



Health by Advanced Therapies

D5.7

Publications and material for communication second report

Public

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www.restore-horizon.eu

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1. Deliverable's description

This document describes the Communication and Dissemination activities of RESTORE – Health by Advanced Therapies, a Large-Scale Research Initiative candidate funded by Horizon2020. The purpose of this document is to summarize all communication and dissemination actions implemented during the funding period, including the various activities aimed at raising awareness of the RESTORE Initiative, main topics, events and outputs. The activities addressed the citizens of Europe and beyond, the public and scientific community, supporters' community and relevant stakeholders at different levels, with the aim of increasing interest in RESTORE topics as well as to attract key opinion leaders and stakeholders to contribute to the achievement of the goals of the mission.

The current document represents an update of the first report submitted as deliverable 5.6.

2. Communication Tools and Material

In this section the **communication tools** implemented during the 12 months of the CSA are reported:

Press Releases

The first press release was prepared to publish announcement of funding and project start via Core Team Institutional Website and Official RESTORE website.

In the course of the project, press releases have been prepared, published and distributed aiming to advertise project events or report about them. Specifically, the following issues has been released:

- Report on the kick-off meeting
- advertisement of the 1ATSM, Advanced Therapies has been published and distributed in Europe, Israel and United States,
- report of the 1ATSM
- report on EU parliament meeting
- report of the Momentum Workshop

A copy of the above-mentioned issues is enclosed to this deliverable in Annex 1- Published Material.

Messages to Community

Messages addressing RESTORE Community are regularly distributed via the RESTORE mail account to supporters signed up in the supporters mailing lists in accordance to GDPR Policy.

Messages in the form of e-mails are sent to keep the RESTORE Community engaged and informed about activities, events, access to website, working groups activity and share documents and informative material.

The supporters have also been engaged in the preparation of some deliverables as for example D1.4 “Map of European’s ecosystem and non-European network activities for Advanced Therapies”.

In addition, periodic **Newsletters** are distributed within RESTORE Community and available for download via supporter’s reserved area and enclosed to the deliverable Annex 1 Published material.

Project website

The **project website** was established during proposal preparation and improved in the new domain www.restore-horizon.eu during the first month of the project with an appropriate protocol for updating information on activities, techniques, and results of the project.

The website represents an important tool for communication and documents sharing with Public and Community. It includes a public facing section and two private sections, one for Supporters and one for Partners.

The public web pages provide the description of the project, its objectives, its mission, the events, the project beneficiaries and RESTORE supporters. It is mainly directed to the scientific and public community to raise awareness and interest regarding the research and to create a contact tool to facilitate collaborations. It also includes overall information of meetings, conferences, news, announcements and press-releases.

Website for patients A section of the website has been conceived as a communication tool with patients and their families and it is currently available in English, German, and Italian languages and recently, a French version has been completed.

In this section users (patients, patients relatives interested public, etc.) can address specific requests to RESTORE partners via a dedicated form. A feedback has been provided to all requested received.

RESTORE FOR PATIENTS

SUPPORT RESTORE

Information for Patients, Relatives and Patients Advocates

Select the available translations:



English version.

▼ Chronic Diseases

A great number of people worldwide suffer from a broad array of chronic medical conditions ranging from cardiovascular diseases, cancer, diabetes, lung diseases, (auto) immune diseases, musculoskeletal and neurodegenerative diseases through to mental illnesses.

If you are one of those who are suffering, or know someone who is suffering with a chronic illness, you may have noticed that whilst for many of these medical conditions there are treatments available which help treat the symptoms, curative treatments appear to be a distant prospect. Since most of the currently prescribed and administered drugs often only alleviate the symptoms, they frequently have to be taken over long periods of time, or more often than not, for the rest of the person's life.

Contact Us

Name *

FirstLast

Email Address *

Comment or Message *

SUBMIT

A **blog** section <https://www.restore-horizon.eu/category/blog/> is used to share general articles of RESTORE related topics.



World Kidney Day 2020

📅 12/03/2020 📁 [blog](#)

This year world kidney day falls on Thursday March 12th 2020. World Kidney Day is celebrated annually to continue to raise awareness of chronic kidney disease and its increasing burden worldwide. The theme of the 2020 campaign is to highlight the importance of preventative measures to avert the onset and [...]

[Read More →](#)



Rare Disease Day 2020

📅 29/02/2020 📁 [blog](#)

Each year, Rare Disease Day is celebrated on the last day in February, a rare 28 day month that once in every four years has an even rarer day, the 29th February. This year, 2020, Rare Disease day falls on the 29th February. The main objective of today is to [...]

