

INCLUSIVENESS AND EQUALITY PLAN

HELIOS ACTION

CA22119 - Haemoglobinopathies in European Liaison of
Medicine and Science (HELIOS)

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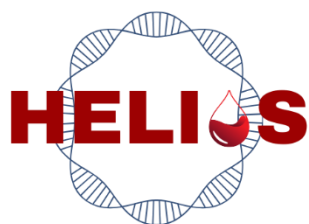
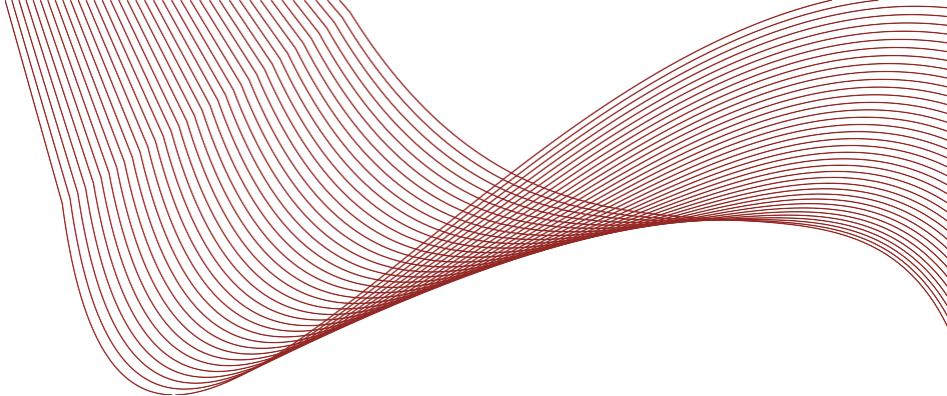


Table of contents

1. INTRODUCTION TO HELIOS ACTION.....	3
2. INCLUSIVENESS AND EQUALITY	4
3. GENDER EQUALITY PLAN	4
4. HELIOS ACTION - FIRST INCLUSIVENESS AND EQUALITY PLAN.....	7
5. HELIOS ACTION - GENDER ANALYSIS	8
6. HELIOS ACTION - GEOGRAPHICAL DISTRIBUTION ANALYSIS.....	12
7. HELIOS ACTION - ACTIONS & MEASURES.....	16
8. CONCLUSION	19



1. INTRODUCTION TO HELIOS ACTION

The Haemoglobinopathies in European Liaison of Medicine and Science (HELIOS) Action is an Action funded by COST, the European Cooperation in Science and Technology¹, a funding organisation for research and innovation networks.

The HELIOS Action aims to build a network of excellence for integrating, harmonising and spreading the existing knowledge on haemoglobinopathies, including Sickle Cell Disease and thalassaemia syndromes. In addition, it intends to develop innovative services and tools, thus improving knowledge accessibility and healthcare equally across Europe and beyond.

HELIOS also contributes to the continuous training and capacity building, particularly for next generation scientists to effectively tackle recent challenges and potential treatment opportunities. This will allow to create a critical mass of highly skilled and trained researchers, who through mentoring from experienced scientists, will be able to foster and extend research in the field of haemoglobinopathies. To achieve its aims, the Action has brought together a diverse group of professionals from different disciplines (e.g., clinical research, laboratory genetics and molecular diagnosis, computational biology, bioethics, data management) and sectors (e.g., universities, research centres, healthcare centres, biobanks, private sector).

HELIOS comprises a well-structured governance, a Management Committee and five working groups. The five working groups coordinate existing and emerging haemoglobinopathy-related activities, ranging from clinical and molecular research to data analysis and bioinformatics, aiming to advance health care systems, contribute to informed policymaking and improve survival and quality of life for existing and future patients. According to the project proposal, HELIOS represented a balanced network with regards to seniority of the proposers and gender, as 41.6% of the proposers (32 in total) are Young Researchers and Innovators (YRIs), while 62.3% are women (48 in total). The Action seeks to expand among COST countries, International Partner Countries and Near Neighbour Countries, while respecting gender balance and promoting the active participation of young researchers and innovators. One of the objectives of the Action is to promote the participation of YRIs, women, and researchers from Inclusiveness Target Countries (ITCs) in leadership roles and throughout all project activities. Equality and inclusion principles will be promoted to fight any form of discrimination (such as sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation).

More information about the project is available on the HELIOS website ([Home - Helios \(heliosaction.eu\)](https://www.heliosaction.eu)).

