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STEERING COMMITTEE FOR HUMAN RIGHTS
IN THE FIELDS OF BIOMEDICINE AND HEALTH (CDBIO)

REPORT ON THE PILOT YOUTH FORUM

6 JUNE 2023

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BACKGROUND AND OBJECTIVES

In the framework of the Strategic Action Plan (SAP) 2020-2025, the Steering Committee for Human Rights in the Fields of Biomedicine and Health (CDBIO) stated that one of its strategic objectives is to ensure the communication and dissemination of the outputs of the Committee to internal and external stakeholders, to maximise their uptake and utility.

The importance of involving the youth perspective in the work of the Committee was underscored, in order to bring on board the younger generations' viewpoints in forming the future work of the Committee. To this end, the CDBIO decided on the strategic action of hosting a youth forum to provide young people with an opportunity to share their views on bioethical topics and to inform its work.

Thanks to a voluntary contribution made by Ireland, a *pilot youth forum* was held in Strasbourg on 5-6 June 2023, providing an opportunity to hear the voices of a group of young people from Ireland. The topic they selected was AI and Healthcare. The purpose of the event was two-fold: to gain insight on the optimal organisation of a larger event, on the one hand, and to receive input on an important topic on the agenda of the CDBIO, on the other.

The objective of the pilot youth forum was thus to bring together CDBIO delegates and a group of young people to share information, knowledge and views on a bioethical topic. The dialogue between the group and CDBIO delegations in an intergovernmental setting was also aimed to help the Committee in developing the future engagement and consultation of young people in its work. This report therefore aims to identify key factors to successfully organise a youth forum, as well as to summarise the learnings on the subject topic chosen by the youth, namely on AI in health care.

The discussion of the forum is summarised below, including proposals made by the youth for the CDBIO to consider. The description of the work entailed in organising the pilot youth forum is followed by remarks and learnings made retroactively by the youth participants on their needs in each step of the process. These are included in the column titled "Needs expressed by youth". Other key factors that are deemed to be of importance for a successful exchange are included in a third column. Lastly, the report draws some conclusions on lessons learned for organising future events as well as mentions of topics to consider for a larger youth forum.

THE PILOT YOUTH FORUM

A summary of the forum on AI in Healthcare

Preparing for the pilot youth forum, the youth were given four topics to choose from. The topic that resonated with the majority of the group was "AI and Healthcare". It was felt that AI will have a tremendous impact on healthcare and could become highly valuable if integrated properly.

Having decided upon the topic of AI and Healthcare, the youth forum decided to focus on four key areas, namely:

- bias mitigation,

- training,
- equitable access to healthcare and
- accountability.

Having identified these key areas, they decided to further describe:

- key challenges,
- what resonated the most with young people, and
- solutions for CDBIO to consider, named proposals below.

The youth decided to present their deliberations in four parts, focusing on the key areas concerning AI in Healthcare. Their messages can be summarised in the following way.

Bias mitigation

AI can help reduce bias in healthcare, but it is important to understand how the data used in AI technology is collected to prevent entrenched bias. In order to mitigate bias it is important to have broad representation, and reaching out to underrepresented groups may be needed. There is often a reluctancy to collect and share data from some marginalised groups, making it even more important to implement methods to mitigate uneven representation, such as setting inclusion criteria and establishing benchmarking frameworks. Promoting digital literacy may help these populations understand why their active participation matters. Transparency is needed in the development of AI, as well as quality assessments by different population groups of the collected data.

It is also important to consider the responsibility of the engineers developing AI. How does one ensure that computer engineers apply ethical thinking, such as bias mitigation in the development process? Perhaps there is a need for a codex similar to the Hippocratic oath.

AI can help improve communication between the doctor and the patient since the patient's medical history can be made known to the doctor before the appointment. This also prevents bias as some patients may today feel questioned when they present the background at each meeting with a new physician.

Proposals:

- Computer engineers who develop AI and healthcare professionals should undergo implicit bias training. Their responsibilities regarding the ethical development in this regard should be made clear.
- Creating standards for what a "representative" data set should be. It may include assessment by underrepresented groups in society.
- Promoting data literacy and transparency as to what data AI-systems are based on helps build trust in the systems, and thereby promotes participation by diverse groups.

- Ensure safeguards for how patient data is used in AI, respecting requirements on informed consent.

Training

The question of training is two-fold: the AI needs to be trained by updating it with relevant and correct data, and the healthcare workers need training to benefit from the technology and remain critical of any miscalculations.

AI must be trained/updated with information from peer-reviewed medical articles, new research findings and new medical practices. It would be important to set the standard for what is valid data.

The patient-doctor relationship can be improved by AI, if the technology helps to build trust in the healthcare system and frees up time for the doctor to focus on the patient's needs. A key factor is setting a standard for all stakeholders to be trained in digital literacy and to have the same level of understanding for what AI can do.

Proposals:

- A standardised framework when educating and training healthcare staff and other stakeholders using or implementing AI. Training should be mainstreamed and mandatory for all stakeholders.
- Promote critical thinking among the users of AI in healthcare.
- Review the quality of AI technologies regularly, updating them as new scientific evidence emerges. Consider benchmarking the data used for AI, e.g. only peer-reviewed, open-source datasets. Regular quality assessment of the technologies should be required.

Equitable access to healthcare

It is important to retain access to 'in-person' care while also benefiting from AI in healthcare in all its forms, leaving no one behind. AI can be a supporting device in healthcare or replace some functions. It may also impact the cost of healthcare. We need to consider the number of AI devices needed and the costs of introducing AI systems in healthcare. Access can depend on how commercialised AI in healthcare will be.

Digital literacy barriers may affect marginalised groups' access to healthcare, who do not always have the required skills. These groups should be included in consultations on AI development. Geographic and demographic divides may impact the implementation of AI healthcare, including whether everyone has access to a device and to Internet access. No one should be left behind as healthcare and systems evolve.

AI developers should consider the language and tone used in its offers, to ensure that it is accessible to different people and caters to different needs. AI is an opportunity to help migrants receive appropriate healthcare.

Proposals:

- Guidelines and frameworks should be developed to support healthcare workers.
- Government support is necessary at all stages of development and use of AI.
- There should be consultations with different groups, coupled with possibilities for those involved to receive and provide feedback.
- There should be the option of non-digital spaces and 'in-person' support. AI-hubs would be helpful where competent staff could support AI-users.
- There should be digital literacy and training, which is made available as early as possible to everyone from all areas. Especially professionals, not only within healthcare, but also e.g. social workers, support workers, youth workers, should receive training, not just healthcare professionals.

Accountability

There is a need to consider the potential consequences of the development of AI systems and accountability. Companies and computer programmers play a significant role in AI technology. AI brings both potential benefits and unknown risks to healthcare. The reliance on AI in healthcare will require that it is fair, just and does not compromise human rights. It is important to recognise liability and demands for accountability of AI systems.

AI must be regulated by quality control carried out in four stages: development, acquisition, during medical practice and updating the algorithms after feedback from patients and practitioners.

- Developers should be accountable for the development of the AI system, responsible for creating it to the safest possible level and in being clear about its limitations. Development of algorithms should be done in accordance with best medical standards, done ethically including best ethical practices for developers, and by ensuring that all datasets are legally acquired and without concerns for privacy.
- In acquisition and authorisation of AI systems one must ensure very strict standards for AI used in healthcare. The purchasers of AI systems must ensure that staff using them receive the requisite training.
- Doctors, and healthcare workers, are responsible for good clinical practice regardless of the technology they are using and are medically responsible in any case. Healthcare must be provided with the requisite standards for safety. All practitioners must be adequately trained for using AI technology.
- Those responsible for the continuous updating of the AI system, must establish a process to reflect on and learn from mistakes made by AI in healthcare.

A 'shared liability' is necessary, this would promote collaboration between different actors. The classification of liability is important, noting that AI can contribute to medical malpractice.

It is necessary to establish whether the fault is due to the AI, or by incorrect inputs by medical practitioners or other forms of misuse.

'Forum mapping' is a point of concern, whereby AI developers export AI systems to countries where regulation is the least burdensome. It would be important to consider the harmonisation of rules and introducing import measures.

As regards the harmonisation of medical AI protocols, this is very important because we can have more leverage when there are harmonised protocols. Harmonisation is a more stringent way to ensure compliance of companies. AI as a 'black box' necessitates harmonisation, especially to overcome the opacity associated with the protection of proprietary interests; there needs to be a minimum standard for the code used to encourage better understanding of what is going on in the AI algorithm and how to better ascertain liability for error.

A question to be asked is how will youth be affected by the lack of accountability mechanisms for AI systems; how will it affect future generations and the generations before? This current youth cohort are probably the most affected by AI because of recent technological advancements.

