

# CFRE (Centre for Research Equity) GOVERNANCE and Membership Principles 2023

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## 1. Purpose of this document

**The purpose of this document is to articulate CFRE’s governance, the structure, and the systems by which CFRE is directed and controlled. It also depicts how CFRE makes operational and strategic decisions.**

Expertise, commitment, and agility are key principles for CFRE; thus, the governance structure should always be interpreted as respecting these principles.

## 2. Preamble

**The Centre for Research Equity (CFRE)**, established in October 2022 and launched in May 2023, is an independent, collaborative health and care research centre intended to improve the lives of the population. Research that is relevant and accessible requires a full understanding of population needs and priorities, which can be gained only through direct, sustained, and constructive interactions with communities. Pharmacies and Healthcare providers are a conduit to accessing the population and embedding research in prevention, treatment and management of health and wellbeing.

Our aim is to increase research equity through a unique collaboration that spans boundaries, to share knowledge, expertise and resources to increase research equity and therefore health disparities in the population.

Currently, the approach to inclusive research is fragmented and siloed, producing inconsistency and inequity. Only an open and neutral, collaborative platform of all stakeholders can achieve the common objectives to improve outcomes for all.

## 3. Key principles of CFRE

The following principles are founding principles above any other governing rule or policy.

### 3.1. *Inclusion and agility*

Since establishing CFRE, the patient engagement landscape has evolved from considering the potential risks of engagement with patients to a new reality that outlines the risks of NOT engaging with patients. The patient engagement approaches have progressed tremendously over the last five years, which creates an even greater opportunity for the future to connect some still fragmented pieces of the patient engagement landscape. Only a diverse partnership across all major stakeholder groups can effectively leverage this opportunity and reduce fragmentation. Based on this belief, the strategic **expansion/ development** of CFRE members' network needs a solid & balanced representation of relevant industries, patient organizations, and other relevant stakeholders (such as regulatory, HTA (Health Technology Assessment), academia, medical societies, and NGOs).

CFRE Members invest in a collaborative platform that delivers tools, projects, and methodologies that openly support sustainable, systematic, and meaningful patient engagement beyond the CFRE membership for the entire patient engagement ecosystem.

This approach fits the philosophy that only a balanced & diverse inclusion of all stakeholders and agile operations deliver results. As patient engagement evolves, CFRE must continue to lead by acting quickly and decisively

See [membership representation](#) and [inclusion criteria](#) (art. 5.2 and 5.1, respectively)

### **3.2. Commitment and expertise**

CFRE membership is based on expertise and commitment toward better and meaningful patient engagement within and beyond member organizations. In addition to supporting patient engagement best practices in general, membership in CFRE also represents a commitment to ambassador CFRE practices within one's organization. CFRE Members, by making this transition and demonstrating patient engagement benefits act also as exemplary cases for other organizations and stakeholders to follow.

When signing up for a membership, organizations commit to co-create, adopt, and adhere to the patient engagement frameworks principal, activities, and learnings developed with CFRE and help deploy them internally, externally, and across all other stakeholders.

### **3.3. Collaborative leadership**

The Program is non-competitive as a core principle and does not exist to promote the interests of any specific organization, their brands, or products. Members must always work for the common goal's interest, leaving individual interests at the door.

There should be a balance between what each Member brings to and takes away from the collaboration. Any deliverables should be defined in a way that creates value for all participants. Resource sharing is a value exchange. In general, tools and information produced should be open and accessible to anyone.

Finally, in committing to the common goal, Members recognize that CFRE's role is to be a catalyst and support other initiatives working towards the same purpose.

## **4. CFRE's purpose: make systematic patient engagement happen**

CFRE's goal is to improve global health by co-designing the future of healthcare for patients WITH patients. Its mission is to bring together initiatives and best practices that integrate the voice of the patient thereby speeding up the creation and implementation of a practical, globally standardized framework - that involves patients as partners - as well as the necessary tools, services, and support to allow the adoption of the framework by various stakeholders. To reach this goal, CFRE's strategy is to build the demand and create conditions for all stakeholders to implement patient engagement more systematically and with a consistent approach. Partnering with stakeholders to design and develop novel solutions means to co-create methods to help them achieve and maintain their health goals.