¹ <https://www.cost.eu/>



2. INCLUSIVENESS AND EQUALITY

The European Commission is fully committed in the promotion of the inclusiveness and equality principles and adopted five strategies to create the conditions for everyone to live, thrive and lead regardless of differences based on gender, racial or ethnic origin, religion or belief, disability, age or sexual orientation.² Moreover, to make sure the fundamental rights of equality and non-discrimination are upheld, the Commission continuously proposes new policies and initiatives, focusing on promoting equality and inclusion.

COST is fully committed as well to bringing out excellence and inclusiveness in science Europe-wide and clearing away obstacles by offering low-barrier entry research networks and creating interdisciplinary research cooperation opportunities for researchers. Its inclusiveness policy is developed around three main elements: geographical spread (including less research-intensive COST members, known as COST Inclusiveness Target Countries (ITCs)), career stage (involving young researchers) and gender balance.

The objectives are to identify excellence in science and technology across Europe, increase research communities' access to funding and infrastructures and trigger structural changes in Members' national research systems.

3. GENDER EQUALITY PLAN

Requirements set by the European Commission's Strategy for Gender Equality 2020-2025³, including policy objectives and actions to make significant progress by 2025 towards a Gender-Equal Europe, must be considered for the creation of a Gender Equality Plan (GEP). Strengthening gender equality and gender mainstreaming in the European Union's main research and innovation funding programme, Horizon Europe, is one of the means to achieve the objectives of the strategy. The Horizon Europe Guidance on GEPs⁴, supporting organisations to meet the GEP eligibility criterion of Horizon Europe, was used as guidance document for the development of the HELIOS Action GEP.

Moreover, COST is fully committed to promoting gender equality and supporting both talented women and men in research and innovation.⁵ The COST Excellence and Inclusiveness Policy strongly

² https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/new-push-european-democracy/equality-and-inclusion_en

³ [Gender equality in research and innovation - European Commission \(europa.eu\)](https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/new-push-european-democracy/equality-and-inclusion_en)

⁴ European Commission. Directorate-General for Research and Innovation. Horizon Europe Guidance on Gender Equality Plans. 2021

⁵ <https://www.cost.eu/about/strategy/gender->



encourages gender balance of research networks, as well as the take up of leadership positions by (young) women COST Action participants. As such, COST aims to ensure equal opportunities and gender-friendly career advancement.

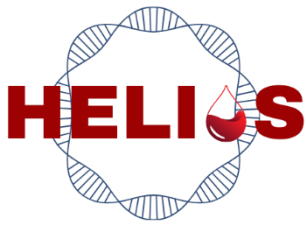
Advancing gender equality in research and innovation is a key objective of the European Union's gender equality policy. Across Europe the numbers have increased over the last years (women are indeed a majority among PhD graduates), however, only a third of women are scientists, a phenomenon especially visible in STEM (Science, Technology, Engineering and Mathematics) where women are even less represented.

A GEP includes essential elements, named 'building blocks'. To comply with the Horizon Europe GEP eligibility criterion⁴, a GEP must meet **four MANDATORY PROCESS-RELATED REQUIREMENTS**, standard minimum components of action plans to promote gender equality, as retrieved from the guideline:

1. **Public document:** *The GEP must be a formal document published on the institution's website, signed by the top management and actively communicated within the institution. It should demonstrate a commitment to gender equality, set clear goals and detailed actions and measures to achieve them.*
2. **Dedicated resources:** *a GEP must have dedicated resources and expertise in gender equality to implement the plan. Organisations should consider what type and volume of resources are required to support an ongoing process of sustainable organisational change.*
3. **Data collection and monitoring:** *organisations must collect sex/gender disaggregated data on personnel (and students, for the establishments concerned) with annual reporting based on indicators. Organisations should consider how to select the most relevant indicators, how to collect and analyse the data, including resources to do so, and should ensure that data is published and monitored on an annual basis. This data should inform the GEP's objectives and targets, indicators, and ongoing evaluation of progress.*
4. **Training:** *The GEP must also include awareness-raising and training actions on gender equality. These activities should engage the whole organisation and be an evidence-based, ongoing and long-term process. Activities should cover unconscious gender biases training aimed at staff and decision-makers and can also include communication activities and gender equality training that focuses on specific topics or addresses specific groups.*

In addition to these four mandatory requirements, there are also **five RECOMMENDED CONTENT-RELATED (THEMATIC) AREAS**, key gender equality issues that organisations should seek to address, as retrieved from the guideline:

[equality/#:~:text=COST%20is%20fully%20committed%20to,young\)%20women%20COST%20Action%20participants.](#)



1. Work-life balance and organisational culture: GEPs aim to promote gender equality through the sustainable transformation of organisational culture. Organisations should implement necessary policies to ensure an open and inclusive working environment, the visibility of women in the organisation and externally, and that the contribution of women is properly valued. Inclusive work-life balance policies and practices can also be considered in a GEP, including parental leave policies, flexible working time arrangements and support for caring responsibilities.