In response, the youth participants expressed concern around how private companies might take advantage of product ambiguity, the amount of health data collected and used without the knowledge of patients. Without accountability, youth may begin to lose trust in the technology. Therein lies the importance of raising awareness and discussing the usefulness of the technology, helping to build trust further.

Accountability mechanisms for AI systems should be 'future proofed'. AI policies should be harmonised and compatible with current ethical principles and other human rights standards, all to encourage trustworthiness of the actors at different levels. There should be proportional consequences for breaches of rules by medical AI systems, this disincentivises bad behaviour and protects victims.

Proposals:

- Harmonisation of regulations on AI systems between countries, new regulations for minimum standard of quality and ethics of AI technologies, with an emphasis on transparency as to how these technologies work.
- Need to develop a framework for liability for if/when technology goes wrong. Clear regulations on liability for developers, acquisitions and medical professionals, stating the shared responsibilities.

Rapporteur reflections

The group presented many interesting views on AI in Healthcare, a topic relevant to the CDBIO work. Some of the youth referred to their personal experience as patients whereas others had reflected upon the impact of AI from their backgrounds as e.g. physicists, training physician and mental healthcare workers. There were insightful proposals as to how the CDBIO could support the introduction and governance of AI in healthcare. Many of the delegations in the CDBIO were impressed with the ambitious approach undertaken by the

youth. One of the clear strengths of the discussion was the varied backgrounds of the members of the group and at the same time many whom were academics and as such were used to reading articles and drawing their own conclusions. Another clear advantage was that all were speaking in their native language, English, and seemed quite at ease with speaking in front of the meeting room.

The reflections and proposals presented could feed into the ongoing work of the CDBIO, a report on the impact of AI on the doctor-patient relationship. The working group may want to consider taking onboard, among other things, the notion of shared responsibilities in developing and using AI in an ethical manner. The role of the developers could be highlighted, and their responsibility to respect some code of ethics, acknowledging bias in pre-existing data and promoting equity for all groups. The working group may want to consider how to promote harmonised standards for AI in regulations and guidelines.

THE PROCESS OF PLANNING AND ORGANISING THE PILOT YOUTH FORUM

This section describes how the pilot youth forum was prepared and organised. As the purpose of the event was partially to prepare for an upcoming larger pan-European youth forum, the report seeks to analyse strengths and weaknesses in the process. In a conclusion, the report makes proposals for what to consider when organising the next youth forum.

Concept note/Setting the format

A concept note was prepared by the Secretariat, which set out the milestones and corresponding responsibilities (and expectations) at each stage of the forum process. During a CDBIO plenary, there was an open exchange on possible forum topics and the designation of a rapporteur.

Responsibilities of Secretariat and chair	**Responsibilities of CDBIO**	**Key to successful setup**
Concept note to help frame and plan process steps, to determine needs, responsibilities, and expectations Planning how to prepare youth for the exchange with the committee Communicating the process, needs, responsibilities and expectations to the CDBIO and the youth participants	Shortlist topics that would correspond to the work of the committee, and resonate with the youth Designate rapporteur Clarify what CDBIO expects from youth	Preparing thorough information, to be prepared to carefully explain the topics and making efforts to demonstrate openness and transparency between CDBIO and participants. Multidisciplinary composition of youth participants under 25 years of age, who demonstrated an interest and/or experience in the fields of health care or social care, in the selected topic or patient organisations. To further the diversity of participants some should

Planning the practicalities and setting the budget		represent minority groups, different social backgrounds, professions and educational backgrounds as well as ethnical backgrounds.

Recruiting process

The objective was to recruit diverse young people with different backgrounds and an interest in discussing bioethical topics. An informal call for expressions of interest was opened to different youth organisations and academic institutions in Ireland, seeking young people between the ages of 19-25. This was followed up with Council of Europe invitation letters sent to the organisations and institutions to provide further information and context. In the weeks thereafter, the Secretariat prompted replies to the letters via email exchanges and phone calls. Nominations arrived shortly afterwards, and a list of nominations was prepared.

Responsibilities of Secretariat and Chair	**Needs expressed by youth**	**Keys to successful recruiting**
Invitation letters Identifying relevant organisations and academic institutions Informal onboarding of youth organisations and academic institutions via emails and phone calls	Clear information and context Clarity on the process and how much time it would take	CoE label/legitimacy Domestic legitimacy and network via (the Irish) CDBIO chair Diversity in organisations and institutions warrants diversity in participants

Onboarding youth

To onboard youth, a series of online (and one-to-one) meetings were held to introduce, frame and explain the forum. These events were organised as zoom calls, with almost all nominated youth participants in attendance. The CDBIO chair attended along with representatives of the Secretariat to manage the discussion and answer questions from the participants. A young moderator with considerable experience and expertise in public debate was recruited locally by the CDBIO chair to coordinate/moderate the youth in their internal discussions.

Responsibilities of Secretariat and Chair	Needs expressed by youth	Keys to successful onboarding
Email exchanges and zoom calls, booking and attending digital meetings Explain the role of the CDBIO and the purpose of the youth forum	Understanding expectations from CDBIO both in terms of the amount of work required and the quality and detail of output Inclusion by picking times for zoom calls that works for most participants and following up with those that could not attend Being able to consent to participate only after all relevant information was retrieved	Creating a group dynamic by letting participants introduce themselves to each other by name and background Inclusion, prompting everyone to take turns in speaking by careful moderation and guidance by chair, CDBIO representatives and/or Secretariat. Transparency about responsibilities, benefits and expectations

Rapporteur's reflections

Setting the format is one of the most important steps in planning a successful event. Selecting appropriate organisations and academic institutions is essential. The invited organisations will need to know the preferred competencies and, in the case of a youth forum, the age span of the representatives they are expected to appoint. One of the key questions for the organisers is the profile of the participants, the ideal number of participants and how to best introduce the format and engage the participants in the topic.

When planning the pilot youth forum this task was simplified by the fact that the CDBIO chair knew of relevant organisations and institutions to contact. When planning for a larger event it will be important to send the same message across to relevant organisations in several member states, and the delegations from those countries will need to facilitate contacts. It would then be advantageous if these delegations could also describe the planned format and topic in the native language of these organisations to find the most relevant participants to the selected topic. After having enrolled relevant representatives from different organisations across several member states, it would be helpful to organise an online meeting describing the purpose of the event, the process up to the event, and the expectations from the CDBIO. When planning a larger event the secretariat will need to appoint at least one person whose responsibility should be to plan and prepare the event together with the Chair of the CDBIO and the Bureau.

Preparation meeting for topic selection

A face-to-face meeting was held in Dublin in preparation of the forum. The objective of this meeting was to brief the youth participants so that they could reach an informed decision on the selection of a forum topic. Written briefings on the shortlisted topics were prepared beforehand and sent to the youth participants. The meeting was then held to present and discuss the topics, with a view to the youth reaching a final decision on the topic of the forum. The group selected "AI in Health Care" as a topic that resonated with the majority of the group. The choice was mainly based on a common interest in the topic, and that the majority felt they had fair knowledge and insight on the topic.

Responsibilities of the Secretariat and the Chair	**Needs expressed by youth**	**Keys to a successful preparation meeting**
Written briefings on shortlisted topics prepared List of links to relevant news, articles and studies	Having a moderator for the meeting Ensuring practical arrangements were in place to enable youth to attend/participate Freedom to choose topic Accessible and immediate communication channel (e.g. via Whatsapp) besides e-mail Sufficient time to prepare and study the proposed topics Clear agenda and time-line	Inclusion of all participants Letting the participants choose the topic where they had most interest and insights Having a moderator The chair and members of the secretariat actively exchanging with the participants

Rapporteur's reflections

However engaging it may be for the youth to take part in deciding the topic to be dealt with, the CDBIO needs to decide whether there is a certain topic, or several topics, on which it would be equally relevant for the Committee to hear the youth perspectives. It may be an advantage for the youth participants to know the selected topic before the enrol so that they can make an informed decision on their participation and prepare themselves for the selected topic discussion. Even if the participants are not expected to have special knowledge or competencies in the selected topic, knowing the topic would allow them to come up with relevant leads and questions before a first preparation meeting. If the topic is already selected by the CDBIO, the first meeting could serve the purpose of team building, setting the agenda and meeting the organisers and the other participants.

In a larger format, it may be difficult to afford organising a physical preparation meeting before the actual event. Depending on resources, an online meeting could serve the purpose well enough. If the group is very large, the online meeting could also break into smaller groups

which will later be the working groups preparing for the presentations in the forum. This could have the advantage of engaging the working groups on a more detailed level, perhaps under the lead of a moderator for each working group appointed during this preparation meeting.

Preparations before the event

Council of Europe invitation letters were prepared and sent to the youth participants, and arrangements for travel, accommodation etc., were made. As regards substantive preparations, several academic/scientific articles on the chosen topic, AI in Health Care, selected by the CDBIO Chair, were sent to the group.