[Read More →](#)

World Childhood Cancer Day 2020

📅 15/02/2020 📁 [blog](#)

Established in 2002 by Childhood Cancer International (CCI), international childhood cancer day takes place on the 15th February each year. On this day members of CCI stand united to raise awareness of childhood cancer, to support survivors and their families and to campaign for the rights of every child and [...]

[Read More →](#)

World Cancer Day

📅 04/02/2020 📁 [blog](#)

Today marks the 20th anniversary of World Cancer Day. Since its inception on 4th February 2000, World Cancer Day has helped to raise the profile of cancer research, generate greater understanding of the disease and promote respect for those living with cancer, as well as highlighting the need for funding [...]

[Read More →](#)

The **Supporters private section**, password protected, currently hosts documents (as kick off meeting, working groups description, etc.) and a data base tool to facilitate collaboration on specific working groups activities. The **partners' reserved area** contains data base platforms for supporter's data collection and it is an important share point for internal communication and knowledge management, to collect project documents (meeting and TC minutes, presentations, partners full details contacts)

Social media   

RESTORE regularly communicates via [Twitter](#), [LinkedIn](#) and [Facebook](#) pages posting messages of RESTORE activities as participation in events, or news of topics related to Advanced Therapies to keep the community and followers updated. This tool allows RESTORE to reach a wide public audience, patients, their families and the scientific community.





RESTORE @RESTOREhorizon · 18 feb

Thanks everybody for a great #RESTOREmomentum workshop, your participation, excellent talks and useful feedback. The day gave us all much to think about, widening our bubbles of perception about how to go forward with RESTORE in the future.
[#advancedtherapies](#)



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RESTORE @RESTOREhorizon · 17 feb



RESTORE @RESTOREhorizon · 13 feb

Patient organisations are important stakeholders in [#healthcare](#). Can they play an even broader role in the development of [#advancedtherapies](#)? We'll be discussing that at the #RESTOREmomentum workshop next Monday in [#Berlin](#) @IntDiabetesFed @eurordis @myESMO restore-horizon.eu/wp-content/upl...



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[Mostra questa discussione](#)



It is World Kidney Day 2020!

There is currently no cure for CKD. There are however many options to slow or halt the progression of the disease at the early stages.

For end stage renal disease ESRD, when the kidneys stop functioning, long term dialysis (removal of waste and excess fluids by machine) or transplantation are the main treatment options.

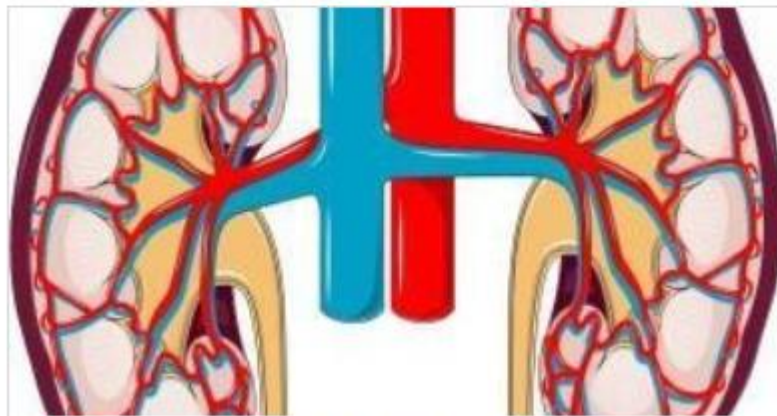
Work done by the ReSHAPE consortium, an EU funded project headed by Prof. Reinke from the Charité Universitätsmedizin Berlin (<https://lnkd.in/dEqCiyN>), could potentially solve the problem of graft rejection or the need to take immunosuppressive drugs for the rest of the patient's lifetime.

The ReSHAPE consortium are focused on developing regulatory T cell (Treg) therapy to overcome undesired autoimmunity, to reshape the immune response and allow future transplant patients to live a life free of a complex immunosuppressant treatment regimen.

A role for stem cell treatment for kidney disease?

Currently there are no stem cell therapies for kidney disease, however it is an active area of research. The kidneys are an incredibly complex organ and damage to the kidney can affect many different cell types. Find out more here:

<https://lnkd.in/dRfD7yi>



Kidney disease: how could stem cells help?



Restore Research Initiative

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World Cancer Day 2020

Today marks the 20th anniversary of World Cancer Day. Since its inception on 4th February 2000, World Cancer Day has helped to raise the profile of cancer research, generate greater understanding of the disease and promote respect for those living with cancer, as well as highlighting the need for funding not just in the public eye but also in world health policies.