2. Gender balance in leadership and decision-making: Increasing the number and share of women in leadership and decision-making positions touches upon all aspects in the GEP. Measures to ensure that women can take on and stay in leadership positions can include providing decision-makers with targeted gender training, adapting processes for selection and appointment of staff on committees, ensuring gender balance through gender quotas, and making committee membership more transparent.

3. Gender equality in recruitment and career progression: Critically reviewing selection procedures and remedying any biases can ensure that women and men get equal chances to develop and advance their careers. Establishing recruitment codes of conduct, involving gender equality officers in recruitment and promotion committees, proactively identifying women in underrepresented fields and considering organisation-wide workload planning models can be important measures to consider in a GEP.

4. Integration of the gender dimension into research and teaching content: The GEP should consider how sex and gender analysis will be included in the research or educational outputs of an organisation. It can set out the organisation's commitment to incorporating sex and gender in its research priorities, the processes for ensuring that the gender dimension is considered in research and teaching, and the support and capacity provided for researchers to develop methodologies that incorporate sex and gender analysis. Research funding and research performing organisations both have a role to play in ensuring this.

5. Measures against gender-based violence, including sexual harassment: Organisations establishing a GEP should consider taking steps to ensure they have clear institutional policies on sexual harassment and other forms of gender-based violence. Policies should establish and codify the expected behaviour of employees, outline how members of the organisation can report instances of gender-based violence and how any such instances will be investigated and sanctions applied. They should also consider how information and support is provided to victims or witnesses and how the whole organisation can be mobilised to establish a culture of zero tolerance toward sexual harassment and violence.



Therefore, the commitment to gender equality should be based upon the objectives and desired outcomes of the GEP, the relevant baseline data and targets and the actions/measures that are or will be taken to implement the plan, including the allocation of dedicated resources.

4. HELIOS ACTION - FIRST INCLUSIVENESS AND EQUALITY PLAN

In the context of the HELIOS Action, with the objective to adhere to the requirements set by the European Commission, an Ethics, Gender Equality and Diversity Coordinator (Annalisa Landi, Fondazione per la Ricerca Farmacologica Gianni Benzi onlus) was appointed. The Ethics, Gender Equality and Diversity Coordinator must ensure gender balance in networking and training activities; inform about special opportunities for women in science and encourage candidates from ITCs, YRIs, and female scientists to apply for all management positions. In addition, she is in charge of guaranteeing compliance with applicable ethical standards and appropriately address any ethical issue arising during the project.

In order to promote an inclusive culture and to embed the need to mainstream a gender and inclusiveness dimension in all Action activities, Inclusiveness and Equality Plans are foreseen. This plan represents the first plan of the Action thus covering the period between September 2023 and April 2024. It aims to describe the gender equality and inclusiveness dimension of the Action and introduce preliminary actions and measures that will be implemented during its whole duration (planning to end in September 2027).

HELIOS Action Inclusiveness and Equality Plan aims to fulfil the **four MANDATORY PROCESS-RELATED REQUIREMENTS** as follows:

1. **Public document:** The plan will be made publicly available on the HELIOS Action website after the approval of the Management Committee and shared within the Consortium.
2. **Dedicated resources:** A dedicated resource, an Ethics, Gender Equality and Diversity Coordinator, was appointed and, together with the Action Chair and Vice-Chair, will be responsible for implementing and updating the plan.
3. **Data collection and monitoring:** Gender and geographical distribution data will be collected and/or monitored and included in the annual reporting. Indicators, actions and measures will be revised on annual bases and improvements made, if deemed necessary.
4. **Training:** Training sessions on these topics will be scheduled during the Action to raise awareness about the topics and the actions/measures to be taken by the Consortium.

In addition, HELIOS Action Inclusiveness and Equality Plan aims to implement the **five RECOMMENDED CONTENT-RELATED (THEMATIC) AREAS** as follows:

1. **Work-life balance and organisational culture:** This plan aims to promote work-life



balance policies and practices by ensuring an inclusive project environment and that the involvement of women, ITCs researchers and YRIs in the project activities is properly recognised. Equality and inclusiveness principles will be promoted. Advice and support can be provided on work-life balance.