Secretariat responsibilities	**Needs expressed by youth**	**Keys to successful preparations**
Find reliable ways to communicate efficiently with youth participants, such as 'Whatsapp' or 'Teams' group (e.g. regarding travel, accommodation and other admin arrangements) Anticipate, prepare and communicate info sheets (on e.g. travel arrangements, planning, timetable of each step, etc)	A high level of structure and curation of topic A face-to-face meeting with youth to discuss shortlisted topics More advanced planning More time needed to read and digest substantive information on the forum topic More time getting to know each other, in advance More information and explanation about process steps	A detailed travel itinerary, including tips on what to do in case of delays (many had not travelled before) Send carefully selected inspirational articles in good time before the event to allow for participants to start preparing at their own pace

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Preparation day – led by moderator

In preparation for their engagement with the CDBIO, the youth participants gathered one day prior to the event at the European Youth Centre in Strasbourg, where facilitated discussions and collaboration took place on the topic of the forum. The meeting allowed the group to listen to presentations from experts in the field[1] who, in a 'Chatham House' rules environment, were able to provide personal reflections and experiences. These discussions led to a discussion on advantages and disadvantages of the developments in the field, also benefitting from the articles on the topic provided by the CDBIO Chair and Secretariat.

[1] Outi ÄYRÄS-BLUMBERG, Ministerial Adviser, Legal Affairs, Ministry of Social Affairs and Health, Finland, and Sabine SALLOCH, Head of the Institute of Ethics, History and Philosophy of Medicine at Hannover Medical School, Germany.

The group then went on to identify key areas within the topic to prioritise. They decided to present to the CDBIO their conclusions on *key challenges, issues which resonate for young people, and possible solutions to consider.*

To identify key areas, the moderator conducted different interactive exercises. To encourage reflection and engagement the invited experts, who had presented different aspects of AI and Health Care, interacted with the participants in an online discussion The youth participants then engaged in (i) open discussion on attitudes about AI in healthcare and the doctor-patient therapeutic relationship, (ii) "open card call" to explore ideas, to focus on commonalities, and to prioritise key areas for examination, (iii) a trade show, comprising rotating groups of youth to consider, present and exchange views on specific challenges, areas which resonate, and proposed solutions. It was agreed that each group would prepare a presentation of their conclusions on one of the following aspects of AI in healthcare:

1. Bias mitigation

2. Training

3. Equitable access to healthcare

4. Accountability

The expertise of external experts, coupled with interactive exercises led by the moderator, allowed the group to prepare their statements and speaking points for the forum proper. The groups agreed to structure their presentations into the three parts; *key challenges, issues which resonate for young people, and possible solutions to consider.*

Secretariat responsibilities	**Needs expressed by youth**	**Keys to successful engagement**
Organise and reserve accommodation for the youth participants (i.e. European Youth Centre in Strasbourg) Reserve meeting rooms for preparations the day before the plenary Organise presentations and questions to get the discussion started Make travel arrangements Reserve meeting venue	Additional time needed to prepare and plan the presentations The input by external expertise was much appreciated Having a moderator and some representatives of the CDBIO added to the value of their contributions More structured organisation and planning of preparatory work, including on expectations in addressing the CDBIO Clear objectives	Information and communication on expectations from the CDBIO Active contributions by experts Engagement from representatives of the CDBIO to interact at an early stage Clear objectives Secretariat supporting the youth in structure when presenting the conclusions Having a detailed agenda

	Information on "tips and tricks" on how to address the CDBIO, what questions to pose and to expect Having a travel coordinator and a clear travel plan and event schedule	Ensuring that the scope and topics to be addressed correspond with the CDBIO time allocated

Rapporteur's reflections

Having a structured and engaging preparation day leading up to the forum proper is the most important element to make the forum successful. The youth will need some guidance from the organisers and their moderator/moderators to know how they are expected to inform and interact with the CDBIO. Depending on the size of the group, it may be wise to divide it into several groups discussing different perspectives of the topic at hand. The youth may want to structure the presentations themselves, but it may be helpful to have prepared some ideas from the part of the secretariat and the Chair if more guidance is needed.

If the group of participants is very large, it may be necessary, from a time-management point of view, to consider having a spokesperson for each working group presenting the outcome of their respective discussions. This may also be advisable, since most of the participants will not be speaking their native language, which may make some hesitant to speak in front of a larger audience although it should not be an obstacle to participate in the discussions during preparations.

An option to consider in planning for the event would be if the spokespersons should be the same persons who were moderating the working group already in the preparation meeting. If the role of the moderator carries more responsibility it would also create a sense of dedication in the planning phase.

The youth requested more support in the practical details of travelling and clear schedules for the days they are in Strasbourg. This could probably be solved with having a person solely dedicated to organising the event, who could be prepared to advice on optional routes if there are problems during travel, and who could send detailed information and agendas before the event.

Forum proper

The forum was developed to provide the youth with as much space as possible to express their views and perspectives, openly and freely. There was attention not to overly structure the agenda from the Secretariat's side, instead to keep it lightly structured, enabling the group to transpose much of their preparatory work (statements, small working group structures) to the forum proper. The structure was determined by the youth, with the support of their moderator, during the preparation day.

The forum took place on the morning of 6 June (agenda in Appendix I). The meeting room was configured, as far as was practicable, to give the group prominent seating positions next to the chair and facing CDBIO delegations. With a very supportive approach from the CDBIO chair acting as moderator, coupled with equally encouraging words from the Irish Ambassador and Irish Chief Medical Officer, the opening of the forum provided an appropriate environment for the youth to speak with confidence.

CDBIO delegations were equally as encouraging and constructive in their replies to the youth. This enabled engaging discussions to take place, demonstrating that the member states were listening actively, and that the youth considered that they were being heard.

The detailed forum discussion can be found in a transcription (see Appendix III to this report).

There is also a report made by the moderator of the preparation day, describing the presentations and proposals at the Youth Forum (see Appendix II*)*.

Responsibilities of Secretariat and Chair	**Needs expressed by youth**	**Responsibilities of CDBIO**	**Keys to successful forum proper**
Preparing the agenda Chairing the discussion in an encouraging way to give youth confidence to speak Keeping track of time	Convivial atmosphere and engagement from audience Knowing the seating plan beforehand Keeping the time schedule as to allow all groups to finish their presentations Having a clear agenda and speaking order for presenters	Planning and preparation, led by the Bureau, of the CDBIO regarding their responsibilities vis-à-vis dialogue with the youth participants Constructive interventions, allowing all youth enough speaking time	Having notified the CDBIO delegations beforehand on their role and responsibilities Having a clear objective and agenda during the forum Effective chairing Taking notes of the conclusions to reflect on future actions

Rapporteur's reflections

The forum proper was very successful in providing the CDBIO with insightful perspectives on the selected topic. It was also conducted in a very friendly and transparent atmosphere, welcoming everyone to speak. It would be important even for a larger youth forum to invite all participants to make their views heard. If spokespersons are to present each working group's discussions, the active participation of CDBIO delegates would be necessary to

continue a lively discussion in which other members of each group would feel welcome to join in.

As for the structure of the pilot youth forum, it would be advisable to screen the agenda to the auditorium for the sake of clarity. The structure of four key areas and three questions was presented only orally in the beginning of the forum.

Feedback

Following the close of the forum, a short session was held to have feedback from delegations during the afternoon of the CDBIO. The comments were predominantly positive, and the delegations showed much appreciation for the work organising the event, but not least to the quality of the presentations and discussion during the forum. It was agreed that it would be a challenge to recruit such a diverse, well-informed and well-spoken group for a larger event in a more international context, especially considering language barriers, and that it would be important to meet these challenges with more deliberation on the form.

The week after, an online feedback session with youth was also organised, to allow them to reflect on the forum process and results. The youth were pleased with the outcome in general. There was however some feedback urging the CDBIO to consider giving the youth more time for preparation before the forum proper, and to provide more details in the travel planning. The needs expressed by the youth can be seen in the columns throughout this report.

Communications and visibility

Having given their consent, photos and video clips of the youth were gathered and posted as news on the Council of Europe bioethics portal and on the dedicated youth forum webpage. They were also disseminated via social media platforms Twitter (X), Facebook (or Meta) and Instagram.

CONCLUSIONS

The conclusions to be made from the pilot youth forum concern, on the one hand, the results of the discussion on the topic itself, AI in Healthcare, and, on the other hand, the learnings from having organised such an event in preparation for a larger one.

