



Gene editing for the treatment of human disease (GenEHumDi | COST action CA21113) Communication and Dissemination Plan





Each Action MC shall adopt a Science Communication Plan including a communication, dissemination, and valorisation strategy, as well as a plan to implement this strategy. The Science Communication Plan shall reflect the MoU in particular connecting to the aims and

objectives of the Action. It is <u>recommended that the Science Communication Plan is approved by the</u> <u>Management Committee not later than 6 months</u> after the start date of the Action. It is recommended that the Science Communication Plan, including progress on implementation, is discussed on a yearly basis by the Action MC and reviewed or amended where necessary. (<u>Annotated Rules for COST Actions</u>, article 5)

VERSIONS AND HISTORY OF CHANGES

Version	Date of adoption by MC	Notes (e.g. changes from previous versions)	Author(s)*
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* The Science Communication plan is developed, updated and its implementation monitored under the overall supervision of the Science Communication Coordinator, and in close collaboration with other relevant contributors.

This document further elaborates on the <u>MoU</u> of the "Gene editing for the treatment of humans diseases" (COST Action CA21113 | GenE-HumDi), supported by COST (European Cooperation in Science and Technology).

www.genehumdi.eu

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

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1. SUMMARY

GeneHumdi Mission

Gene Editing for the treatment of humans disease" Cost Action CA1113 (GeneHumdi):

"[...] The main aim and objective of the GenE-Humdi Action is to bring together pharmaceutical companies, academic institutions, scientific and regulatory agencies, biotechnology firms and patient advocacy associations, with the aim to accelerate the translation of GE technologies for the treatment of humans diseases."

-extracted from the GeneHumdi MoU.

GeneHumdi Dissemination

Within the GeneHumdi Cost Action CA21113, communication is paramount not only to have sufficient **impact and widespread reach outside the network**, but to achieve articulated communication among **Action members**, specially between **Working Groups**. Besides it is our goal reaching external audiences covering scientist (with emphasis for young and early career vocations), clinicians, industry professionals, patient associations, regulatory lobbies, and general public.

For that purpose, different strategies are set in motion from the beginning of the action, setting:

- Platforms for exchange between members: Working group meetings (either online or in person), COST Action restricted website resources and contact directory of members.
- Dissemination of the Action activities will include scientific texts/publications and summary records of the Working group meetings.
- Courses, and training schools either organized on the GeneHumdi Management Committee initiative alone or co-participated by GeneHumdi members.
- Dedicated Financial support grants will also help making mobility accessible for networking and formative European activities to promote equality.
- Public Website and media accounts to echo GeneHumdi Action initiatives, informing and engaging general public and patients' associations in the public activities of the action.

Our GeneHumdi communication will depend on the Action structure.

Dissemination task	Warrantors inside the GeneHumdi action.
Events and Calendar	Action Chair/co-Chair
	Core Group
	Managing Committee
	Grantholder Manager
WG Meetings	WG leaders
	Grantholder Manage
Dissemination Deliverables	Action Chair/co-Chair
	WG leaders







GeneHumdi members may suggest and organize courses after approval of Core Group/MC
ITC Coordinator Grant Coordinator Core Group/MC
Grant holder Manager WG8 leader and WG8 members SCC
Grant holder Manager WG8 leader and WG8, members SCC

- To further boost the action repercussion outside the members already active in our network, deliverables in the form of peer reviewed papers, white papers, GeneHumdi Meetings, courses and open calls for ITC/NC and STSM grants will be timely and adequately announced in the public Webpage (<u>www.genehumdi.eu</u>) and social media accounts (twitter, Instagram, facebook, linkedin). Also members' initiatives and post aligned with the goals of the GeneHumdi Action will be supported and broadcasted through our social media.
- All working groups have public deliverables that are specific of the WG topic. Besides, the working group 8 in the GeneHumdi organigram is a task force fully devoted to increasing the value of the action by promoting dissemination and elaborating reporting and educational materials to reach all targeted audiences. Furthermore, the GeneHumdi Action will appoint a Science Communication Coordinator (SCC) to promote valorization of internal WG achievements and to oversee and ensure that relevant achievements and announcements are publicly shared.

2. GENERAL AIM AND TARGET AUDIENCES

DISSEMINATION & COMMUNICATION GOALS

The first purpose of the dissemination strategy is to raise awareness of the gene editing for the treatment of Humans diseases among general public, academic and industrial researchers (specially young researchers and early career), healthcare and pharmaceutical manufactures and clinicians as well as international regulators and funding sources.