2. **Gender balance in leadership and decision-making:** A good gender balance in leadership and decision-making roles was ensured since the start of the Action. Moreover, the sharing of opportunities for women regarding leadership roles is foreseen by this plan.
3. **Gender equality and inclusiveness in recruitment and career progression:** Selection procedures for the participation in the HELIOS WGs takes into account the gender equality and inclusiveness principles.
4. **Integration of the gender and inclusiveness dimension into research and teaching content:** This plan aims also to ensure that the gender and inclusiveness dimension is considered in research and training activities.
5. **Measures against gender-based or other forms of violence, including sexual harassment:** Awareness is raised also on the sexual harassment and other forms of gender-based violence.

This Inclusiveness and Equality Plan will be updated annually as a living document, allowing for information and details to be added, modified, and updated over time, thereby increasing its long-term impact. Annual reports are foreseen at M12,24,36,48.

5. HELIOS ACTION - GENDER ANALYSIS

The first analysis of the state-of-play of the gender distribution was performed by the Ethics, Gender Equality and Diversity Coordinator on the main subgroups (e.g., committees and working groups) part of the HELIOS Action considering the information as retrieved from the HELIOS Action COST webpage⁶ on April 5th, 2024. The gender information was given by participants at the time of the application to the COST Action considering the COST binary classification (male/female).

In detail, a total of 64 males and 88 females are involved in the Action. Interestingly, out of the total of 152 HELIOS participants, the 49% is represented by YRIs of which 51/75 are females. Importantly, women's valuable involvement in the Action also extends to leadership and management roles.

An overview of the gender distribution in the HELIOS Action by subgroups is shown in **Table 1** and in **Figure 1**.

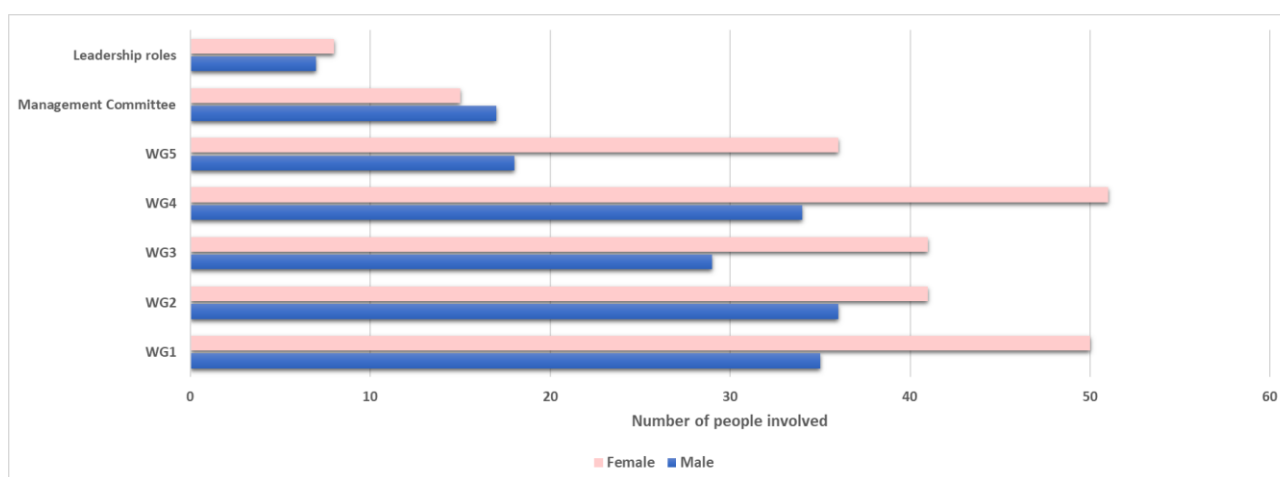
⁶ [Action CA22119 - COST](#)



Table 1. Overview of the gender distribution in the HELIOS Action by subgroups

Male	7	17	35	36	29	34	18
Female	8	15	50	41	41	51	36
	Leadership roles	Management Committee	WG1	WG2	WG3	WG4	WG5

Figure 1. Illustration of the gender distribution in the HELIOS Action by subgroups



In detail, 7 males and 8 females cover leadership roles (see **Figure 2**), including the Action Chair and Vice-Chair, the Working group Leaders and the other coordinators (e.g., Patient Liaison Coordinator and International and Cross-sectoral Expansion Coordinator). Gender balance has therefore been a key consideration in the appointment of these relevant roles.