Concerning AI and Healthcare, many of the perspectives presented by the youth were insightful and provided the CDBIO with new reflections. One of the immediate contributions to the work of the CDBIO would be for the CDBIO drafting group preparing a report on the impact of AI on the doctor-patient relationship to take onboard some of the proposed solutions. For example, the notion of shared responsibilities in developing and using AI in an ethical manner, respecting equity for all groups and applying professional standards. Promoting standard setting in regulations or guidelines, prompting AI developers to reach for a minimum standard no matter where the AI system is launched, would also be something to consider for the CDBIO in future actions.

As for the organisation of the event, the outcome was highly appreciated much due to the great efforts that had been made in the preparation phase. The youth were extraordinarily

engaged and the group dynamic they demonstrated in the forum proper made the event ever the more rewarding. Having many interventions from the CDBIO helped forward the exchange in a positive and welcoming way.

Some of the keys to such a successful forum were **thorough preparations from the part of the Chair, the Secretariat and the youth and their moderator**. Organising a preparatory meeting in Dublin seems to have been very helpful for the youth, starting off the thinking and learning process by choosing a topic that resonated with the group. **Appointing a moderator** for the preparations seems to have been greatly appreciated also by the youth. **The selection of engaged and educated youth of diverse, yet largely academic, backgrounds was a key factor, made possible by recruiting youth through academic institutions as well as diverse youth organisations**. It was a strength to already have had informal contacts with these organisations through the chair of the CDBIO. **The size of the group was ideal (14), and in a larger context one would need to divide the group into smaller ones, and appoint spokespersons rather than everyone presenting during the forum.**

A clear advantage of the pilot youth forum was that the youth had a common language and were able to present in their mother tongue. This not only facilitated the exchange during preparations and in the forum, but also made the youth more comfortable presenting. When organising a pan-European event, the common language will likely be English, but **one will need to take language barriers into consideration in planning the format**. It may be advantageous to **appoint moderators for each smaller group to make sure everyone is heard**, before concluding on points to present to the plenary, and then **appointing a spokesperson** who feels comfortable with presenting in English.

The feedback from youth included that they wished they had more time for preparation and that the travelling was difficult, especially for those who encountered delays and missed connections. As for the travel plans one can either choose a venue that is more accessible or prepare to have a travel coordinator prepared to take phone calls and guide youth in case of any disruptions. As for preparations, the group was clearly high achieving, and a substantial part of the time was used for preparations. **As for the needs of the CDBIO, more in-depth reflection and preparation would not be required**. The youth also appreciated choosing the topic themselves. However, **for the CDBIO to make use of the outcome it would be relevant to choose a topic that is linked to its current work**. In this case, there was a benefit for the CDBIO drafting group preparing a report on the impact of AI on the doctor-patient relationship.

The CDBIO Bureau will need to consider what **the objective of the next Youth Forum** should be before **deciding on a topic, or on a selection of topics to** be decided by the youth. As the rapporteur, **I would advise on the former choice, also making it easier for the youth to understand what topic to expect before they enrol**. Furthermore, the Bureau will need to reflect upon **how to manage the preparatory phase, taking into consideration the efforts required from the Secretariat in organising preparations across several countries**. One will need to **coordinate several smaller working groups and appoint moderators for each of these**. Although the preparatory meeting in Dublin certainly helped in the group dynamic, facilitating communication, depending on resources this could be possibly be managed as an

online exercise. However, the bonding during preparations should not be underestimated, as this facilitates an open discussion and creativeness in the group.

A larger event would require the engagement of several CDBIO delegations facilitating contacts with youth organisations and academic institutions in their countries. The Secretariat will need to be prepared for administrating the preparatory work as well as the event itself, and supporting the group through the process.

The pilot youth forum was in conclusion very well organised and delivered, thanks to several positive factors. Amongst those a very dedicated Chair, a dedicated Secretariat and above all dedicated, engaged and educated youth participants. It will be a challenge to juxtapose a similarly successful event on a larger scale, but through true dedication it will be possible.

APPENDIX I

Pilot Youth Forum on AI in healthcare, 6 June – AGENDA

Moderator - Siobhan O'Sullivan, Chair of the CDBIO

09:30-10:00 Opening

- Breifne O'Reilly, Ambassador Extraordinary and Plenipotentiary, Permanent Representative of Ireland to the Council of Europe
- Tour de table – youth participants
- Breda Smyth, Chief Medical Officer, Ireland (video message)

10:00-11:00 AI in healthcare - main messages, key challenges and priorities

- youth participants
- exchanges with CDBIO members

11:00-11:30 Coffee break

11:30-12:30 AI in healthcare - main messages, key challenges and priorities

- youth participants
- exchanges with CDBIO members

12:30 Close of forum

APPENDIX II

Report of the youth moderator, Liam Hawkes

Part 1: Youth Attitudes towards AI in Healthcare and the Therapeutic Relationship

The Forum considered the following statement and questions:

*The therapeutic relationship is a **critical component of good patient care**, which AI systems have the potential to improve or adversely affect*

1. **"When I think of the role that AI might play in the patient-doctor relationship, right now I'm generally…"**
    a. *Fearful*
    b. *Neutral*
    c. *Hopeful*

2. **"When I think of how I have experienced the patient-doctor relationship (either as an individual or as witness to a family member), I generally feel…"**
    a. *Let down*
    b. *Reasonably satisfied*
    c. *Well cared for*

Delegates then indicated on a 3 x 3 chart where they "placed themselves" on each of these issues, prompting engaged and reflective discussion on their personal feelings on the topic.

A high-level summary of some of the points raised by delegates having identified where they stood on each of these questions is provided in **Appendix 1**.

Part 2: Ask the Experts

The Youth Forum received presentations from key experts in the fields of AI, Healthcare and Bioethics, namely:

- *Outi Äyräs-Blumberg, Ministerial Adviser, Legal Affairs, Ministry Of Social Affairs And Health, Finland*
- *Sabine Salloch, Head of the Institute of Ethics, History and Philosophy of Medicine at Hannover Medical School, Germany*

- *Siobhan O'Sullivan, Chair of the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO)*

At the end of each presentation, the Forum participated in a lengthy Q&A session regarding specific aspects of the work of each of the experts, as well as more general questions regarding what they see as the key issues in the field.

Part 3: What did the Forum really want to focus on - Open Card Call

The Forum generated ideas together using a structured "open card-call" process in response to the following statement:

"To me, the areas that deserve real focus in terms of AI and Healthcare's interaction are.."

After evaluating over 40 individually generated ideas, and clustering by consensus these ideas together based on similarity/interrelatedness, the forum identified 11 key areas to consider. After a collective voting process, 4 areas in particular were prioritised for more in-depth focus for the Forum's engagement with CDBIO:

Key Area	Tally of Votes	Priority?
Bias Mitigation	**10**	**Priority 1**
Accountability	**10**	**Priority 2**
Training	**7**	**Priority 3**
Equal Access	**6**	**Priority 4**
Safeguards around Commercial Involvement	2	
Informed Consent	2	
Data Access & Processing	2	
Trust & Transparency	1	
Therapeutic Relationship	1	
Backhouse Functions	1	
AI Enhanced Research	0	

Part 4: Digging Deeper into the Issues - Trade Show

All delegates of the forum considered the following questions under each of the 4 areas identified:

1. ***What do you see as the key challenges to address regarding this area of AI and Healthcare?***
2. ***What resonates with you in particular about this area of focus as a young person?***
3. ***What kinds of solutions do you think CDBIO should consider regarding this area of AI & Healthcare into the future?***

Dividing into 4 subgroups of 3-4, participants took 20 minutes at each topic, giving their observations to each of the questions posed. At each rotation, one member of the subgroup remained behind to give a 2-minute summary to the subgroup coming fresh to the topic of what had been discussed, creating the impression of a "trade show" throughout the work space.

As groups rotated between each topic, delegates added to what previous groups had said, highlighting areas of agreement and potential new areas for consideration, thus allowing for cross-collaboration and mutual peer-review under each topic.

Part 5: Preparing the Specifics

At the end of the Trade Show, the subgroups of 3-4 delegates returned to the key area with which they had started in order to prepare for their engagements with CDBIO. Given that roughly 30 minutes was to be allocated to each of the 4 key areas identified for engagement with CDBIO, each group was tasked with preparing the following:

1. **Opening Statement**
2. **Statement on Key Challenges**
3. **Statement on most resonant aspects as young people**
4. **Possible Future Solutions for CDBIO to consider.**

A high-level summary of the points made by each group, which served as the basis for engagement with CDBIO, is provided below.

1. Bias Mitigation

Key Challenges

- How can we eliminate bias in AI systems if these systems are written by humans who are inherently biased by growing up in a particular setting/culture?
- Is it possible to create standards for what a truly 'representative' dataset on which an AI can act should be? Realistically, how available is data from groups that we have found harder to reach?