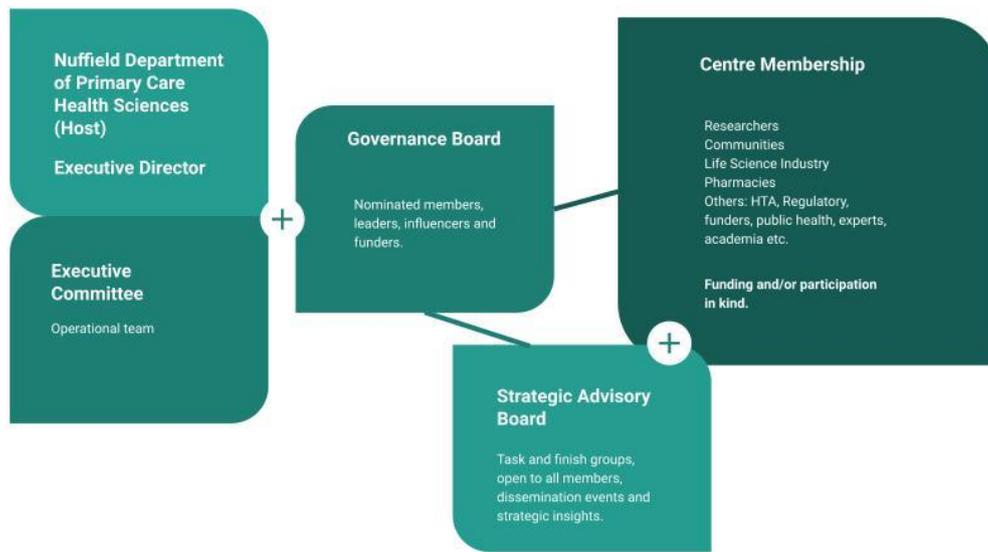
### **4.1. Nature of the Centre**

The CFRE is not a distinct legal entity. CFRE is hosted by NDPCHS (Nuffield Department for Primary Care Health Sciences) (more information can be found [here](#)) with organizations becoming members via a Membership Agreement entered into between NDPCHS and individual members.

## 4.2. Centre structure

CFRE is governed by a CFRE Board, representing members, and taking the strategic decisions for the Centre (see sections [Composition of the board](#) and [Board role & decision matrix](#); art. 6.1.1. and 6.1.4, respectively). Day-to-day operational decision-making is delegated to the Executive Director, who runs the organization.

The Executive committee is a subset of the CFRE Board. The Executive committee acts as advisor and ‘sounding board’ to the Executive Director, with no extra decision-making power.



## 5. Membership

CFRE welcomes members from all institutions, organizations, and individuals that support a better future for patients and society and are willing to invest in such a future through collaboration with the commitment, passion, and expertise to generate better patient and health systems outcomes. To become a CFRE member, prospective members must make an application to the Executive Director, who submits a recommendation together with the Executive Committee to the CFRE Board for validation.

Members’ rights include:

1. having the right to participate in the CFRE’s Strategic Advisory board;
2. having the right to participate in CFRE’s works streams and expert committees;
3. having the right to access and use CFRE data, tools, and services;
4. having the right to be benefit from services provided by the Secretariat and having the possibility to access specific licenses from CFRE (e.g., "labels," certification marks); see [intellectual property and creative common license](#) (art. 11)

Members’ obligations include:

5. contributing to the development of CFRE research inclusion good practice, tools,

methodologies, and support materials

6. upholding and applying the CFRE principles and key commitments;
7. acting as 'CFRE Ambassadors' within member organizations and externally, to actively contribute to and disseminate CFRE work, tools, and outcomes within and beyond their organizations to help drive patient engagement.

**'For-profit' members** are required to sign a membership agreement with NDPCHS and pay a membership fee.

**'Not-for-profit' members** are required to sign a Membership Agreement with NDPCHS but are not required to pay a membership fee.

### **Associate members**

Associate members are organizations that commit to funding (for-profit organizations) or participating in-kind (not-for-profit organizations) in CFRE's specific [research] projects without being official CFRE members. The commitment of an associate member for a particular [research] project shall be detailed in relevant agreement(s) with NDPCHS. Associate Members are not entitled to participate in the CFRE Strategic Advisory Board, nor take part in the governance of CFRE activities but may join the steering committee of one or more specific [research] projects.

In the context of specific [research] projects all types of membership are considered equal, and perspectives of contributing members will be considered regardless of their member status.

## **5.1. Eligibility criteria to become a CFRE Member**

All CFRE members shall demonstrate substantial experience, expertise, and/or commitment in the patient engagement area to collaborate and advance systematic patient engagement. This translates into collaborative leadership that respects the principle of non-competitiveness (3.3) and respect for every individual's expertise and background (3.1).

The following criteria are reviewed when assessing member candidatures.

### **On organization level**

- **Shared vision and values** described in the expression of interest and application form
- **Capacity to contribute:** The applicant should outline broadly the capacity of their organization to participate (describing the level of engagement) in CFRE in tangible terms.
- **Ambassadorship and people empowerment:** When signing up for membership, organizations commit to co-create, adopt, and implement patient engagement frameworks and help champion them across their organization & other stakeholders. Organizations give a clear mandate to their representative to vote and influence decisions.
- **Geographic remit:** CFRE members should normally be global or regional organizations; national umbrella bodies; or organizations, individuals, or institutions with substantial international standing or reputation in Patient Engagement.
- **Signed commitment:** Membership Agreement: with a 3-year commitment in order to be eligible for election to the CFRE Board.