• **THE DISSEMINATION GOALS INVOLVING AUDIENCES OUTSIDE OUR NETWORK ICLUDE:** The first purpose of the dissemination strategy is to raise awareness of the topic among a wide and diverse audience in Europe. The Genome Editing to Treat Humans Diseases's general dissemination tasks cover the need to reach as many as possible relevant beneficiaries of the project. We also are committed to support the project results dissemination at regional, national and European level, producing recommendations and promoting the produced training content among beneficiaries. Concretely engage target groups in project activities,







namely contributing to the discussion and constructing of the main project outputs, and participating in project events (actively, directly, and indirectly). All This can be summarized in the following Communication Goals:

Raising public awareness of the Therapeutic Potential of a cohesive pipeline to translate cutting edge genome editing technologies into Medical tools for patients for whom traditional medicine and pharmacologic formulas cannot treat. Public engagement is instrumental for the consolidation of European policies.

- **Reaching Professionals** to provide a standardized and solid pipeline to minimize the expensive cost of translating basic research ideas into medicines while maximizing the chances of regulatory and market success. Consolidation of Genome Editing technologies with actual human therapeutic potential requires a joint effort by the different researchers, healthcare production facilities and caregivers involved.
- **Educate healthcare stakeholders and regulators** at European or local level to recommend or request alignment to our guidelines. The reduction of differences in the design and production of new Advanced Medical Therapeutic Products will expand the profitability of each initiative yielding a pan European market and, at the same time, benefit patients ensuring easier access to such therapeutics developed elsewhere within the EU.
- The communication tasks regarding the COST Action will need to spread and make available to the public relevant information about the results achieve and the work progress, And they include:
 - inform and involve the target groups about project activities and results;
 - Inform and involve stakeholders about their expected contribution to the project;
 - Involve policy makers which should contribute to achieving project goals;
 - Inform and aware public authorities at national and EU level about lessons learnt derived from the implementation of the project;
 - Inform the general public and all those involved in the project about the support received from the European Union and the Erasmus+ Programme.

• THE COMMUNICATION & DISSEMINATION GOALS INVOLVING AUDIENCES INSIDE OUR NETWORK ICLUDE:

Coordination of Working Groups is paramount inside the GeneHumdi COST Action. And the network is sustained in solidarity of members sharing their knowledge and discoveries.

Coordination among the Working Groups is the major asset of our Action unveil the strategic burdens that can be evaded by the thorough design of the common guidelines for each development stage. The dialogue between the individual task forces ensures that the blueprint is not threaten by lack of attention to bottlenecks along the path that fall out of the individual working groups scope.

Education of early career and young scientist is the best resource to ensure that our effort to align and optimized protocols is not wasted as provide a continuous turnover of scientist/professionals/caregivers well educated in







therapeutic use of Genome Editing tools. Furthermore, it provides a "common tongue" to increase dialogue and understanding between the different tiers from bench to the bed side hat makes possible to rapidly adapt the pipeline when concerns arise at any point of the medicine's development.

- Summarizing on the above: **internal communication** goals will need to facilitate exchange of information among partners; Support diffusion of information inside partners' organisations and feedback. The action will appoint a Science Communication Coordinator (SCC) to motivate and observe communication. Group leaders will organize Internal reviews and reports, while the Science Communication Coordinator will cooperate with the Working Group 8 (See Bellow) for the creation of an online communication site. Also each working group will organize conference calls, in order to discuss specific subjects, and follow project progress. Dissemination will be performed at various levels. Training School and courses will serve for the education of young investigators / Early Career Scientist. Besides, the WG8 will promote production as well as coordinate the rest of the groups for impactful reporting of scheduled task.
- The following specific objectives described in this MoU, depending on or helping to disseminate the Action mission shall be accomplished:

"[...]

Research Coordination

- Establishment of standard operating procedures for the assessment of the safety of GE. Comparison of different approaches for the off-target estimation, including sampling, quality assessment, experiments, data analysis and reporting. This can provide the first guidance determining the safe level of offtarget indels for GE approaches.
- Coordination and sharing of scientific output related to the most recent and optimized delivery methods, so that project setup can be based on the most up-to-date data and ensure a higher rate of success.
- Dissemination of research results to the general public impaling a societal discourse.
- Communicate with legislators and regulators in order to promote efficient and safe GE biomedical research.

Capacity Building

- Translation and dissemination knowledge activities targeting early Career Investigators and researchers from less research-intensive countries, with the aim to promote the use of these novel technologies.
- We will promote gender equality and women leadership in this field of research in general and Genome editing field in particular.
- The organization of several online Courses platforms in order to disseminate knowledge obtained in the Action, thousands of people around the world, including undergraduate and/or graduate students will be the target, assuring a strong dissemination of the Action.