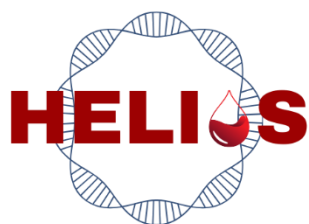
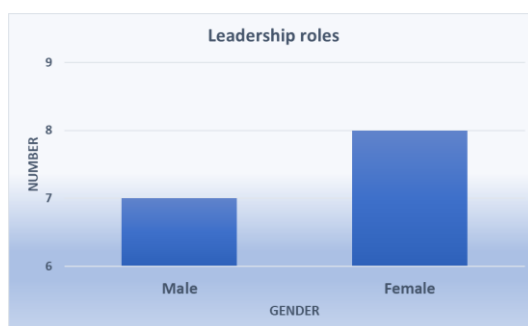
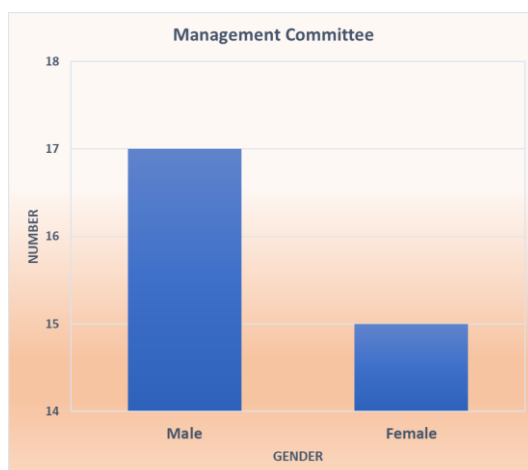


Figure 2. Gender distribution in leadership roles



Moreover, there is also a good gender balance in the HELIOS Action Management Committee (17 males and 15 females involved, as shown in **Figure 3**).

Figure 3. Gender distribution in management positions



Finally, the gender distribution among Working Groups (WGs) was assessed. It is worth noting that, at the time of the analysis, women represented a higher percentage than men in all the Action's working groups. In detail, the WG1 consists of 35 males and 50 female (**Figure 4**), the WG2 consists of 36 males and 41 female (**Figure 5**), the WG3 consists of 29 males and 41 female (**Figure 6**), the WG4 consists of 34 males and 51 female (**Figure 7**) and the WG5 of 18 males and 36 females (**Figure 8**).

Figure 4. Gender distribution in WG1



Figure 5. Gender distribution in WG2

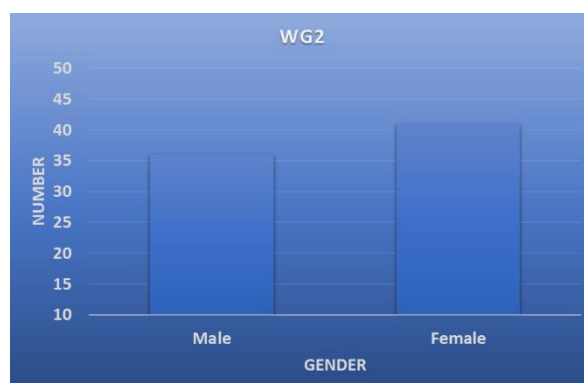


Figure 6. Gender distribution in WG3



Figure 7. Gender distribution in WG4





Figure 8. Gender distribution in WG5



6. HELIOS ACTION - GEOGRAPHICAL DISTRIBUTION ANALYSIS

An analysis of the geographical distribution of the HELIOS participants was carried out as well by the Ethics, Gender Equality and Diversity Coordinator. Information as retrieved from the HELIOS Action COST webpage⁶ on April 5th, 2024, was used to perform the analysis.

Interestingly the 58% (89/153) of the researchers are from Inclusiveness Target Countries (ITCs) such as Greece, Turkey, Portugal, Albania, Cyprus, Slovakia, Slovenia Serbia, Hungary, Bosnia and Herzegovina, Moldova, Malta and North Macedonia. Moreover, 5 researchers are from Near Neighbour Countries (NNCs) such as Morocco, Kosovo and Egypt.

This highlights the willingness of HELIOS Action to adhere to the inclusiveness principle and to promote the participation of YRIs, women, and researchers from ITCs and NCCs in leadership roles and throughout all activities.

The most represented countries are Cyprus (19), Greece (17), Italy (15) and Turkey (15).

An overview of the geographical distribution in the HELIOS Action participants in total is shown in **Figures 9 and 10**.