## On individual level

- Individuals representing their organization on CFRE Board or SAB shall **demonstrate substantial experience and/or commitment** in the patient engagement area.
- **Commitment to collaborative leadership:** This translates into a clear motivation to practice collaborative leadership that respects the principle of non-competitiveness and every individual's expertise and background.
- **Complementarity of the candidature profile to the current CFRE diversity** (CFRE members representation criteria). Each candidature will be assessed against CFRE diversity criteria (5.2.1 below) to provide value to CFRE and ensure a balanced representation.
- **Transparency and constructive collaboration:** The applicant is expected to be transparent about their participation in similar initiatives and commit to connecting any relevant initiatives in which they may or may not be involved.

### 5.2. CFRE Members representation criteria:

CFRE strives for diversity & inclusion in its members' representation. Therefore 5 diversity criteria have been identified based on current gaps & good practices which will be monitored closely:

#### 1. Diversity of Stakeholders groups:

- Balanced representation from the communities, research and from the pharmaceutical/life sciences industry;
- HTA, Regulatory, academia, public health authority, and experts who add value to the program through their expertise, diversity, and impact whether acting from an organization, or as individual representatives.
- Looking for a broad spectrum of industry representation: Integrating members from the Device and Digital world

#### 2. Geography, culture & race:

- Increase racial and cultural diversity through members and the Board. Geographic diversity should reflect membership composition and the CFRE strategy. We are committed to seeking a broader representation of race through our members, particularly given the importance of race as a principal determinant of health outcomes.

#### 3. Gender:

- Sustain the current good gender balance at the CFRE Board and continue to monitor & report gender balance throughout overall CFRE membership

#### 4. Skills:

- Commitment to increase connection with champions that can support the implementation of the CFRE 2025 Strategy Goals in areas such as Digital, HTA, Device.

#### 5. Community organization (or industry) size and scope:

- Aspiration to build the membership with organizations with more specified or focused impact and scope (still with substantial international standing or reputation in research equity) that strategically align with CFRE's goals.

## 6. CFRE Board, Executive Committee, Independent Experts, and Strategic Advisory Board

Positions on the CFRE Board are nominative and should be based on the merits and active participation in CFRE’s work and the exemplification of CFRE principles.

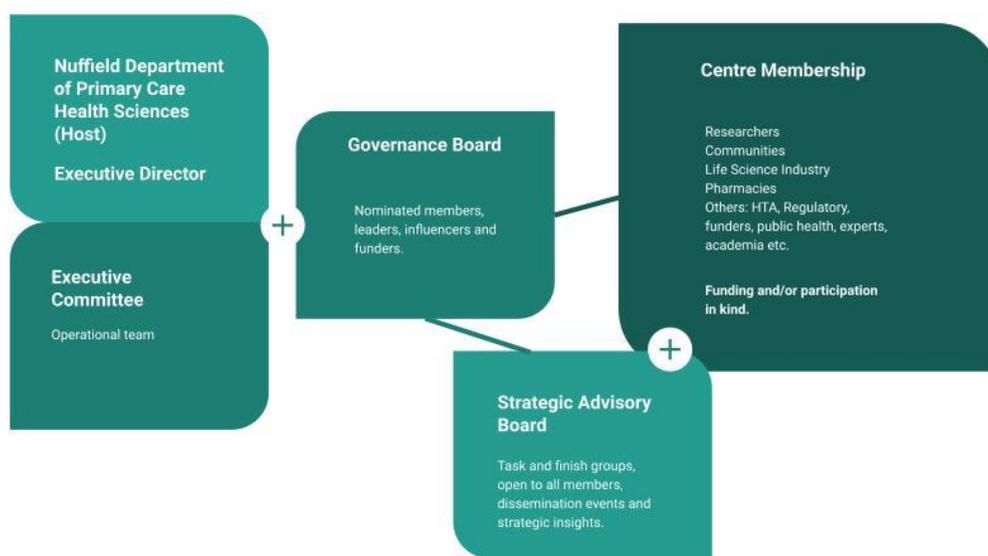
### 6.1. CFRE Board

#### 6.1.1. Composition of the CFRE Board

The number of Board members shall be 21, including the Executive Committee (a subset of the Board). This number may be changed at any annual Board meeting by a simple two-thirds majority vote. The CFRE Board shall be composed according to the following principles:

- Min. 30% to max 50% of representatives from communities;
- Min. 30% to max 50% of representatives from the pharmaceutical/life sciences industry;
- Target 20% Regulatory, academia, public health authority, and experts who add value to the program through their expertise, diversity, and impact whether acting from an organization, or as individual representatives.

As a guiding principle, the CFRE Board shall be composed respecting the principles of representation in gender, geography, race, skills, and different stakeholder communities according to the “CFRE Representation Criteria”



#### 6.1.2. Independent experts

**Principle:** CFRE looks for independent experts who add value to the program through their expertise, diversity, and impact, whether acting from an organization, or as individual representatives.