Construction, where appropriate, of a new information tool such as websites serving as a panel of publicly available directory of experts serving as an easily accessible source of information."

-extracted from the GeneHumdi MoU.

The GeneHumdi Action approaches the completion of its objectives by splitting the load into 8 working groups (WG) with a discrete scope and well-defined set of deliverables:

WG1. Organization & management

A dedicated web site will be hosted and maintained by the lead applicant's institution to allow all the members to be aware and join the Action. The web site will include all the details about the Action members and ongoing activities, including details of all members, ongoing activity, and key document. (Month 3)

WG2. Improvement of GE technologies.

- Reference documents (including efficacy, specificity and catalogue of producers) of the available endonucleases independent GE tools. (Month 12)
- Reference documents (including efficacy, specificity and catalogue of producers) of the available endonucleases and new developments. (Month 18)

To establish research priorities required to advance GE into clinic. (Month 18) Reviews and Co-authored papers on at least 2 model gene editing approaches. (Month 24)

WG3. Delivery strategies

- Reference document with a consensus on the best GE tool/delivery method combination for each cells type. (Month 12)
- The development of a consensual hand-book describing those cells types where further improvements are required to achieve efficient and specific GE. (Month 18)
- Reference document with a consensus on the best GE tool/delivery method combination for each targeted tissue of the different animal models and patients. (Month 24)
- State-of-the-art manuscript describing current delivery technology that appear to have promise in the field (Month 24)
- WG4. Safety issues: Monitoring and standardization
- A consensual guide of predictive models to use in preclinical and clinical studies. (Month 18)
- Standardized procedure protocols for the determination of off-target for experimental use in preclinical and clinical studies. (Month 18)
- Communication strategy for the biosafety and socio-economic impact to stakeholders and general public. (Dissemination: During the Action)

WG5. Translation into the clinic

Outline(s) for future clinical trials. (Month 24)

Roadmap and consensus protocols for cost reduction, yield optimization and reproducibility of the relevant gene editing tools. (Month 36)

Roadmap and consensus protocols for GMP production of gene editing tools. (Month 36)

WG6. Technological transfer and industry

Patents application files (Month 36)







Industrial agreement (Month 24) Formulation of guidelines and documents for translation of gene editing from bench to bed/market (Month 36) WG7. Regulatory Issues Peer-reviewed articles analysing different regulatory issues related to human genome editing. (Month 36) Formulation of guidelines and documents concerning regulatory aspects of new gene editing tools. (Month 24) WG8. Dissemination A strategic plant for the liaison between networks members, work groups and external stakeholders. A proceeding booklet summarizing all the main conference of each WG. (Month 24) A friendly implemented Website with Action description, protocols, social media, measurable deliverables. (Dissemination: During the Action) White paper on best practice of clinical application of genome editing. (Month 36) Intervention in scientific and medical Assembly at EU Commission. (Dissemination: During the Action). GeneHumdi Implementation of the Action Dissemination Plan (ADP) There are dissemination deliverables already integrated in the different WGs, and the specific in the case of the Dissemination group are as follows: "[...] WG8. Dissemination A strategic plan for the liaison between networks members, work groups and external stakeholders. A proceeding booklet summarizing all the main conference of each WG. (Month 24) A friendly implemented Website with Action description, protocols, social media, measurable deliverables. (Dissemination: During the Action) White paper on best practice of clinical application of genome editing. (Month 36) Intervention in scientific and medical Assembly at EU Commission. (Dissemination: During the Action). The media support to disseminate and exploit and action activities will be Coordinated between active members of the WG8 and the Action designated Science Communicator Coordinator THE TARGET AUDIENCE OF THE GENEHUMDI COMMUNICADION AND DISEMINATION PLAN. As presented before our GeneHundi Disemination Plan Encounters a challenging broad and diverse Audience. This is because we aim to set bridges across a the tiers focused to specific processes from the generation of basic knowledge about genome editing tools, to the optimization and adaptation to its use in disease models, to the vectorization and translation into preclinical pipelines, their evaluation and authorisation for patient care and the healthcare escalation, production and marketing of the medicinal products. Not forgetting that we are dealing with cutting edge scientific tools that may raise ethic debates; considering that the field is not evidence based-regulated yet; and the public







opinion is vastly under educated as many scientific concepts are new even for academic standards.