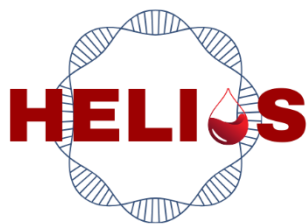


Figure 9. Geographical distribution of HELIOS participants

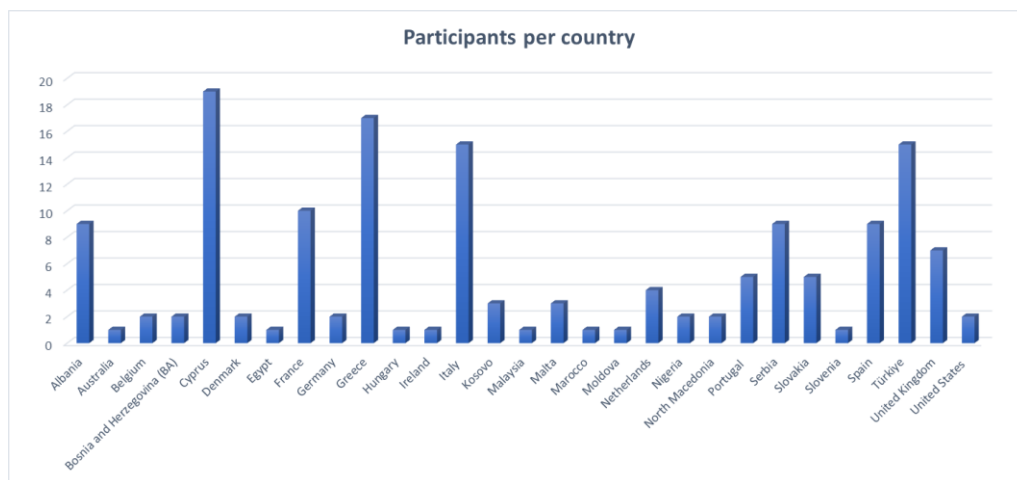
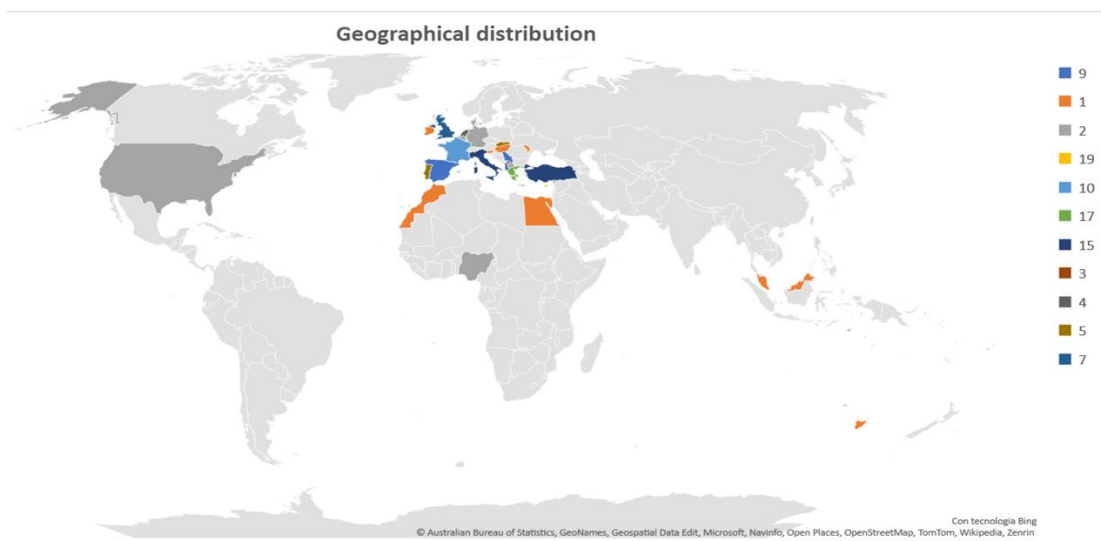


Figure 10. Map of HELIOS participants



Here below the geographical distribution of HELIOS members per subgroup (**Figure 11, Figure 12,**