- Given that bias usually only becomes apparent post-development, is there a way we can assess how biased an AI-driven tool is becoming on an ongoing basis? What is the feedback loop?
- Bias is a lived experience – no AI technology has or will ever "live this experience".
- Importance of distinguishing between harmful bias (unstructured, concept depending on people development) and equity-driven decision making (structured).

Most Resonant as Young People

- Recognition that if AI systems are developed appropriately, it could be revolutionary for how we deliver healthcare. By taking the time to instil a focus during AI development on the values we want for our society, we reduce the risk of needing to fix this in future, and promote trust in these technologies on a more widespread basis.
- If we can approach a scenario where existing biases are further highlighted by AI tools, creating opportunities to remove these biases in how we deliver healthcare currently, we could help to ensure that the benefits are share by all (including groups that we currently aren't reaching sufficiently)
- This generation has been at the forefront of recent pushes for equality in Ireland, and the need for more diversity in the field of AI development/tech is echoed here.
- Recognition that successful delivery of this transition to AI and healthcare could foster benefits for other important fields in today's age of 'polycrisis' (e.g. climate change, globalisation).

Possible Solutions

- Important that developers as well as healthcare professionals undergo implicit bias training in the short-term.
- Creating standards/best-practices for what a "representative" data set should be. This should include diverse and currently underrepresented populations (e.g., in the Irish context, the Traveller Community/Roma). This could include opportunities for collaboration/data sharing arrangements between countries, whilst ensuring high standards of data protection.
- Ongoing need to promote public awareness as these technologies becoming more mainstream, especially among groups that are less represented in our datasets currently.
- In recognition that no person can be completely free of bias or their own sociocultural context, continue to highlight the importance of diversity in the field of STEM and develop specific programmes to familiarise students with STEM at a younger age, particularly among groups that have been marginalised.

2. Accountability

Key Challenges

- Very difficult to identify who/what is responsible if an AI-based tool 'gets it wrong' – is the computer scientist, or the doctor to blame, or is there shared liability? Is it possible to breakdown the process of AI development to identify where the problem occurred and can blame be limited to a particular point in time? Who is responsible for deeming something "harmful"?
- Recognition that this has the potential to be a highly lucrative space into the future – how can we ensure a consistent and widespread adoption of standards to ensure that "forum shopping" for the lowest standards possible does not occur?

Most Resonant as Young People

- Young people have already grown up in a world where tech companies have leveraged their significant power which have impacted in ways that we still don't fully understand. "*Accept all cookies*", without reading the fine print, is the way most of us go about our digital lives.
- Sense of responsibility for the safe stewardship and introduction of these technologies for the "digital native" generation – "*it is our future*".
- Young people have experienced how lack of accountability can damage trust in their institutions.

Possible Solutions

- Creation of a new regulations/regulatory body for assessing and approving the use of new AI technologies, with an emphasis on explainability and transparency as to how these technologies work. This can help ensure a common level of quality control as these technologies become more ubiquitous. Thought is required on whether this would be most suitable at a national or transnational level;
- Needs to be clear cut parameters for when, where and why AI is being used, with particular care shown regarding its use in more sensitive settings such as a healthcare delivery environment;
- Need to develop a framework for liability for if/when technology goes wrong.

3. Equality

Key Challenges

- There are pre-existing challenges and issues - healthcare is not currently equal access e.g. public-private healthcare divide, urban vs rural, socioeconomic inequality, Existing backlogs in care

- Inclusion of minorities and Digital literacy barriers - marginalised groups, homeless, and older people – what is the best process for this, and how can we prevent "tokenistic" engagement?
- Ensuring that all healthcare professionals can provide AI assisted care, not just in wealthy settings/countries
- Cost of development/acquisition of AI systems - accessibility and affordability

Most Resonant as Young People

- equal access to healthcare is already a significant issue for young people. Many of us often find our problems dismissed by healthcare professionals because of our age, and this is particularly prevalent for young people who are part of historically marginalised groups.
- If AI brings about a "tiered" healthcare system, that younger people will be relegated to the lower tier, both because we are not seen as a priority group in healthcare and because we are a generation that has grown up with technology and may be perceived to be more comfortable with the use of AI in healthcare.
- There may be a tendency to say *"you'll be fine with the AI"* – but young people may need or prefer in person care and should have that option
- Existing inequalities in healthcare are worsening – how can AI combat it? - could AI be used to reach people that may not have immediate access to in-person care?
- How can AI systems be made customisable to preferences and needs – language/tone/mood/colour
- Digital divide - not all have access to devices
- One group of people that may rise in international migration – climate refugees

Possible Solutions

- Firstly, we suggest a guideline or framework that will support all healthcare workers to ensure access remains equitable.
- Important that AI development in healthcare is government-led.
- Need to have consultations with diverse groups and the developers of these technologies is key is the development stages. Importance of outreach/awareness campaigns (in places like homeless services and refugee centres.)
- Need to encourage options for non-digital healthcare services/in-person healthcare services and appointment setting - alternate AI hubs where there will be an individual who can help you person to person support.
- Need for improved and modernised health/digital literacy programmes.
- Prioritised focus on impoverished and rural area.

- Ensure training is provided for other professions such as healthcare workers, youth workers, social workers, etc.

4. Training

Key Challenges

- Recognition of the risk of healthcare workers becoming 'de-skilled' if there is an over-reliance on AI-driven tools. 'Full reliance' on AI-driven tools is an unlikely future *panacea*, so alternative approaches and ensuring the capability of healthcare workers to continue delivering in their roles without these technologies will be important.
- Need for efficient and timely training of healthcare professionals. Training will need to occur early in health career process and be constantly updated, but there is recognition that this is a time intensive process.
- Acknowledgement that healthcare training and computer science are entirely different disciplines, and work must be done to build a collaborative relationship between the fields.
- Possible need for new 'non-traditional' roles within the healthcare system to ensure the successful delivery of these new technologies across various settings of care.
- Wide uptake of this training will be important – very difficult to build trust in the technology without this.

Most Resonant as Young People

- If done correctly, could engender confidence in the healthcare system for young people that is currently lacking.
- Noting how overwhelmed the health system feels at present, it is important that any training with new technologies is focussed and targeted, so as not to burden healthcare workers with unfeasible additional responsibilities.
- Have experienced of IT skills and the willingness to adopt new technologies differs between healthcare professionals.
- The human interaction between the healthcare professional and patient must be maintained.
- Could see real value in this job and would be especially motivating as a young person.

Possible Solutions

- Need to develop standardised training framework and guidelines for both pre-service and in-service training for healthcare workers who will be using AI.
- What can be done by governments to incentivise the development of new roles within the healthcare system that can foster uptake in AI skills training and adoption of suitable technologies on a bigger scale? Creation and promotion of transdisciplinary qualifications for AI and healthcare could be a way forward.

- Recognition that AI-technologies are also "learning" as they are deployed – some consideration is required as to what kind of information is relied upon in the development of these systems (e.g., peer-reviewed, open-source datasets). Review quality of AI technologies. Regular review and quality assessment of these technologies will be required.

Reflections of the Youth Forum regarding their experiences of the Therapeutic Relationship & potential impact of AI

"When I think of the role that AI might play in the patient-doctor relationship, right now I'm generally…"	**Hopeful**	*Experience of healthcare as a woman has been particularly negative – pain not taken seriously, voice minimised in an often "pale, male and stale" clinical relationship – AI-enhanced decision-making gives the change to override those in-built biases* ***(however,*** *aware that these biases could be worsened in an AI-decision making system).* *There are significant pressures on doctors in primary care settings, and the demands they face. The potential power of AI to "free up" time for these doctors to spend with their patients, by streamlining back-office and other administrative tasks was noted.*	*While not related to the therapeutic relationship some noted the potential power of AI if applied to the drug research process. Trying to get an accurate "control" in research is notoriously difficult, and AI has the power to change that.* *We are too quick to jump to "extreme examples" when discussing AI in healthcare. By "Starting small" on elements of healthcare not directly influencing the patient, the potential benefits could be huge. However, careful aligning of incentives is required – many of the companies current making these technologies operate on an exclusively "for-profit" basis.*	
		Negative experiences of the therapeutic relationship come from a therapists' "minimisation" of problems, and any new	*Negative experiences of the therapeutic relationship could be partially explained by the extent to which the system is overwhelmed –*	

Neutral	*health issue simply being considered another symptom of an existing health issue. Following particularly negative experiences, one can think that "an AI has to be better than this".* *Not much faith that an AI-based decision making tool can be truly representative of everyone.* *What inequalities might be generated if there is inconsistent uptake across different practitioners? Not all practitioners wholeheartedly embrace new technologies such as AI*	*if done right, AI could alleviate this burden.* *AI-driven systems could help with the rationalisation of waiting lists and better triaging of patients, however, is it a problem that we mightn't know how it comes to these decisions?*	
Fearful		*There are ways this can go "very wrong" or "very right" – in relying on an algorithm, what do we lose?*	*Importance of the human aspect of the patient-doctor relationship as an inherent component in good care – fearful of how AI could undermine that relationship, or even replace it entirely.*

	Let down	**Reasonably Satisfied**	**Well cared for**

"When I think of how I have experienced the patient-doctor relationship (either as an individual or as witness to a family member), I generally feel…"

APPENDIX III

Non-verbatim transcription of discussions during the pilot youth forum, prepared by the Secretariat

I. Bias mitigation - presentations by youth participants

- The integration of AI in healthcare is an opportunity to make access to healthcare available to all.
- Bias is prevalent in modern medicine because it has been developed using data predominantly from white male men.
- AI healthcare must avoid reinforcing existing bias, by being vigilant in how AI systems are designed and trained.