- In this scenario we need to open our target audiences as much as possible and try to reach at least:
 - **Public Opinion/General Public**, we need to divulgate and educate in the current potential of the Gene Editing therapies, the robustness of the scientific principles and the sound quality control that we enforce for these treatments.
 - **Early Career-Young Scientist**, we need to engage and educate future stakeholders in the value of standardization and promotion of therapeutic use of genome editing. Besides, we need to educate and provide the next generation with the language and tools necessary to maintain the current standards.
 - **Basic/Industry Scientist** have to be reached outside our network to attract talent to participate in our COST action and to secure widespread benefit of the researchers through the publication of our guidelines and deliverables. Appealing leader scientist, pharmacist, regulatory tecnicians and industry member to join or endorse the GeneHumdi as individuals or as part of their organizations, or even other COST Actions, is a key step towards the success of the Action.
 - **Clinicians/Healthcare Production** need to be reached. We aim to facilitate a toolbox to interpret and trust the continuously growing written evince of the possibilities and safety of gene editing technologies. Besides, lasting harmonization needs the feedback from the experts close to the bedside to provide a realistic framework for the guidelines promoted from our Action.
 - **Regulatory and funding agencies** need to be educated and informed of the value of high standards for Gene Editing products development. They have the capacity of acknowledge GeneHumdi work and implement /request our guideline for further spread and benefit of the field form the Action's work.

CUSTOMIZING THE MESSAGE

- As presented before our GeneHundi Dissemination Plan Encounters a challenging broad and diverse Audience. This is because we aim to set bridges across all the tiers involved in the multistep of bringing new advanced medicaments to the clinics. To get the response and engagement wanted, it is vital to communicate in a way that resonates and is relevant to the people that receives it. This means reversing the thinking from what a project wants to tell to considering what is important to each target audience.
- We plan to resource in social media (LinkedIn, Twitter, Instagram, Facebook) using lay language and Exploiting Visuals to capture the attention of new audiences, general public and young students. While we need to use peer review scientific publications and white papers to reach and impact researchers, heath care professionals and Fact-driven regulatory technicians and legislators. Adapting our messages will make them more memorable and familiar to the audiences to maximize acceptance and engagement. When possible, we will keep key messages simple, assuring that all (project teams, staff, decision makers, associate partners, target groups in general) can articulate them easily. Furthermore, we will invite members from the different EU countries to help







translate and promote GeneHumdi messages to their national tongue to make them familiar and increase the reach of the action in the general public.

MANAGING DISSEMINATION

Scientific activities are coordinated by the chair and co-chair, who work closely with the leaders of the working groups to promote and review scientific advancements in a concise manner. They also collaborate with the Grant Award Manager, Grand Holder Admin, and the ICT Coordinator to develop and oversee collaborative and educational initiatives within the GeneHumdi Action. Dissemination involves promoting planned activities and sharing news of the results through channels that best suit the targeted audience.

The Science Communication Manager and Working Group 8 are responsible for shaping the final messages, but they rely on fluent contact with the higher-level structures to keep them regularly updated. This ensures that meaningful communications are produced, engaging and motivating the audiences to stay informed.

Internal channels will be established on the www.GeneHumdi.eu website, providing easy access to updates for members. Regular posts on the website will report on the action's activities and will be announced and shared on Twitter, Instagram, Facebook, and LinkedIn.

To enhance communication with non-members, a newsletter summarizing the posts may be encouraged for subscribers of the Action Website.

The management rights of the proposed channels will be granted to the Action Chairs, SCC, WG8, and Grant Holder Manager. Members of WG8 who are willing to contribute, WG8 leader, SCC, Grant Holder Manager, and the Chairs of the action will have access to social networks.

THE ACTION WEBSITE: <u>www.GeneHumdi.eu</u>

The website is intended to be a crucial tool for internal communication and organization. But will provide strong support for the action visibility and for that reason we have plan the web to provide the following services:

- Public access basic information about the science behind GeneHumdi aims and links to educational tools.
- Public and transparent publication of GeneHumdi calendar and links for activities and the contents of each.

Public announcement of GeneHumdi Calls for ICT/NC calls and links for the application bases/process.

- Public disclosure of GeneHumdi Members and application for COST acceptance.
- Private WG organizative chats/registry for WG members

Private WG exchange of ongoing documents and files.

Private GeneHumdi administrative file exchange with MCs/WG leaders

• THE ACTION LOGO:









The GeneHumdi Logo serves two purposes: to provide a consistent visual identity for Action documents and to represent and acknowledge the production and initiatives of the action.

The components of the logo symbolically draw inspiration from the biological science that underlies the technology supporting this network. At the same time, it appeals to the human aspect of the network, which strives to bridge the gaps in the fragmented pipeline and develop new medicines based on advanced basic biology concepts.