Although progress in cancer diagnosis and treatment has come a long way, for example in the UK, cancer survival (10 years or more) has doubled in the last 40 years, an estimated 9.6million people died worldwide from cancer in 2018. More than half of these deaths occur in the least developed parts of the world. Even in higher income countries, there is inequality in access to treatment, especially for those in immigrant, refugee, rural and lower income communities. Thus, in addition to the need for adequate funding for research, there also needs to be a greater emphasis on equal access to cancer prevention, diagnosis and treatment, which could save thousands of lives each year (see attached infographic from the World Cancer Day initiative from the UICC).

There are many new and promising Cancer Therapies on the horizon; continue reading here: <https://lnkd.in/dWryV4C>

World Cancer Day

<https://www.restore-horizon.eu>

Consigliato 1 volta

Consiglia Commenta Condividi



RESTORE

14 novembre 2019 ·

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World Diabetes Day is marked every year on the 14th November, a date chosen to coincide with the birthday of Sir Frederik Banting, who, along with Charles Best, discovered insulin in 1922.

Insulin, a hormone made by the pancreas, is a key player in diabetes. Insulin is required to maintain blood glucose homeostasis. It is produced by beta cells in the pancreas in response to high glucose levels in the blood stream. Insulin then signals to liver, muscle and fat cells to take ...

Continua a leggere

TES ATLAS
9

463 million PEOPLE LIVING WITH DIABETES

International Diabetes Federation

World Diabetes Day | Diabetes: protect your family
Diabetes: protect your family

World Diabetes Day | Diabetes: protect your family
Diabetes: protect your family

Portuguese
Suomi
Svenska
日本語

한국어
중국어
日本語

>



Advertisement Material

Details of advertisement material have been given in the previous report 5.6

Meetings and project events

During the past 12 months of the CSA activities the RESTORE Consortium has organized meetings with the European Commission, UK Embassy, Policymakers, scientists and patient organisations to present the objectives and strategy of RESTORE.

The **Kick Off meeting** gathering over 200 participants was held on 6-7th May 2019 in Berlin. During the event breakout sessions for Working Groups were organized allowing initial discussion and involvement of supporters in RESTORE activities. Subsequent to the meeting we created an online tool that enabled the participation and contribution of supporters to the work in the working groups. An evidence for the success of the kick-off meeting and the general interest in RESTORE is the number of supporters that signed up for the online tool – we counted roughly 1000 registrants (some supporters signed up for more than 1 working group) that actively contributed to the work.



The **RESTORE 1st Advanced Therapies Science Meeting** took place in Berlin from the 25th - 26th November 2019. The meeting brought together experts from industry, patient organisations and academia to discuss the challenges within the field of Advanced Therapies and to drive forward a concerted interdisciplinary effort, making use of the excellent science, infrastructure and funding landscape within Europe, to make regenerative therapies a reality for all.

More than 400 participants attended the event.

The event has been advertised via social media, via website, via core partners' network and via press releases published in Europe, Israel and United States

Speakers and participants, from across Europe and beyond, congregated to take part in discussions highlighting the challenges facing Advanced Therapies and to hear about the latest advances from basic research and preclinical models to manufacturing processes, clinical trials, ethics, economics, regulatory issues and clinical implementation. The details and graphical material of the meeting are reported in the deliverable 5.8 and the press release in enclosed in Annex 1-Published Material.

A **Momentum Workshop** which took place on 17th February 2020 in Berlin, brought together the RESTORE community to reflect on the progress made in the last 12 months and how to continue fulfilling the RESTORE mission in the future. There were thought provoking talks from patient advocates, Bettina Ryll (MPNE), Karolina Hanslik (EURORDIS) and Sabine Dupont (IDF-Europe), on how to make the patient voice heard among the many players in the ATMP development pipeline and the importance of clear communication between all stakeholders.

Supporting material in enclosed in Annex 1-Published Material.

A **meeting at the EU Parliament** took place on 5th December 2019 as also reported on the website <https://www.restore-horizon.eu/restore-at-the-european-parliament-in-brussels/> and on the supporting material enclosed in Annex 1-Published Material.



Scientific events, Conferences and seminars

The RESTORE Consortium (partners & supporters) participated to a numerous events (conferences, B2B meetings,..) that are summarized in Tables 1 (RESTORE Joint partner & supporter events) and Table 2 (RESTORE partners individual events).