- AI healthcare needs inclusion criteria and a wide representative dataset, to effectively treat everyone from all backgrounds, so that treatment can be available to all.
- AI healthcare should be based on diversity in the teams building the technology and the diversity in the data (from representative patient cohorts) training the AI system.
- AI should not instill fear and anxiety of mistakes being made when using AI.
- The challenge will be to understand how pre-existing bias impacts AI so that we may act responsibly 'doing no harm', achievable by measuring AI (by monitoring algorithms) and developing protocols.

- Young people experience increasing uncertainty in life (e.g. COVID-19 impacts), and do not seek to exacerbate this uncertainty with AI.
- Young people want AI deployed in healthcare, provided it is stable and easy to navigate.
- Young people seek to ensure pre-existing biases in healthcare are not exacerbated by AI.
- With first-hand experience in suffering from biased healthcare treatment, young people do not want to be dismissed by human doctors who perceive them in a wrongful way, effectively biased in their perceptions of them. AI healthcare could be an opportunity to overcome such biases if AI is appropriately and transparently implemented.
- AI healthcare should benefit the many and not the few (e.g. the wealthy).

- Outreach programmes including underrepresented groups will be able to gather more representative datasets, carried out in a trustworthy manner.
- Diverse groups (e.g. sociologists, local representatives etc) can help to assess data quality such as by way of stress tests, proxy identification, looking not just at the data but at other factors such as indigeneity lying beneath the data to explain why the data collected as it was.
- Bias benchmarking frameworks can help to assess quotas and proportionate amounts of data vis-à-vis local population data in the datasets.

- More open development of AI systems can help to overcome the secrecy and protection of proprietary rights of AI systems.
- Exercises for AI developers (e.g. related to cognition) will enable them to focus more on the doctor-patient relationship and understand the effects of AI on the relationship.

Chair CDBIO

- A key point to note is the need to collect diverse datasets so there is better representation of groups, including marginalised groups who can be more difficult to reach and may be more sceptical about handing over their health data.
- The benchmarking of data bias, coupled with post hoc analysis, are important to underline.

Exchanges with CDBIO delegations

CDBIO representative

- A question to pose is how to embrace new technologies such as AI coupled with the uncertainties it brings without stopping its introduction in healthcare?
- A further question is whether codes of ethics (like the Hippocratic oath) exist for AI developers and, if not, how can this be encouraged?

Replies by youth participants

- There is a need to start early in embracing AI systems, establishing parameters, reviewing/reassessing regularly to ensure they correctly address different patients from different backgrounds.
- It is suggested that 'back end' AI used in health admin etc., be in place to alleviate pressures in healthcare.
- Determining the obligations of developers will depend on who is deemed liable for the AI system.

CDBIO representatives

- AI developers do not feel they have obligations similar to doctors.
- Progress is possible when AI developers have diverse backgrounds.

- Support is expressed for the proposal of inclusion criteria and benchmarking systems to mitigate bias in data collection, both from women and men, from different countries and diverse backgrounds.
- A question to pose is how can we build trust so that marginalised groups have the confidence to share their health data, while ensuring that privacy and data protection standards are protected and respected?

Replies by youth participants

- Digital literacy could enhance education, including those from diverse backgrounds.

- The transparency of the process for data collection is important, explaining what and why is the data being collected for and how is it contributing could help to encourage data sharing.

- Education to better understand AI, including open conversations between people, is needed to overcome fears surrounding AI. This enables people to accept AI and share their data, to build bridges between the public and those seeking health data to fuel and enrich the outputs of AI systems.

- Informed consent requires that information about AI systems is accessible and understandable for individuals (also to overcome any distrust in the healthcare system from some parts of the population) can have longer term benefits.

- It is important not to dehumanise the process of healthcare, by using AI to free up time for health professionals to talk with patients and build trust.

CDBIO Chair

- Building trust with all population groups is important, this includes showing oneself to be trustworthy.
- Important to explain the benefits of data sharing to the individual/diverse groups.

CDBIO representative

- Communication with the individual is a critical point. Considers that AI will never help communicate with patients.
- AI can help mitigate bias, but collecting data which is then input into AI systems will be time consuming, frustrating for the patients etc.
- AI is a tool but cannot see how AI can improve the doctor-patient relationship, especially considering the importance of clinical skills assessment of doctors.

CDBIO Chair

- A question to pose is how the power dynamics will evolve between doctors and patients, especially as patients become more informed via AI systems.

Reply by youth participant

- It may take a while to implement, and notwithstanding the need for human empathy, but there will be undeniable progress to current healthcare arrangements brought about by AI (e.g. having immediate access to patient history; not requiring the patient to repeatedly explain history and symptoms; less stress on doctors etc).

II. Training - presentations by youth participants

- We should prepare and adapt for AI healthcare.

- A question to pose is how can we ensure that our health professionals are trained to use AI? Not everyone has the same level of digital literacy. Also knowing how time is precious in healthcare, so training should be time-sensitive too (i.e. not taking time away from doctors seeing patients).
- It is underlined that empathy, human contact and reassurances cannot be replaced by AI systems, so the challenge is how we should use AI in healthcare systems, including how far should the training go, what kinds of tasks should be given to the AI system, etc., all on the understanding however that health professionals are not "deskilled" and their purpose and competences are maintained (especially important in the event of a cyber-attack when AI systems fail).
- AI systems should be trained too, so what information should AI be trained on (e.g. only on medical journals, literature, on new medical practices etc.,) so that it is understandable and comprehensible in the same manner that a human doctor would be, allowing the same standard of AI healthcare throughout the country.

- It is hoped that, if trained correctly, AI could have tremendous impact (e.g. in diagnostics, in surgery etc).
- AI could allow information about patients to be shared and accessed immediately, reducing the administrative burden and improving the doctor-patient relationship.
- Maintaining human interaction is critically important. Humanity cannot be replaced by AI machines and should be limited to having an assistive role. Invited CDDBIO delegates to consider the balance to be struck between human interaction and AI technology.
- There is concern about the ambiguous nature of how AI is trained. This concern could be somewhat alleviated if all stakeholders, including patients and healthcare professionals, interacting with AI systems could be comprehensively trained and brought up to a minimum standard of digital literacy. This standard would allow everyone to utilize the benefits of AI. This standard would also produce a trusting relationship between the public and AI developers/health professionals in AI healthcare, which is built on the transparency of the digital literacy training provided to the individual.
- The outcomes of AI in healthcare are dependent on training, which should be mainstreamed and mandatory.

- There is a need for a standardised framework for educating and training health staff to use or implement AI.
- The design of dual modules and certifications, which combine health sciences and computer sciences or IT, will assist with collaboration and a deeper understanding of AI systems.

- Only credible per reviewed information should be used for training, learning and development of AI systems.
- There should be clearly set and defined interactions and boundaries between AI systems and healthcare staff, both pre-service and on-going in-service training, whilst also ensuring the efficiency and effectiveness of these dual modules.
- Assessing regularly the quality of training modules developed within healthcare systems to ensure that they are as effective and efficient as possible.
- Accountability for AI in healthcare should reside with health professionals.

CDBIO Chair

- We need to be careful about "upskilling" healthcare workers to use AI while at the same time not "deskilling" them so that they are unable to work without AI.
- There is a need for clarity concerning the quality of health data used to train AI systems (i.e. can we scrape the Internet and social media for health-related information and behaviours (is it appropriate?) or should that data only be from medical records et al?

Exchanges with CDBIO delegations

CDBIO representative

- An important question concerns whether mandatory AI skills training for health workers are needed to address the issue of liability and to prepare them for AI more generally (its failures, gaps etc); also noting the concern that such training might result in a "tick-box" exercise to demonstrate that training is done?
- Only relying on credible information and literature to train AI models could reinforce existing bias in that data (which can be driven by wealthier Western countries). The 2015 example of Google Deepmind's using data from hospital patient records demonstrated how to go beyond the raw data supplied in order to extract new findings notwithstanding the data protection concerns about how the data was collected (i.e. without patients' informed consent). The issue is how to get the best training data in order to improve the AI model albeit in compliance with human rights standards. In summary, what is meant by the right training dataset?