- The **polygonal base** appending represents a nucleic acid base representing the biological base of genome editing residing in understanding the bases of biology and being able to expand them to treat diseases.
- The **4 color pallete** is reflection of the diversity of the **4-letter code** that is also a reflection of inclusive a diverse society that we hope we can rightfully reflect in our GeneHumdi Network.
- The **logo represents the interaction** among parts of a circos plot often used in science infographics chromosomal contents. In this case extending bridges between North, South, West and East as the GeneHumdi is a European integrative initiative to integrate in the same conversation to all the stakeholders involved in making current investigative Genome editing tools a clinical reality for patients.

3. PLAN FOR THE COMMUNICATION OF ACTION RESULTS

Dissemination will be an ongoing aspect throughout the lifespan of the action, aimed at engaging and attracting an audience that is interested in scientific results, regulatory recommendations, and consensus guidelines when the Action results need to be communicated.

THE ACTION COMMUNICATION WILL COMPLETE THE LIST OF DELIVERABLES

The progress of each working group will be closely monitored by the WG leader/co-leader, with assistance from the GeneHumdi Chair and Co-chair. The deliverables will include documents that review, summarize, and present the current state of various topics in the rapidly evolving field of Genome editing for the treatment of human diseases. The chart below provides a summary of the expected deliverables and their corresponding dissemination and communication timelines:







MC: GeneHumdi General Meeting																	
WG: Working Grooups Meeting			Y1 20	22 23	3		Y1 20	22 23	3		Y1 20	22 23	3		Y1 20	22 23	3
TS:Training School/Workshops		Q1	Q2	Q3	Q4												
DA:Disemination activities		NDJ	FMA	WJJ	ASO	NDJ	FMA	WJJ	ASO	NDJ	FMA	WJJ	ASO	NDJ	FMA	WJJ	ASC
ORGANIZATION	WG1		мс					MC				MC					мс
GE technologies	WG2		WG		TS			WG					WG	TS			WG
Delivery Strategies	WG3		WG		TS								WG	TS			WG
Saffety Issues	WG4		WG			TS		WG					WG		TS		wG
Clincal translation	WG5		WG			TS	TS	WG					WG			TS	WG
Transfer and Industry	WG6		WG				TS	TS					WG			TS	WG
Regulatory	WG7		WG				WG	TS					WG				WG
Disemination	WG8	DA	DA	DA	DA												

- For each publication a public entry will be included in our website using a generalist lay language to ease the comprehension and dissemination of the results that summarizes and promotes interest for the documents generated.
- Furthermore, media announces of the GeneHumdi activities and reports will be also linked to each new document disclosed to promote social awareness. We will use English as base language for communication and formative activities. However, GeneHumdi Member directory covers members from over 24 countries and will be posted publicly to facilitate the general public in Europe to ask for information or engage in the discussions in their own languages. From the WG8 dissemination group we will recurrently inviting members to replicate the @genehumdi post in their media in their country language to help non- English speakers participate of the mission of the GeneHumdi Action. We also highlight that the WG8 devoted to dissemination has a specific calendar for the promotion of the action Mission and accomplishments summarized in the following chart:

	[Y1 20	22 23	3		Y1 20	22 23	5		Y1 20	22 23			Y1 20	22 23	5
AD:Deliberable		Q1	Q2	Q3	Q4												
DA:Disemination activities		NDJ	FMA	WJJ	ASO												
Corporative Image		DA															
Social Media Set up		AD															
Website Set up			DA	AD													
Disemination plan			DA	DA													
Conference proceedings					DA				AD					DA			
Media engage/Website update			DA	DA	DA	DA	DA	DA	DA	DA	DA	DA	DA	DA	DA	DA	DA
white paper best practices													AD				
EU medical assembly invervention	TBD																

The communication priority over the 1st year will be the establishment of a functional website to support internal and communication deliverables.







4. PLAN FOR THE DISSEMINATION OF ACTION RESULTS

It is crucial to maintain active dissemination channels throughout the lifespan of the action, with the aim of nurturing and attracting an audience interested in scientific results, regulatory recommendations, and consensus guidelines. Specific channels tailored to reach targeted audiences should be maintained.