Table 1 RESTORE Joint events

Event Name	Location	When	RESTORE Partner	RESTORE Persons	Approached Audience	Content
	Brussels	22 February 2019	Charite, INSERM	A. Bennaceur-Griscelli, P. Reinke, A. Turhan, HD Volk		RESTORE in general, specific aspect pluripotent cells & their application in disease models & therapy, incl. haplobanking
	Brussels	25 March 2019	Charite, Telethon, Miltenyi	S Miltenyi, L Monaco, P Reinke, A. Turhan, HD Volk	EU officials and officers, policy makers	RESTORE specific aspects, manufacturing, rare disease
British-German Alliance for Advanced Therapies	Berlin	26 March 2019	Catapult, Charite, Miltenyi, TissUse	M Apel, U Marx, P Reinke, HD Volk	UK-DE SME and industry, policy makers	RESTORE in general and specific aspects, collaboration with UK-based scientific institutions and companies
Cell and Gene Meeting on the Med	Barcelona	23-25 April 19	Catapult, Charite, Pluristem	Z Aberman, C Feest	SME and industry	RESTORE general aspects, international awareness, industry/CDMO support
RESTORE Kick off meeting	Berlin	6-7 May 2019	All Partners	All Partners	Academia, Industry, Patients, Regulators	RESTORE
BioMed	Tel-Aviv	13-17 May 19	Charite, Pluristem	Y Yanay, G Goldsobel	SME and industry	RESTORE general aspects, international awareness, industry/CDMO support
CAAT Europe & Center of Entrepreneurship of TU Berlin Information Day on Microphysiological systems	Berlin	17 June 2019	TissUse & Charité	U.Marx; P.Reinke	SME, Industry; Academia	RESTORE general aspects, international awareness, industry/CDMO support

FOCIS	Boston	20 June 2019	TissUse, Miltenyi, Charité	H.-D. Volk; B. Atac-Wagegg; NN; S. Weber, A. Aiuti; P.Reinke	Academia, Industry	RESTORE general aspects, international awareness, industry/CDMO support
Phacilitate Leaders Europe	London	17-18 September 2019	Pluristem, Charite	Zami Aberman, Petra Reinke, HD Volk, Mohamed Abou El-Enein	SME, Industry; Academia, Venture Capitals	
IMI2 proposal on 'Engineered T cells'	Germany	26 September 2019	Miltenyi, Charité	Michael Apel, HD Volk	European Research Consortium, 20 participants	Joint participation in IMI2 call on 'Engineered T cells', Acronym T2EVOLVE
Survey on regulatory and ethical issue of ATMP therapy		Start in Nov 2019	Miltenyi, Charité	Michael Apel, Mohamed Abou EL-Enein	RESTORE members	Joint survey on regulatory and ethical issues of ATMP therapies
RESTORE 1ATSM	Berlin	25-26 November 2019	All Partners	All Partners	Academia, Industry, Patients, Regulators	RESTORE
Meeting at EU parliament	Bruxelles	5 December 2019	Charite + RESTORE Core team			Pursuing FET Flagship in Horizon Europe: Strategic Planning on Living Drugs by RESTORE
RESTORE Momentum workshop	Berlin	17 February 2020	RESTORE Core team			

Table 2 (RESTORE partners individual events)

Event Name	Location	When	RESTORE Partner	RESTORE Persons	Approached Audience	Content
ARM Directors meeting	San Francisco	5 January 2019	Pluristem	Zami Aberman	ARM members	RESTORE in general
Press release	Europe	14 February 2019	Miltenyi	Michael Apel	European researcher institutions, Journals, Press Agencies	The research initiative RESTORE Health – Therapies that cure
DECHEMA Board and Steering Committee	Frankfurt	25 February 2019	TissUse	Dr. Uwe Marx		RESTORE in general to attract the DECHEMA e.V. as a LOI partner
9th Orphan Drugs and Rare Diseases Global Congress 2019 Europe	London	5-6 March 2019	Telethon	Dr. Lucia Faccio	SME, Industry; Academia, Venture Capitals	RESTORE HEALTH BY ADVANCED THERAPIES – A EUROPEAN LARGE-SCALE RESEARCH INITIATIVE
CARAT consortium Meeting	Frankfurt, Germany	7 March 2019	Miltenyi	Michael Apel	European researchers	Presentation of collaboration joint opportunities between CARAT and RESTORE
CD20CAR-TIME consortium Meeting	Bergisch Gladbach, Germany	13 March 2019	Miltenyi	Patricia Marschall	German researchers	Presentation of collaboration opportunities with RESTORE