**Nomination/Election:** Same election process for individual representatives, as for members representing an organization.

**Criteria for selection:** Applicable Members selection criteria are applicable for individual representatives

**Seat at the Board:** Individual representatives, elected to the board, have a seat on the Board, like any other Board member.

**Vote at the Board:** Individual representatives, elected to the Board, have the same voting rights at the Board as any other board member.

**Member Titles:**

- Independent Community Partner
- Independent Industry Partner
- Independent Other Partner (HTA, Regulatory, academia, public health authority, etc.)

**6.1.3. Eligibility and application to the Board**

Members apply to the CFRE Board by submitting an expression of interest via the website to the Executive Director and the Executive Committee, who will assess eligibility based on the criteria below.

Individuals are eligible for the CFRE Board upon fulfillment of the following criteria.

- The individual is an employee of a CFRE member organization that has a signed commitment to CFRE for at least 3 years, or the individual is an independent expert fulfilling the eligibility criteria and committing to support and promote CFRE’s activities in one’s network for at least 3 years.
- The Member organization/individual has proven commitment and value to CFRE, based on their participation in CFRE activities.
- The individual has the approval and a mandate of the organization she/he represents to take an active part in CFRE and to devote appropriate time to CFRE activities.

**6.1.4. Role of a Board member**

CFRE is governed by a CFRE Board representing the members and taking the organizational strategic decisions detailed in the “Board decision matrix.” The Board mandates the Executive Committee to advise the Executive Director in implementing the strategy. Operational and day-to-day decision-making is mandated to the Executive Director by default. The Executive Committee has no decision-making power beyond the other Board members.

CFRE Board members are elected to make decisions in CFRE’s best interests ahead of their role as representatives of their respective organizations.

**Board role is to:**

- 1. Establish Organizational identity and direction:**
  - Determine mission & purpose and advocate for them
  - Develop long term strategy & ensure effective strategic planning
- 2. Ensure Resources:**
  - Participate in building a competent board
  - Ensure adequate financial resources
  - Enhance CFRE’s position, perception, and reputation in their role as ambassadors within their own organization and externally.
- 3. Provide Oversight:**
  - Support & evaluate Executive Director

- Monitor that programs are aligned with strategy
- Provide financial oversight
- Ensure legal and ethical integrity

**Board decision Matrix:**

Board Roles requiring a decision	Topics to be decided by the Board	Board Decision
<b>Establish Organizational identity</b>	<b>Strategy &amp; Strategic Planning</b>	
<b>Mission &amp; purpose</b>	Review, update and approve Mission	Approves
<b>Strategic planning</b>	Develops mid- and long-term strategy (2 to 5 years)	Approves
	Approve high-level strategic planning and authorize Exec Director to execute	Approves
<b>Ensure Resources</b>	<b>Members &amp; Resources</b>	
<b>Build a competent board</b>	Change CFRE Governing body's structure, including naming and dissolving ad-hoc and standing committees and/or working groups	Approves
	Criteria for governing bodies composition	Approves
	Criteria for membership composition	Approves
	New Members to CFRE	Approves
	New Board Members of CFRE	Approves
	New ExCo Members of CFRE	Approves
<b>Provide Oversight</b>	<b>Monitoring</b>	
<b>New projects</b>	New projects above 10% of the annual budget	Approves
<b>Provide financial oversight</b>	Annual high-level Operating Budget	Approves
	Financial reports 2x/year	Approves
<b>Manages major crisis</b>	Validates action plan in case of major crisis (e.g., reputation damage putting CFRE at risk)	Approves
<b>Appoints Executive Director</b>	Appointment of Executive Director	Approves
<b>Support &amp; Evaluate Executive Director</b>	Executive Director support and evaluation run through Exco representatives based on performance	Approves

**All other decisions are the responsibility of the Executive Group.**

**Individual Board members commit to upholding the following as part of their role:**

- **Duty of Care:**  
Board members must use their best judgment in all dealings with the organization by, for example, preparing for and attending board meetings, raising questions, and providing careful

oversight.

- **Duty of Loyalty:**

Board members must be faithful – avoiding conflicts of interest when making decisions affecting the Centre.

- **Duty of Integrity:**

Board members must stay true to the Centre’s mission and applicable laws when making decisions for the Centre.

### **6.1.5. Nomination committee: role, composition, appointment by the board, and rotation**

The nomination committee drives the election process of the Board members (details in the following chapter related to the election process).

Every two years, the Board votes by a simple majority on a delegation of four volunteer board members proposed by the Executive director and Executive Committee to compose the Nomination Committee. The nomination committee will reflect a diverse selection of board members, including a minimum of one executive committee member.

The Nomination Committee appoints a chairperson.