- The responsibility for shaping the final messages lies with the Science Communication Manager and Working Group 8. However, they rely on higherlevel structures to ensure regular updates, enabling them to produce meaningful communications that engage and motivate the audience to stay informed. Internal channels will be established on the www.GeneHumdi.eu website, providing easy access to updates for members. Regular posts on the website will report on the action's activities and will be shared and announced on Twitter, Instagram, Facebook, and LinkedIn Pages.
- To enhance communication with non-members, a newsletter summarizing posts may facilitate better communication with subscribers of the Action Website. Management rights for the proposed channels will be granted to the Action Chairs, the SCC, WG8, and the Grant Holder Manager. Members of WG8 who are willing to contribute, the WG8 leader, SCC, Grant Holder Manager, and the Action Chairs will have access to social networks.
- Announcements regarding Action initiatives such as meetings, training schools, courses, seminars, grants, calls, or other scheduled activities will be included on our website <u>www.genehumdi.eu</u> and announced as early as possible. The Grant Award Coordinator, ITC coordinator, and Grant Holder Manager will be consulted regarding specific deadlines. Our goal is to provide enough time for COST events, newsletters, and other news outlets to echo our announcements, reaching a wider audience and raising awareness of our Action initiatives.
- The dissemination of results will be coordinated with the Chair, Co-chair, and WG leader, considering strategic deadlines and relevant dates such as dedicated EU days, professional or academic international conferences, meetings, or other events of interest to the Action. The Action Chair, Coregroup, and ITC coordinator will determine the key dates.
- We have implemented a three-tier management system to fulfill the deliverables while maintaining an interesting flow of news from the Action.
- Dissemination and promotion leadership will be shared by the Science Communication Coordinator and the Leader of Working Group 8 (Dissemination of GeneHumdi Action Results). They will be responsible for developing, supervising, and implementing the promotion and dissemination plan tailored to GeneHumdi's needs and aligned with COST and other European guidelines. They will coordinate a team of volunteers within the action to manage the dissemination networks and ensure the consistent interpretation of the Action's identity and MOU in messages adapted to different target audiences. They will collect and coordinate the Action news shared through the website.

They are expected to promote the action in international forums where relevant professionals participate and may act as COST Action Ambassadors for







dissemination and communication purposes. They should support and represent the Action when opportunities arise to engage in conversations or collaborations with other actions, international associations, funding bodies, or regulatory agencies.

- **The Dissemination Team**, composed of members in WG8, will be of utmost value. They will disseminate and promote the Action activities within their country, including media releases, dissemination events, contacting target groups, and managing their own social media. They will implement actions and report on promotions under the supervision of the Dissemination leadership. They can utilize the Action's partnered communication channels and media to further promote the objectives of the Action's communication and dissemination plan. Regular meetings are expected to maintain active dissemination channels throughout the life of the Action.
- All **GeneHumdi members**, regardless of their working group and leadership roles, are expected to actively engage in the action's mission to reach public opinion and stakeholders and ensure that our goals of unity and standardization are heard beyond our network. Members are encouraged to join social media platforms and actively promote the Action's news and posts.
- **Members are encouraged to actively participate** by commenting, retweeting, and liking the Action's posts (in that order). Additionally, they are encouraged to report and suggest activities, conferences, and forums that can help promote the visibility of the action. Members can also request media coverage aligned with the action's memorandum to support their own initiatives. By actively participating in these activities, GeneHumdi members can contribute to raising awareness of the action and amplifying its impact. Together, we can make a greater impact on public opinion and engage stakeholders in our mission.

5. PLAN FOR THE VALORISATION OF ACTION RESULTS

Valorisation deals with the exploitation of Action results by specific target audiences, creating potential significant societal, economic or policy impact. As such, this section describes how the Action plans to support the envisaged scientific, technological and/or socio-economic impacts.

To support this, this section may also highlight potential end users to reach out to during and after the lifetime of the Action, a mapping of (expected) Action results which may be relevant outside the strict scientific sphere and methods and formats to promote synergies between the Action and partners for valorisation.

Data protection and IPR issues, if relevant, should also be discussed within this section.

Links between the plan and any Action deliverable related to valorisation listed on e-COST should be explained.







VALUE OF SHARING GENEHUMDI ACTION RESULTS

European medical science finds itself in a challenging situation where our research has gathered sufficient genetic information on human health and disease, and we are developing efficient and safe tools to intentionally modify genes associated with diseases. However, the pipeline for building effective therapies from this point is fragmented, and the stakeholders involved in preclinical evaluation, clinical-scale use, and regulation are also fragmented. And on top of that, our society needs to decide and regulate technologies that are complex to understand even for versed professionals.

Despite this situation, we firmly believe that we cannot abandon the implementation of gene editing into the XXI century medical portfolio, given its potential to alter the course of human diseases. We recognize the immense value in establishing bridges that facilitate and expedite the development of the next generation of gene editing medicines to treat diseases that elude traditional medical control.