Replies by youth participants

- There is an inevitable transition towards AI healthcare, assisting healthcare staff now because AI is advancing so fast. Having a standardised approach would eliminate ambiguity among healthcare staff, in the belief that accountability should reside with the human professional thus any healthcare system using AI should have a standardised approach to its introduction.

- IT skills among health staff will differ so the objective is to help these staff interact with new technologies on a daily basis.
- Giving away health data to big tech companies is a concern vis-à-vis data protection, so how should health data sharing be managed and by whom – should this be led by states or companies?

- The scraping of Internet data for use in AI models used in healthcare is not to be trusted. That said, existing health literature is inherently biased and, consequently, there is a need to review what data (from which control groups) is collected and how.
- It is asserted that patients' informed consent is necessary before using their data to train AI systems. Trained health professionals with critical thinking skills are best placed to collect and share health data with AI systems.

CDBIO representatives

- Critical thinking of health professionals is very important to bear in mind. It is important to train them in collaboration with others (i.e. AI developers) in order to train the AI systems.
- Criteria are needed when sourcing training data for AI models.
- It is important to collect real life data, data that has been assessed and scrutinised by health personnel who treat patients (e.g. as done in genomics field), which can be corrected and confidently used for training purposes.
- The responsibilities of users of AI models should be acknowledged, they cannot simply blame AI errors on others. These responsibilities extend to AI developers.

- A question to pose is what certification of AI systems is needed to protect patient safety (noting that is unsure whether a human health professional can be held responsible for such systems used in practice)?

Replies by youth participants

- The hierarchy in healthcare should always reside with the doctor (AI being an assistive technology) because she/he has undergone extensive testing and training and thereby competent, which is why AI training is developed by all stakeholders (patients, doctors etc who will see/experience the outputs of AI systems) – this is crucial for the next steps forward in AI healthcare.

- There is a need for "shared responsibility" and "shared liability" between stakeholders for AI errors; this requires a common understanding between them.
- The training of health professionals would be an important safeguard and measure of protection for the safety of AI in healthcare.

III. Equitable access - presentations by youth participants

- It is important to retain access to 'in-person' care while also benefiting from AI in healthcare in all its forms, leaving no one behind.
- A desire was expressed not to withhold the possibilities for AI to be more than an assistive technology, perhaps even a "partner" in healthcare.
- We should consider how AI will impact healthcare - as a supportive device, a partner, and as a commercial device.

- We need to consider the number of AI devices needed, the costs of introducing AI systems in healthcare, public vs private healthcare, socio-economic access to healthcare.
- Digital literacy barriers affect marginalised groups access to healthcare, who do not always have skills and confidence. These groups should be included in consultations on AI healthcare occur; this means access for all members of these groups to speak and to be heard.
- Geographic and demographic divides may impact the implementation of AI healthcare, including whether everyone has access to a device and to Internet access to AI benefits so that everyone has equal access. No one should be left behind as healthcare, individuals and systems evolve.

- Equitable access to healthcare is a challenge for young people (feeling that they are not prioritised), they should not be left behind.
- Concern is expressed about how AI healthcare could lead to a tiered healthcare system, with young people relegated to a lower priority tier of people who need less much human 'in-person' care.
- It is suggested that 'in-person' care should be offered to all, including young people.
- A question to pose is how can AI overcome current inequities to access, to bridge the gap, rather than becoming a permanent offer which maintains a gap between 'in-person' and AI offers.
- AI healthcare should consider the language and tone used in its offers, to ensure that it is accessible to different types of people with a degree of personalised care provided (nudging, providing tailored information) to cater to different needs.
- AI is an opportunity to help migrants not be left behind.

- Guidelines and frameworks should be developed to support healthcare workers.
- Government support is necessary at all stages of development of AI healthcare.
- There should be consultations with marginalised groups, at different developmental stages of AI, coupled with feedback loops for those involved.
- There should be the option of 'in-person' support when using digital healthcare devices and/or AI spaces.
- There should be digital literacy and training, which is made available as early as possible to everyone from all areas.
- There should be possibilities to train other professionals (e.g. social workers, support workers, youth workers), not just healthcare professionals,
- There should be awareness campaigns about AI healthcare, for refugee centers and homeless services.

CDBIO chair

- Note that there is support for the proposal for 'AI hubs' in health settings to explain aspects of AI healthcare (e.g. patient records, what health data is used by AI system).
- Note also that there is support for early-stage interaction with different diverse groups are included in AI development coupled with feedback loops for them; we need to see AI healthcare as an iterative process, we cannot wait for AI healthcare to happen, it is under ongoing evaluation.

Exchanges with CDBIO delegations

CDBIO representative

- As regards the choice of 'in-person' or AI access to health, there may be situations where AI care is the preferred option (e.g. mental health) when discussing very personal matters. In contrast, one could envisage the opposite happening, when the preference is for access to human provided support and guidance. Were both types of access to occur, how would access to both be provided equally?

Reply by youth participant

- Interaction with an AI system might be the preferred option in some cases, while in other cases it might be better with a human via videoconference. Consequently, it is important for options to be made available to enable choice and individual preferences to prevail.

CDBIO representative

- Bias, whether unavoidable or not, is a threat to equal access to healthcare. But what is the role of the doctor to mitigate bias in the AI system to ensure equitable access is ensured?

Replies by youth participants

- The voices of young people (and older people) are not being heard properly, which is the same problem for marginalised groups (e.g. ethnic/racial minorities) who are not represented in, for example, advisory panels for the development of healthcare; they must be actively engaged and listened to when discussing health policy.

- We must be more aware of bias before we even start to educate people on AI in healthcare. More education is needed now, not later, across all levels of healthcare in preparation for AI healthcare so that bias can be recognised and effectively addressed.

CDBIO representatives

- A good example of AI used in Türkiye is the use of software to improve patient management decisions which supports clinicians in reaching decisions on transfusions. This software is offered (i.e. it is non-obligatory) in healthcare settings offering transfusions (approx. 1200 across the country) to monitor patient information (e.g. lab test results, blood and blood components history of the patient, and

indications for blood and blood components). Clinicians are trained to use this software support system, which will help clinicians and patients to protect against transfusion risks, and to use blood and blood components more efficiently.

- Listening (to young people) is a two-way process. We have seen benefits and dangers of AI over last 10 years. What do young people understand as equity (is it differences between genders, vulnerable groups etc?). How is AI going to help older persons, for example with mild dementia, the blind etc.?

- A question to pose is whether young people have thought about what they will need from AI in the future, when they are older? This question extends to the future of AI in caregiving.

Replies by youth participants

- There is a need to bridge the gap for older persons to use AI, making sure people have spaces (skills hubs) to acquire literacy skills gradually in using, for example, IT devices, smartphones, applications etc. With this gap bridged, the transition to AI healthcare is more manageable.

- AI as an assistive technology is already helping older persons, especially in home settings. This is supported by the Irish policy of "Ageing in place" (i.e. living securely and autonomously at home) which promotes longevity and quality of life. For dementia sufferers, there is already AI assisted technology in use and being developed to help caregivers (e.g. via smart wearable devices).
- Considering the delays and waiting lists for access to healthcare, it is very important to see how AI can help now to alleviate the stress on those waiting, in pain, and on the doctors faced with excessive workloads. Investing in AI will be beneficial, it is the future, it is already here and cannot afford not to be prepared once it mainstreams.

IV. Accountability - presentations by youth participants

- Considering the definition on accountability of AI by the European Commission high level expert group on AI, there is a need to consider both the development of AI systems and their potential consequences.
- There is an awareness that companies play a significant role in AI technology.
- There is also an awareness that AI brings potential benefits and unknown risks to healthcare.
- The reliance on AI healthcare will require that it is fair, just and does not compromise human rights. It is important to recognise liability and demands for accountability of AI systems as soon as possible.
- Holding healthcare workers accountable for setting high AI standards and correcting errors is necessary in a democratic society and for ensuring human rights (this should remain unaltered with the advent of AI in healthcare).
- We believe that the process of AI must be regulated as a form of quality control, performed sooner rather than later and carried out in four stages: development,

acquisition, during practice, future upkeep and consistent checking – these enable accountability.
- Whilst many companies self-regulate, we cannot trust that they will respect human rights.