To ensure continuity and transfer of knowledge, members of the committee shall rotate a maximum of two members every two years (the duration of the role at the Nomination Committee can therefore fluctuate from a minimum of two years to a maximum of four years as needed).

Any Nomination Committee member applying to be reelected to the board will recuse himself/herself from the Nomination Committee.

### **6.1.6. Term, election, and rotation of the Board**

The Nomination committee organizes and monitors the election process. Every year, there are a minimum of three members rotating off the CFRE Board on a voluntary basis or based on a recommendation from the Executive Committee if there are no volunteers. As a guiding principle, the Board shall be composed respecting the guiding principles of representation in gender, geography, and different stakeholder groups (see [CFRE members representation criteria](#)).

Board members may serve a maximum of two consecutive 3-year terms, not including time served when appointed to fill a vacancy in an unexpired term. A Board member who has served two consecutive 3-year terms may serve 2 new consecutive terms after at least one year of absence from the Board.

Board members are elected via a Board vote on a slate of candidates proposed by the Nomination Committee and informed by the representation needs and the diversity criteria principles dictated by the governance.

Any member organization with a 3-year Membership Agreement with CFRE may apply to the Executive Director or may propose nominating an individual to serve on the CFRE Board.

The Guiding Principles for the slate of candidates are:

- Applications are anonymous: only the slate of candidates will be known
- Number of applicants is not disclosed: whether there will be a high or low number of candidates stays confidential
- The slate of candidates proposed by the Nomination Committee aims to reflect the best possible composition of the board respecting the selection & diversity criteria defined in the bylaws.

The Nomination Committee will review, and interview potential candidates proposed by the executive director and will send a final slate of candidates to be appointed by the Board by a single approval or rejection vote.

The results from the selection process will be communicated to the candidates individually by the Nomination Committee members & the Executive director.

#### **6.1.7. Meetings**

The CFRE Board meets at least twice a year, of which a minimum of one face-to-face meeting per year. Attendance at meetings is critical, any absence should be exceptional and covered by bilateral contact between the Executive director and board members who cannot attend pre and post meetings to get views on critical issues.

#### **6.1.8. Decision-making process and Quorum**

The Board reviews CFRE's achievements, work in progress, and reporting on a regular 6-month basis and monitors compliance with CFRE's strategic objectives. Upon receiving the Executive Director's proposal, the CFRE Board revalidates the initiative's scope and/or organization and rules.

The CFRE Board makes decisions ([decision matrix](#)) through a voting process with a quorum of 10 members, by a simple majority.

#### **6.1.9. Resignation, removal and change in affiliation**

Any Board member may at any time resign by written notice to the Executive Committee and the Executive Director.

If a Board member is changing professional affiliation or a member organization ending CFRE membership, her/his Board membership automatically ends either directly or no later than the end of the ongoing year. All membership obligations remain unchanged with the member organization.

Any Board member may be removed for cause by the Board with the Executive Committee, provided that there is a quorum of not less than a majority of the entire Board present at the meeting at which such action is taken and at least two-thirds of those voting endorse removal. Such causes may include, but are not restricted to, absence from three (3) successive meetings of the Board, prolonged incapacitation due to illness or injury, conviction of a crime involving moral turpitude, failure to maintain good standing of one's organization as a CFRE member, neglect or default of assigned and accepted responsibilities, conflict of interest or actions counter to the purposes and policies of CFRE.

If a Board member is changing professional affiliation or a member organization ending CFRE membership, her/his Board membership automatically ends either directly or no later than the end of the ongoing year. All membership obligations remain unchanged with the member organization.

**6.1.10. Declaration of Interests Policy**

Members of the Board shall scrupulously avoid any conflict between their respective individual interests and the interests of CFRE in any and all actions taken by them on behalf of CFRE. Any possible competing interests on the part of such person or persons shall be disclosed in full detail to the CFRE Board and Executive Committee as detailed in the CFRE Declaration of Interest policy<sup>1</sup> and such person or persons shall abstain from voting. In addition, such interested Board members must be absent during the Board's vote on the decisions in question. The disclosure as well as the Board member's abstention from voting shall be made a matter of record within the minutes of the appropriate meeting. Disclosure of interest form can be found in Annex3.

**6.1.11. Orientation process for Board members**

New CFRE contributors, members, or board members will follow an orientation process that was defined will be detailed by the end of the year 2023.

**6.1.12. Co-option to the Board**

Where the number of persons on the Board has fallen below [16] or if there is a need to support the CFRE representation criteria (5.2), the Executive Director and/or the ExCo can request the Nomination Committee to select one or more replacement board members who meet the eligibility criteria (6.1.3). Such co-option must be approved by the Board at its next meeting.

A person appointed to the board by co-option will be expected to serve until the next scheduled Board elections, where they have the option to stand for election of a full three year period as a member of the Board. The period of co-option will be disregarded in calculating their length of service.

