
- Input for the development of the field (not PiCC United's decisions)

Important:

- Clear separation between:
  - Sponsors
  - Board decisions

- Supports compliance and trust

## 6 Amendments to the Bylaws

These Bylaws may be amended, supplemented, or repealed by resolution of the Board.

Any amendment to the Bylaws shall be adopted by a Special Resolution, unless a different majority is expressly required under applicable Dutch law.

Amendments shall enter into force on the date determined by the Board, unless otherwise specified in the relevant resolution.

## 7 Dissolution and Liquidation

### 7.1 Decision to Dissolve

The Foundation may be dissolved by resolution of the Board, adopted in accordance with these Bylaws and applicable Dutch law.

In the event of dissolution, the Board shall appoint one or more liquidators, who may be Directors, to carry out the liquidation of the Foundation.

### 7.2 Liquidation

The liquidation shall be conducted in accordance with applicable Dutch law.

During liquidation, the provisions of these Bylaws shall remain in force to the extent applicable.

### 7.3 Allocation of Remaining Assets

After satisfaction of all liabilities, any remaining assets of the Foundation shall be transferred to one or more organisations with a similar public-benefit purpose.



The recipient organisation(s) shall be designated by the Board at the time of dissolution, provided that the assets shall not be distributed to Directors, founders, or any other private persons.

## 8 Board Approval and Signature Page

This document was reviewed and approved by the Board of Trustees of **Stichting PiCC United**.

The undersigned certify that this document represents the official governing document of the Foundation and was adopted by resolution of the Board.

**Date of Approval: 01 May 2026**

<b>Name</b>	<b>Position</b>	<b>Signature</b>
Lisbeth Oxholm Snedé	President & Trustee	
Jenny Royle	Trustee	

Place: London, 21 May 2026

### **Certification**

We hereby certify that this version of the Articles of Association / Bylaws has been duly approved by the Board of Trustees and shall remain in force until amended in accordance with the governing procedures of Stichting PiCC United.

Adopted by the Board of Trustees of Stichting PiCC United on 08.06.2026.  
Signed by the authorised members of the Board of Trustees.