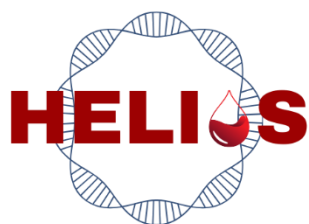


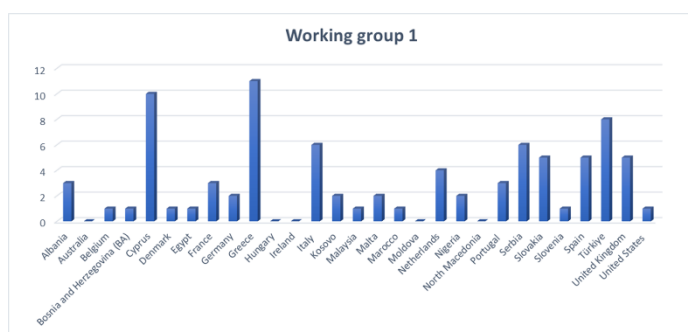
Figure 13, Figure 14, Figure 15, Figure 16, Figure 17).

Figures 11 & 12. Geographical distribution of HELIOS participants in leadership positions





Figures 13. Geographical distribution of participants in WG1



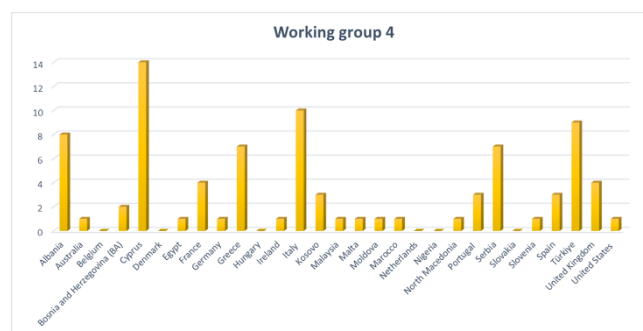
Figures 14. Geographical distribution of participants in WG2



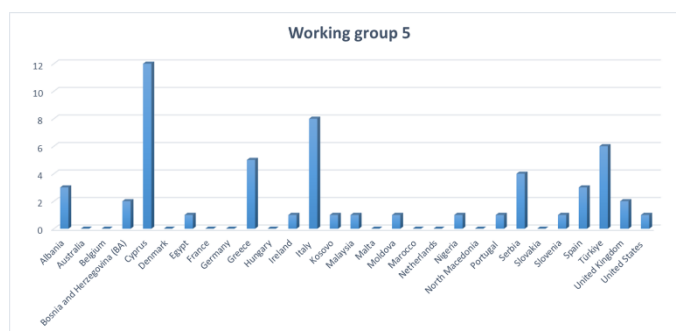
Figures 15. Geographical distribution of participants in WG3



Figures 16. Geographical distribution of participants in WG4



Figures 17. Geographical distribution of participants in WG5





7. HELIOS ACTION - ACTIONS & MEASURES

This Inclusiveness and Equality Plan consists of a set of commitments and actions that aim to promote gender equality and inclusiveness through a process of structural change. The identified actions help conducting periodic assessments to identify any possible gap or gender bias, implement innovative strategies to correct any bias/gap, monitor progress via indicators and improve the existing actions/measures.

Monitoring is crucial to enable seeing where and how actions are being implemented; help identify and address potential sources of resistance to change and indicate whether a transformative dynamic exists. The monitoring and evaluation practices increase the robustness and sustainability of gender and inclusiveness strategies, allow for drawing upon lessons learnt from implemented initiatives and help identify areas for further improvement.

The HELIOS Action Inclusiveness and Equality Plan sets clear goals and detailed actions and measures to achieve them, as detailed below. They are divided according to the thematic areas accompanied by some general objectives and related actions. Moreover, indicators have been defined to allow an easier monitoring process during the whole duration of the project.

1. General

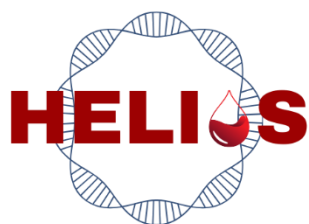
OBJECTIVE	ACTION	INDICATOR	Y1	Y2	Y3	Y4
Ensuring that the gender equality and inclusiveness principles are respected during the whole duration of the HELIOS Action	Appointment of a Gender Equality and Diversity Coordinator	GEP coordinator appointed	x			
	Identification, update and analysis of relevant project data to prepare and share annual project Inclusiveness and Equality Plans	Inclusiveness and Equality Plans annually updated, shared with the Consortium and uploaded on the project website	x	x	x	x
	Implementation of the plan actions and measures with the support of and in cooperation with leadership and	Plan actions and measures implemented	x	x	x	x



	executive bodies					
Promoting initiatives on gender equality and inclusiveness	To share with the Consortium of relevant news and material about past, current and planned initiatives that are relevant to the topics	Number of shared initiatives	x	x	x	x
Investigating national policies and legislations of HELIOS partners on gender equality and inclusiveness	Analysis of national frameworks of HELIOS partners on the topics	Collection of relevant information, material and guidelines on the topics as well as national policies	x	x		
	Informing the Consortium of the need to update institutional GEPs	Information shared during the annual presentations on the topic	x	x	x	x