**6.2. CFRE Executive Committee**

The Executive Committee consists of the Operational Leads who are recognized experts. The Executive committee is a subset of the Board composed of 21 members.

**6.2.1. Role of the Executive Committee**

With their knowledge and knowledge, the Executive Committee provides valuable support for the Executive Director in day-to-day operations and decision-making.

The Executive Committee shall provide oversight functions to the organization ensuring that the Board maintains good governance practices. The Executive Committee shall facilitate communication between the Board and the Strategic Advisory Board.

**The member of the Executive Committee will cover specific roles:**

- Two Members of the Executive Committee will act as Co-chairs of the Board Meetings. The role shall rotate between the Executive Committee members
- Financial oversight.

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<sup>1</sup> See PFMD's Declaration of Interests policy in Annex3

### **The Executive committee members role and goals as Co-chair:**

- Oversee the CFRE Board meetings
- Work in partnership with the Executive Director to make sure the Board's duties are carried out
- Call special meetings as necessary
- Assist Executive Director in preparation of Board meetings (including agenda-setting)
- Initiate the Executive Director's annual performance evaluation
- Identify new Board members to be recruited
- Act as spokesperson for the CFRE Program
- Consult with Board members on their roles and support them to assess their performance individually and through any potential Board self-assessment formats
- Hold regular alignment meetings with the Executive Director

### **6.2.2. Meetings**

The Executive Committee attends all CFRE Board meetings and in addition, meets as often as needed to keep CFRE operations agile and efficient.

### **6.2.3. Resignation and removal**

The same rules regarding resignation and removal as in the CFRE Board chapter apply here.

### **6.2.4. Conflict of interests**

The same rules regarding conflict of interests as in the CFRE Board chapter apply here<sup>2</sup>.

## **6.3. Strategic Advisory Board (SAB)**

The purpose of the SAB is to provide input into most of CFRE activities as well as in the mid-long term strategic direction of the Program. Each member organization will have a seat on the SAB which thus is a way for all members, not only the Board members, to provide input.

With the SAB, CFRE has a collaborative platform for CFRE members to bring their unique insights & perspective into shaping CFRE activities. The SAB provides a forum for all members to gain visibility to be identified as a potential future CFRE Board Member.

### **6.3.1. Composition and Eligibility to the Strategic Advisory Board**

All CFRE Members (except Associate Members) have a seat at the SAB.

### **6.3.2. Role of Strategic Advisory Board members**

The SAB meetings offer the opportunity to feed the CFRE program with members' insights about the Strategy and the projects. Whilst interacting with the audience and engaging with stakeholders outside of meetings, CFRE members follow the principles of:

- **Duty of Care:**  
Members must use their best judgment in all dealings with the CFRE Program by, for example, preparing for and attending meetings, raising questions, and providing careful oversight.

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<sup>2</sup> See Declaration of Interests policy in Annex3

- **Duty of Loyalty:**  
Members must be considerate of their commitment and role as a CFRE SAB member and, to their best judgment, aim to avoid conflicts of interest when making decisions affecting the CFRE Program.
- **Duty of Integrity:**  
Members must stay true to the program’s mission when bringing insights.

## 7. NDPCHS

NDPCHS has been appointed to run the operations of CFRE.

### 7.1. *Role/ mandate*

NDPCHS has multiple mandates encompassing the following items:

#### **Secretariat**

NDPCHS takes care of all administrative duties linked to CFRE management and membership, including organizing and facilitating the meetings, preparing summary reports, etc.

#### **Host and facilitator according to collaborative leadership principles**

NDPCHS hosts CFRE. CFRE will not be incorporated at any stage, therefore NDPCHS will host the program and will act as a proxy holder on behalf of CFRE, under the Executive Director’s guidance.

#### **Project Management**

NDPCHS organizes and makes its teams available to perform the necessary duties to achieve CFRE’s goals as set by the CFRE Board and the Executive Committee.

## 8. CFRE Funding

CFRE funding shall come from several complementary sources described hereafter.

### 8.1. *Core funding*

Core funding of the program shall be provided for by industry (“Industry”) and other ‘for-profit’ members.

Members commit to a 3-year membership and an annual membership fee shall be charged as follows for Industry or for-profit members:

- £50,000 commitment per year – which may be adjusted as per the CFRE Board’s voted strategy and related budget

### 8.2. *Project-specific funding*

Additional funding for specific [research] projects or member-specific products and services is possible.

Organizations can fund a CFRE specific [research] project and thus attain an associate member role. See more under Associate members above.

### **8.3. *Alternative funding***

CFRE may raise alternate funding from other sources, including (but not restricted to):

- Research Infrastructure Grants
- Foundations
- Public Institutions
- Private donors
- For-profit funding for specific projects

Any exception to the above funding principles must be approved by the Executive Committee and the CFRE Board needs to be informed.