We have assessed that our GeneHumdi Network's work will provide the following benefits to the targeted audiences:

- Public Opinion/General Public: The robustness of scientific principles and the rigorous quality control measures we enforce for these treatments may be unfamiliar concepts to the general public, who often have to navigate contradictory and biased news in the media. By curating Gene Editing news through expert voices in our field, we can provide a more reliable source of information for the general public. This will establish a stronger foundation for shaping public opinion not only on gene editing therapeutics but also on the broader category of next-generation medicines reaching clinical stages. It will help alleviate fears and resistance towards the practices proposed by our action, allowing Europe to appreciate evidence-based advancements that will benefit numerous patients and potentially open up a new and promising industrial sector.
- Early Career/Young Scientists: The action will enhance training and education, producing better-informed professionals, which is inherently valuable. Additionally, by exposing early-career scientists to the GeneHumdi Network, we will secure the future of multidisciplinary collaborations and international support among scientists in Europe. Such collaborations are often indicators of excellence and proficiency in both industrial and academic research and development. Moreover, attracting young talent to our network ensures the continued advancement of gene editing for the treatment of human diseases.
- Basic/Industry Scientists: Harmonization and standardization, as outlined in the GeneHumdi plan, will greatly impact basic and industry scientists. Currently, these scientists invest significant resources in validating the chaotic and diverse range of technologies available, and struggle with the challenge of translating basic research tools into successful outcomes without a clear roadmap. We intend to provide a translational pipeline developed by European experts to streamline this stage of novel therapy development. This will expand the accessibility of innovative therapies, facilitating their adoption and implementation in different laboratories across Europe. Furthermore, this harmonization effort will reduce the cost of developing new medicines by minimizing the resources invested in dead-







end experiments that are difficult to replicate or gain acceptance from local regulatory bodies.

- In addition, we aim to collaborate with existing national and international associations in gene therapy, gene editing, and bioethics to strengthen our collective voice in discussions concerning the use and precautions of gene editing for therapeutic purposes. This will contribute to shaping the collective opinion of the European Union in this emerging field.
- **Clinicians/Healthcare Providers:** Clinicians often encounter situations where, despite a thorough molecular understanding of certain diseases, effective treatments are lacking within the traditional pharmacological medicine framework. Moreover, for rare disorders without reference frames, the development of personalized medicines becomes even more costly. Harmonization in the clinical validation of genome editing tools will reduce the cost of developing new personalized medicines from scratch. By forming alliances between clinical manufacturers, patient associations, and basic scientists, we encourage the recognition and value of basic and translational research, ultimately reducing the cost of industrial development. This is particularly relevant for rare diseases, which have a known monogenic origin but lack effective pharmacological treatments due to the difficulty of major pharmaceutical companies generating sufficient revenue from treatments after the expenses of drug research and development. Such diseases are clear candidates to benefit from standardized and safe genome editing protocols, which have lifelong effects and address specific genetic mutations. Furthermore, in the field of cellular therapy and immunotherapy, fine-tuning the gene expression of cellular products can significantly reduce costs and increase effectiveness. It allows for donor-independent immunotherapeutic products, enables secure scaled productions, and improves the persistence and fitness of the cellular products. Our network aims to position EU manufacturing and healthcare facilities at the forefront of the market, benefiting not only EU patients but also the EU economy.
- Regulatory and funding agencies are a primary audience for our efforts. We aim to provide compensated guidelines, developed by leading experts in basic and industrial research, preclinical translation, and clinical care. By doing so, we alleviate the burden of fact-checking and minimize the confusion caused by a non-harmonized and fragmented field. We offer a framework to initiate regulation of novel technologies that may be unfamiliar to regulatory agencies.

Further value to the medical and research field will derive from the accomplishment of the deliverables of the GeneHumdi Action.

- Creation of a European platform for safety analysis of GE tools.
- Generation of a Consensus on the safety analysis that must be performed for clinical applications.
- Creation of platforms to share innovations and collaborations with the aim of generating more efficient and safer GE tools.
- Create standardize protocols to monitor efficiency and safety of GE tools.
- Generate standardize protocols to monitor efficiency and safety of gene therapy interventions using GE tools.







All of them will require of knowledge transference through the mechanisms explained in this communication plan. And, they will, most likely, require the continuation of the website over the 4 year duration of the funded COST Action.

ANNEX 1

The tables below are meant to provide an overview to the Action of relevant dimensions to be considered while structuring the Science Communication Plan. Table 1 highlights the different scope of Dissemination and Communication activities, while Table 2 underlines key questions to be addressed in each plan.

TABLE 1. COMMUNICATION – DISSEMINATION – VALORISATION

	COMMUNICATION	DISSEMINATION	VALORIZATION
Objectives	Promotion of the Action and its results. Raise awareness about the feasibility and necessity of translating Gene Editing technologies to clinical settings for the treatment of otherwise uncurable disorders. Harmonizing the preclinical testing providing a blueprint to speed up future/nobel therapeutics.	Public disclosure about the Action results will be shared in Scientific Meetings/communications. But also will be used for the instruction of young scientist in the form of Training School/Workshop/course. Will be used in regulatory and other forums to level the knowledge of regulatory agencies, healthcare providers and basic researchers about the actual vulnerabilities and possibilities of gene editing.	Harmonization of protocols and shared validation data, can potentially save time and investment needed to starting projects. Besides, the generation of a network of reference in terms of development and design of clinical gene editing strategies will position Europe in a privileged position for the competition for the development of safer ATPMs. Shortening the times will be critical to allow for more disorders to be targeted using these thrapies.