2. Work-life balance and organisational culture

OBJECTIVE	ACTION	INDICATOR	Y1	Y2	Y3	Y4
Ensuring an inclusive project environment	Creating an inclusive project environment by eliminating any form of discrimination during project activities and giving due recognition to the participation of women, ITCs researchers and YRIs	Number of alerts received by leadership bodies on forms of discrimination	x	x	x	x
	Increasing the opportunity to take part in project meetings through the use of hybrid meetings	Number of hybrid/ online meetings per year vs only in person meetings	x	x	x	x
Promoting and supporting work-	Providing advice and support to HELIOS	Number of support/ advice requests	x	x	x	x



life balance	participants on work-life balance issues, if required	received				
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3. Gender balance in leadership and decision-making

OBJECTIVE	ACTION	INDICATOR	Y1	Y2	Y3	Y4
Promoting a gender balance in leadership and decision-making roles	Establishment of a gender-balanced composition of the board of directors and the management committee	Good balance in the number of males and females appointed in the HELIOS Action governance and management committee	x			
Fostering the involvement of women in leadership roles	Sharing relevant work opportunities as well as possible leadership roles for women	Number of news and opportunities shared with the Consortium	x	x	x	x

4. Gender equality and inclusiveness in recruitment and career progression

OBJECTIVE	ACTION	INDICATOR	Y1	Y2	Y3	Y4
Ensuring gender equality and inclusiveness in working groups composition	Monitoring of the WGs composition. The WG leaders will consider the gender equality and inclusiveness principles during the selection procedures of new members	Balanced composition of working groups members	x	x	x	x

5. Integration of the gender and inclusiveness dimension into research and teaching content

OBJECTIVE	ACTION	INDICATOR	Y1	Y2	Y3	Y4
Raising awareness on gender equality	Training sessions organised by the	Number of male and female individuals	x	x	x	x



and diversity during training activities	HELIOS Action Chair during annual meetings and/or dedicated slots during training schools	targeted and reached by gender awareness-raising or planned training actions and related geographical distribution				
Promoting initiatives to support gender equality and inclusiveness	Promotion of the participation of the Consortium in awareness days (e.g. International Women's Day, International Day of Women in Science), through internal communications and sharing of news and relevant websites	Number of initiatives communicated to the Consortium		x	x	x

6. Measures against gender-based or other forms of violence, including sexual harassment

OBJECTIVE	ACTION	INDICATOR	Y1	Y2	Y3	Y4
Ensuring awareness of sexual harassment, of gender-based violence and any other form of violence and discrimination	Increase awareness about these topics during annual HELIOS meetings	Reference to the topics included in the annual presentation on the Inclusiveness and Equality Plan	x	x	x	x

8. CONCLUSION

In conclusion, ensuring gender equality and inclusiveness helps to improve the quality and impact of research and innovation making it relevant to the society as a whole; to create better working environments that enable high quality research and learning as well as to attract and retain talent. The Inclusiveness and Equality Plans aim to promote gender equality and inclusiveness principles through the sustainable transformation of organisational processes, cultures and structures that



generate and perpetuate gender imbalances and inequalities.

In particular, conducting a gender equality and inclusiveness analysis helps to identify areas of relative strength and weakness, which will allow for better targeting of actions and priorities within the Inclusiveness and Equality Plans and ensure that it is fully evidence-based. Setting clear targets and practical objectives as well as ad-hoc indicators proves commitment to implement the planned actions and allows the assessment of progress by making the plan more concrete and tangible. It should be made clear that the implementation of the actions set out in the Inclusiveness and Equality Plan is the responsibility of everyone involved in the HELIOS Action, at all levels.

Finally, periodic review of evidence and information as well as periodic assessment of the indicators identified will also provide space for learning and feedback to enable adjustments and improvements to be made to the interventions.

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COST (European Cooperation in Science and Technology) is a funding agency for research and innovation networks. Our Actions help connect research initiatives across Europe and enable scientists to grow their ideas by sharing them with their peers. This boosts their research, career and innovation.

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