## **9. Deadlocks**

The governance has been designed to avoid deadlocks. However, should a deadlock still arise, the Executive Director will take the appropriate decision and inform the CFRE Board.

## **10. Liability of members**

CFRE not being incorporated, the program cannot therefore be considered liable for anything. All members will be liable for their actions and decisions. Necessary contractual links are enforced by bilateral binding contracts for both contracting parties.

It is therefore not expected that any member (organization and/or individual) would increase or modify its usual liability because of its commitment to CFRE.

## **11. Intellectual property**

As proxy and host for the CFRE, NDPCHS shall exclusively own all intellectual property right (IP) arising and/or resulting from one or more Member's involvement in the CFRE.

In compliance with the philosophy of the CFRE and commitment to open and free access and the rights of all members as defined in this Governance, NDPCHS will make the IP available to all eligible members under Creative Commons licensing terms to be determined.

This clause shall survive the end of CFRE, including, as described below, should the Executive Committee Team decide to put an end to the CFRE.

## **12. Withdrawal or exclusion of members**

Members can decide to withdraw from CFRE as outlined in the Membership Agreement.

The Board may decide to exclude members for serious breaches of CFRE's philosophy or to the Governance. The CFRE Board will validate any member exclusion.

### **13. Closure – end of CFRE**

The CFRE Board may decide to put an end to CFRE either because all expected outcomes of the program have been delivered or because serious and objective forecasts show that it will not be possible to deliver these outcomes.

This decision shall be endorsed by a qualified majority vote from the Members. If a decision to stop the program is made by the CFRE Board, the program's IP and assets can be used by NDPCHS to pursue a similar or related mission. (see [intellectual property](#))

## Annex 1 - About NDPCHS

NDPCHS is an academic department within the University of Oxford, a Higher Education Institute and charitable organization, that offers a symbolic and material- neutral platform where all stakeholders can collaborate in a non-competitive environment, understanding that they join forces on an issue which is beyond a single organization's agenda.

NDPCHS believes that creating shared value and addressing the common causes that link key concerns is what leads to greater results. NDPCHS partners with corporations, influencers, experts, academics, individuals, medical professionals, patients, and NGOs, among others, who share the same philosophy.

NDPCHS acts as an incubator and collaboratively leads various projects including implementation of strategy, management, communication, technical development, and fundraising. To learn more about our activities, please refer to [www.TheNDPCHS.org](http://www.TheNDPCHS.org)

See The [NDPCHS One pager](#) to know more.

## Annex 2 - CFRE Board Members & Executive Committee

### CFRE Board Members & Executive Committee 2023

#### Executive Committee Members

(I): Industry

(C): Community representatives or organization

(O): Others such as HTA's, Research, Regulators, Influencers and leaders

CFRE Board 2023			
1	Prof Mahendra Patel		
2	Prof Chris Butler		
3	Prof Kam Bhui		
4	Prof Najib Rahman		
5	Dr Paula Wray		
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### Annex 3 - Declaration of Interests Policy

## CFRE Declaration of Interests Policy and form

### Introduction and purpose

Individuals serving on the CFRE Board, Executive Committee, Strategic Advisory Board (SAB) or as Associate members have experience and knowledge about medicines and medical device R&D and health systems and the willingness to drive patient engagement forward and collaborate to make it systematic. This experience and knowledge come from long-term and in-depth involvement with all

relevant stakeholders at both a national and international level. As a consequence of that experience, it is inevitable that these individuals will have a number of legitimate ongoing interests with the different public (both government and non-government) and private (e.g., pharmaceutical companies, medical device companies, healthcare providers etc.) organizations. **The purpose of the Declaration of Interests Policy is to protect the individual and CFRE from any suggestion or perception of impropriety.**

Potential conflicts of interest may arise when a person's personal, business, occupational or professional interests or affiliations conflict with the discussions held or decisions made in CFRE. This may be because they serve on multiple boards of potentially competing NGOs, may have commercial or regulatory interests, or other reasons.

CFRE does not want to limit or influence in any way Board members', Executive Committees, SAB's or associate members' involvement with other organizations. This disclosure is to provide transparency and help understand whether a potential conflict of interest exists.

In the light of the above, all CFRE Board, Executive Committee, and SAB members are required to declare their interests on an annual basis by returning the form on the next page. This will be provided to the Executive Committee but not made available publicly.

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Please complete and return this Declaration of Interests form (form only) to the Executive Director (\*\*\*\*\*) AND the CFRE admin office ([CfRE@phc.ox.ac.uk](mailto:CfRE@phc.ox.ac.uk)) during the first 3 months of the beginning of your term and annually thereof.