Expected Impact	Stablishing a multinational network of researchers is the best seed for the articulation of more ambitious European Research projects allowing for solid and reproducible science. Besides this network connects stakeholders distributed from basic research to clinical use creating a synergistic dialogue which is missed in the actual scheme.	Allowing the Action to share their comparative works will allow for better standards and more efficient design of preclinical and clinical trials. This will increase the success rate of new gene editing products reaching clinical stages. This will broaden the number of diseases susceptible to be treated that now lack the resources or manpower to fully develop clinical strategies due to lack of a defined blueprint for translation.	Harmonization and Standardization will: 1 Protect EU citizens producing safer and more solid Gene editing therapeutics. 2 Reduce the waste on animal experimentation and redundant test to the minimum necessary. 3 Save patients from the economic and psychological burden of having chronic treatments/rapid degenerative syndromes that are not chemically treatable but have a monogenic origin.
Audiences	Communication targets a broad spectrum. General public and early scientific vocations. With the aim to reach patient associations and biomedical students and clinicians to nurture interest for the therapeutic possibilities of gene editing.	Results are expected to serve translational scientist. European regulatory bodies and ATMP manufacturing professionals. Healthcare regulatory agencies and funding bodies.	Bioengineers, researchers, and Academic will benefit of our research visibility gaining relevance and impact. Cell manufacturing facility professionals and Clinical trial associated enterprises are likely to receive increased business. Healthcare professionals will expand their portfolio and market.
Languages	English and native European languages will be encouraged in social media. Lay English language will be primary use for Media messages.	Scientific English text , with a bias towards bioengineering and biochemistry jargon will be used for clarity and precision in scientific communication in specialist journals.	English is the most common second language in Europe. Combining lay language and technical precise publications we aim to provide non-specialist listeners with interest and regulatory and gene therapy professionals with solib reliable data and standards.
Channels & Tools	We use A combination of social networks and the action website: <u>www.genehumdi.eu</u> website. Courses and training schools	Our primary choice comes in the form of peer review articles and Public research articles, wide papers and manifesto. We will encourage Presentations at	We will consolidate the network coordinating application for international funding grants . EU related platforms and services such as Horizon Results Booster, Innovation







We will be participating in Social engagement campaigns, and prepare Short videos and newsletter to present our network.	Scientific/Industry conferences. <u>www.genehumdi.eu</u> website.	Radar, Horizon Results platform, European Patent Office.
	Courses and training schools	

TABLE 2. THE 5 W TO STRUCTURE YOUR PLAN

WHY It is relevant to communicate about the Action?	 There is a gap between al partners needed to translate current gene editing tools broadly used in laboratories across Europe towards a medical use in the clinics. Urgent need for a coordinated and joint effort to build a collaborative platform linking science, industry, and management; Raise awareness; Because the patient associations and Clinicians need to realize the impact of developing these medicaments faster. Improve coordination and standardization across European Partners to avoid technological gaps between countries. To spark new collaborations.
WHAT is the key message?	 Improve the coordination and standardization of preclinical translation of genome editing. Harmonize regulation and educational tools among EU members. Fasten actual clinical translation of preclinically cleared Genome editing tools.
WHO is the target audience?	 Scientific community, both industry scientists and academia. Pharmaceutical industry and Healthcare institutions currently involve in Advanced Therapies Medical Products (ATMPS) Clinicians and patient groups whit unmet clinical needs susceptible to be treated with gene editing therapeutics. Policymakers and regulatory bodies at national and European level.
WHERE and how to communicate & disseminate?	 Scientific Publications and standardized procedures should be shared with the scientific community. Workshops, training schools, conferences will be organized to secure proper implication and formation of young and early career scientist. Social Media will be used to gain visibility of the ongoing news and progresses.
WHEN it is appropriate to start communicating & disseminating?	 The Social Media will be initiated before any action and maintained thorough the 4 years of the Action life to gain visibility and thus help recruit new members. Follow up reports from meetings and Working groups will be disclosed after the events at year 1, 2 3 and 4 of the action. But also: When participating to an activity that has a wider scope with key stakeholders;







 When a joint scientific publication is published;
 When other evidence-based results and output are
available.
• At the end of the action a compilation of the insight gained will
be available to the public.