- In considering the AI accountability for patient injury, we see the challenge of grading the consequences based on the severity of the consequences of the injury to the patient. This is reflected in the grading of consequences of the varying liabilities of other actors, from the AI developers to those who acquire AI systems, through to the doctor who provided the treatment. Who is liable for the injury? This has various levels:
    - Developers should be accountable for the development of the AI system, responsible for creating it to the safest possible level and in being clear about its limitations. Recognise the difficulty in holding AI actors accountable considering the 'black box' obfuscation of AI systems.
    - Purchasers of AI systems choose the AI system and then implement them, necessitating that those using the AI system received the requisite training.
    - Doctors, as healthcare workers, are responsible for good clinical practice regardless of the technology they are using and are responsible in any case.
    - Those responsible for the continuous updating of (and training on) the AI system, to ensure that patient care is optimal.
- A 'shared liability' is necessary, this would promote collaboration between different actors.
- 'Forum mapping' is a point of concern, whereby AI developers export AI systems to countries where regulation is the least burdensome; also, noting the need to remain aware of the issues and to consider possible harmonisation of rules.

- A question to be asked is how will youth be affected by the lack of accountability mechanisms for AI systems; how will it affect future generations and the generations before? This current youth cohort are probably the most affected by AI because of recent technological advancements.
- The concern was expressed about how private companies take advantage of product ambiguity, the amount of health data collected and used without knowledge and where it will go. Without accountability, youth may begin to lose trust in the technology. Therein lies the importance of raising awareness and discussing about the technology, helping to build trust further.
- Accountability mechanisms for AI systems should be 'future proofed', AI policies should be harmonised, and that these are compatible with current ethical principles (e.g. Hippocratic oath) and other human rights standards (e.g. Convention 108), all to encourage trustworthiness of the actors at different levels.

- Ensuring quality control will be important in all four stages:

    - Development of algorithms - done in accordance with treatment standards, done ethically including best ethical practices for developers, and by ensuring that all datasets legally acquired and are without concerns for privacy.
    - In the acquisition and authorisation of AI systems – ensuring very strict standards for medical AI.
    - In the uses of AI by practitioners - reassuring the practitioner that the AI system confirms with the requisite standards for safety, and the practitioner is appropriately trained to use it.
    - In reflective examination – the need for an iterative ongoing process to reflect on and learn from mistakes made by AI in healthcare.
- As regards harmonisation of medical AI protocols, this is very important because we can have more leverage when there are harmonised protocols (aspects of which companies developing them will try to avoid or circumvent to increase profits). Harmonisation is a more stringent way to ensure compliance of companies.
- Introducing import measures to avoid 'forum shopping' is enouraged, aware that ethical principles are less robust ways maintained by some companies and aware also that companies are less likely to self-regulate.
- The classification of liability is important, noting that AI can contribute to medical malpractice. Necessary to establish whether the fault is due to the AI, or by incorrect inputs by medical practitioners or other forms of misuse.
- AI as a 'black box' necessitates harmonisation, especially to overcome the opacity associated with the protection of proprietary interests; there needs to be a minimum standard for the code used – this encourages better understanding of what is going on in the AI algorithm and how to better ascertain liability for error.
- Harmonisation enables a better framework for litigation, this avoiding blaming only the medical practitioner and enables blame to be apportioned.
- There should be proportional consequences for breaches of rules by medical AI systems, this disincentivises bad behaviour and protects victims.
- There is uncertainty about the definition of medical AI due to the pace of change and whether AI will be an assistive technology or something else; preferring any definitions, notions or other understanding to be part of a "living document" which comprise basic principles (like the Oviedo Convention) which we can move through into the next era of AI systems.

CDBIO chair

- It is an interesting idea to have harmonisation as the lever for setting standards.
- A minimum standard for openness is compelling and concur on the need for a minimum standard to look inside the 'black box' of the AI system, making this box perhaps "grey" instead.
- The proposal for "shared liability" between actors which encourages their collaboration is to be welcomed.

Exchanges with CDBIO delegations

CDBIO representatives

- It is very interesting and helpful to explore medical AI standardisation/harmonisation coupled with the need for transdisciplinary cooperation (including input from users, patients) on the development of AI algorithms.
- Reference is made to the value of the CDBIO guide to public debate, and the CDBIO guide to health literacy, both of which are helping to building literacy in AI and other technological developments in healthcare.
- Support is expressed for greater transparency of AI algorithms, notably to ascertain what they can do but also what they cannot do (i.e. the honesty of not knowing the answer due to a lack of data, unlike generative AI, such ChatGPT).

- Current decision makers may not have the sufficient digital skills to evaluate digital/AI tools needed by (different kinds of) users.
- As regards equitable access to healthcare, decision makers should demand from AI developers the AI systems which are easy to use for different kinds of users.

- From a legal perspective, how should we regulate AI – at the local, regional, national international level? Would it be possible to segment the questions raised by AI when reaching the agreement between various countries, such as on accountability of AI systems or on research in AI. What type of instrument to regulate AI systems? How to reconcile prevention with innovation in the field? Should there be any prior authorisation required before using medical AI? How to overcome the challenge of identifying errors in AI systems and the potential for legal disputes pitting doctors against AI developers.

- Several concerns are raised about AI liability. There is a need to unify the rules for responsibility and liability of AI, noting that existing fault-based liability in certain countries is not enough. Whereas the existence of strict liability rules in many countries may not need to be changed.

- There is concern that liability will not resolve the task of imbuing AI systems with values. What are the values that AI systems are trained on? On what basis does the AI determine what is the best for the patient vis-à-vis what is the most cost-efficient treatment vis-à-vis what is the best outcome for the people of a given country or for societies generally? Do not yet have a sufficient grasp about how AI will perform certain tasks in healthcare.
- The values that we embed in AI systems, to orient them, are of crucial importance, worthy of reflection in the CDBIO.

- We don’t know what we are trying to define with AI, when we discuss about it in a general way, on the one hand adapting it to fit patients and doctors while on the other

hand considering it as a diagnostic tool (e.g. its success in dermatology), so we have differentiate between the two.

Replies by youth participants

- It is very important to have multidisciplinary approaches, because we don't know what AI is in every situation, so for example the lawyers, the AI developers, the sociologists and others need to be included in the conversation.

- Harmonisation is difficult. By zooming in on specific issues such as authorisation protocols for AI systems one can address the need for high standards and quality control.
- As regards identifying AI errors, it will become more and more difficult to discern what is best for individuals, for society, for people in any given country etc. That said, medical malpractice continues to occur and does not preclude AI being considered within frameworks which already exist to deal with these matters, this will help to respond, to some extent, to the challenges of AI systems.
- Defining AI is very complicated and difficult to predict how the area will evolve, but this does not preclude knowing what AI is basically and the need to regulate the easier aspects of AI systems. Uncertainty in the effectiveness of self-regulation is a concern, especially considering how some companies needing to make economies have quickly disbanded their ethics departments.
- Liability is not a 'silver bullet' in regulating AI, there will always be other issues to address. Also, large companies are likely to lobby to delay regulatory efforts. That said, if liability can be advanced and a minimum standard of openness of the AI 'black box' then established, this box could turn "grey" (i.e. more transparent) making AI developers provide hospitals with more and better information to make decisions whether and how to use AI in their work.

- AI is difficult to predict, it might be better to focus efforts on the positive aspects of AI used today and in the short term.

- As regards the values embedded in the design and development of AI systems, these take a more holistic approach when considering who develops them, where are they being developed, what are the incentives inherent to the AI's development. Such factors provide a helpful start at reflecting on the (biased) values of the AI system.

- There is a point to having conversations about the difficulty in defining AI, because if we do not step in and take steps to try to understand and address AI now then later will need to back pedal and re-write the rules for AI. There are longer term benefits to take the more difficult challenging path now to influence the foundations of AI so that algorithms may be more inclusive and that there is proficient monitoring and regulation of AI going forward.

- The next step is to move from general discussion on AI towards identifying which specific areas of AI in healthcare are, for example, more histological from those which are more ambiguous, such as AI in dermatology which is prone to bias.

- Notwithstanding the need to regulate AI, it is an area which is forever expanding and uncertain, this underlines the need for a "living document" to help regularly review and regulate the field.

- There should be a 'living document" approach to AI regulation which builds in flexibility to resolve future AI uncertainties. Cites the European Convention on Human Rights as an example of such a "living document" which is still in use today. Such an approach could help to interpret AI issues, offering basic minimum standards on what is ethical and permissible.

- A question to pose is whether we are able to set limitations on AI? For example, should it be an assistive tool with parameters and limitations for it to grow as such instead of trying to generally regulate AI unknowing how it will evolve?

- Reference is made to research on AI and the (proportionate levels of) impact AI will be allowed to have considering how value laden the field is, for example AI diagnostics versus AI treatment recommendations where one of them may be less value laden than the other – such an approach could allow values to be attributed to AI systems to help segment its application to uphold human centric care.

- As regards segmenting AI systems, concern was expressed about not being too categorical to optimise the chances for AI to improve/save lives.

- It is better not to be overly dystopian about AI, especially that it would replace humans, and instead to consider how it can support and thereby enhance the relations between doctors and patients, by generating more information and providing more leeway to encourage clarity on health matters.