## **Process of determination**

### **Determinations of Potential conflict of Interest**

A Board, Executive Committee or SAB member who has declared or has been found to have a conflict of interest shall refrain from participating in the Board or Executive Committee meeting while the determination of a conflict of interest is discussed and voted upon, unless for special reasons the Board requests information or interpretation from the person or persons involved or determines that the interested person may remain in the room. He or she shall not vote on the matter in question and shall not be present at the time of the vote unless the Executive Committee and/or Board determines that the conflict is insignificant or immaterial to the issue at hand. A more detailed procedure of determination and addressing conflicts of interest is laid out in the *Determination of Potential Conflict of Interest procedure*- document.

## CFRE Declaration of Interests-form

Your Name:

Position:

Organization(s):

Email:

Date:

Other than my involvement in the abovementioned organization(s) I declare that, to the best of my knowledge, the only interests that are relevant to my role on the (*highlight an option*) CFRE Board/ CFRE Executive Committee / Strategic Advisory Board in companies and organizations are those listed below.

*[All current and/or past interests from the last 3 years should be declared.]*

### Employment

*Employment with a life sciences company means any form of occupation, part-time or full-time, paid or unpaid, in the company. This also includes companies relating to medicinal products, e.g., contract research organizations (CROs), but not academic institutions.*

*Enter text below. If nothing to declare, add "Nothing to declare".*

### Consultancy and/ or Strategic advice

*Consultancy means provision of advice to a life sciences company, public institution or healthcare organization, regardless of contractual arrangements or any form of remuneration or provision of pro-bono services.*

*Strategic advisory role means participation (with a right to vote on/influence the outputs) in an advisory board or steering committee with the role of providing advice, expressing opinions on the (future) strategy, direction or activities of a pharma company, public institution or healthcare organization, regardless of contractual arrangements or any form of remuneration or provision of pro-bono services.*

*Enter text below. If nothing to declare, add "Nothing to declare".*

### Financial interests

*Current or potential ownership, investment interest or holding of stocks and shares, stock options, equities, bonds and or partnership interest in the capital of any entity with which the CFRE has or is negotiating a transaction or arrangement (with the exclusion of an investment fund, pension fund and/or similar arrangements).*

*Current intellectual property rights including patents, trademarks, knowledge and/or copyrights relating to a medicinal product or healthcare service owned by you or of which you are directly a beneficiary.*

*Current or potential compensation arrangement (including direct and indirect remuneration as well as gifts or favors that are substantial in nature) with CFRE or with any entity or individual with which CFRE has or is negotiating a transaction or arrangement.*

*Current position as an officer or board member, employee, or former employee of any entity with which CFRE has or is negotiating a transaction or arrangement.*

*Enter text below. If nothing to declare, add "Nothing to declare".*

**Grant, funding to organization(s) and institution(s)**

*Current grants or other funding (other than compensation for services provided e.g. for consultancy) received from a life sciences company, healthcare organization or governmental institution by an organization/institution to which you belong, or for which you perform any kind of activity, and which is used to support any of your activities whether or not they are related to your work. Any other funding received from a life sciences company by an organization/institution to which you belong, or for which you perform any kind of activity, do not need to be declared.*

*Enter text below. If nothing to declare, add "Nothing to declare".*

**Any other interests or facts**

*Provide information on involvement with additional organizations, institutions, initiatives or projects that may create a potential conflict of interest, e.g.:*

- *Academic and/or publicly funded research initiatives in healthcare*
- *Officer, director, trustee, employee, or consultant to any other professional society, research organization, non-profit organization or corporation in healthcare, which may be funded in full or in part from unrestricted grants from life sciences companies or governmental bodies, or may have potential conflicts of interest with CFRE*
- *Employment, consultancy, strategic advisory role and financial interests of first-line family members (i.e., spouse or partner, children and parents)*

*Enter text below. If nothing to declare, add "Nothing to declare".*

Should there be any changes to the above due to the fact that I acquire additional interests, I shall promptly notify CFRE and submit an updated Disclosure of Conflict of Interests detailing the changes.

Date, place and signature: \_\_\_\_\_

## SCHEDULE 2

### PAYMENT SCHEDULE AND BANK DETAILS

Year of Membership	Membership Fee* (exclusive of any applicable VAT which shall be charged at the prevailing rate)	Timing for Payment
1	£ 50,000	Shortly after signature of the Membership Agreement by both Parties
2	£ 50,000,	Payable by on the first anniversary of the signature [date]
3	£ 50,000,	Payable by second anniversary of the signature [date].
<b>Total</b>	[£150,000]	

\* The annual membership fee may be reviewed and changed according to the number of new members, the strategy and the working plan as decided by the CFRE Executive Team and validated by the CFRE Board.

Payments will be made by the Member to NDPCHS in GBP in accordance with the above payment schedule within [30][60] days of receipt of an invoice. Payment will be made into the following bank account

BANK NAME	
BANK ACCOUNT NUMBER	
NAME OF BANK ACCOUNT HOLDER	
BANK SORTING CODE	
OTHER RELEVANT INFORMATION:	