DECHEMA Meeting - Sections Cell Culture Technology and Medical Biotechnology	Hannover	20 March 2019	TissUse	Dr. Uwe Marx		RESTORE in general and proposal to advise during white paper writing "preclinical models"
European Society for Gene and Cell Therapy - Spring School	Naples (Italy)	3 - 5 April 2019	Telethon	Dr. Lucia Faccio	Academia	RESTORE HEALTH BY ADVANCED THERAPIES – A EUROPEAN LARGE- SCALE RESEARCH INITIATIVE
2019 Society for Biomaterials (SFB)	Seattle, US	3-6 April 2019	Minho	Rui Reis, Nuno Neves	SME, Industry; Academia, Venture Capitals	RESTORE in general
National Transfusion Medicine meeting	Salzburg	13 April 2019	Pluristem	Zami Aberman	Pharmaceutical, Medical	RESTORE in general
ARM Directors meeting	Barcelona	25 April 2019	Pluristem	Zami Aberman	ARM members	RESTORE in general
European Research Area Conference	Berlin	14 May 2019	Charite	C Feest	Policy Makers	RESTORE general aspects, national awareness, institutional support
World Advanced Therapies and Regenerative Medicine Congress 2019	London	16-17 May 2019	Telethon	Dr. Annamaria Merico	SME, Industry; Academia, Venture Capitals	RESTORE HEALTH BY ADVANCED THERAPIES – A EUROPEAN LARGE- SCALE RESEARCH INITIATIVE
13th International Symposium on Frontiers in Biomedical Polymers (FBPS 2019)	Tenerife, Spain	19-23 May 2019	Minho	Rui Reis, Nuno Neves	Academia, basic and applied researchers	RESTORE in general

TERMIS European Chapter Meeting 2019 (TERMIS-EU)	Rhodes, Greece	27-31 May 2019	Minho	Rui Reis, Nuno Neves	Academia, Industry	RESTORE in general
BIO	Philadelphia	3-6 June 19	Charite	C Feest	SME and industry	RESTORE general aspects, international awareness, industry/CDMO support
Advanced Cell & Tissue Culture Meeting 2019, University Cardiff, https://theactc.com/	Cardiff	04 June 2019	TissUse	Dr. Uwe Marx	Academia, SMEs	RESTORE in general and the content of the preclinical programme
Young life Scientists Forum 2019, EMBL https://www.life-science-forum-hd.de/	Heidelberg	06 June 2019	TissUse	Dr. Uwe Marx	Academia, basic researches	RESTORE in general and the content of the preclinical programme
Frontiers in Silk Sciences and Technologies (SILK 2019)	Trento, Italy	11-15 June 2019	Minho	Rui Reis, Nuno Neves	Academia, basic and applied researchers	RESTORE in general
“Long Night of the Sciences”	Berlin	15 June 2019	Charite	P. Reinke H.-D. Volk	General Public	RESTORE general aspects,
European Innovator Week	Bucarest	19 June 2019	Charité	C Feest		
ISACB&ISVTE	Zurich	19-21 June 2019	UZH	Simon P. Hoerstrup	Academia	
First Achilles Conference	Porto, Portugal	8-10 July 2019	Minho	Rui Reis, Nuno Neves	Academia, basic and applied researchers	RESTORE in general
FoReCaST Second Workshop	Porto, Portugal	11-12 July 2019	Minho	Rui Reis, Nuno Neves	Academia, basic and applied researchers	RESTORE in general

Israel Medical Conference	Jerusalem	13 August 2019	Pluristem	Zami Aberman	Medical, Governmental	RESTORE in general
ESAO	Hannover	01 September 2019	Charité	H.-D. Volk		RESTORE HEALTH BY ADVANCED THERAPIES – A EUROPEAN LARGE-SCALE RESEARCH INITIATIVE
XLVI ESAO 2019 Meeting	Hannover, Germany	3-7 September 2019	Minho	Nuno Neves	SME, Industry; Academia, Venture Capitals	RESTORE in general
2nd International Conference on Biomaterials, Bio-Design and Manufacturing (BDMC 2019)	Tianjin, China	4-6 September 2019	Minho	Rui Reis	Academia, basic and applied researchers	RESTORE in general
Summer Research School "Biomaterials and Regenerative Medicine"	Ulaan Baatar, Mongolia	10-13 September 2019	Minho	Rui Reis, Nuno Neves	Academia, basic and applied researchers	RESTORE in general
30th Symposium and Annual Meeting of the International Society for Ceramics in Medicine – Bioceramics 30	Nagoya, Japan	26-31 October 2019	Minho	Rui Reis	Academia, basic and applied researchers	RESTORE in general
Italian Infrastructure for Regenerative Medicine	Bologna	30 September 2019	Charite	HD Volk		

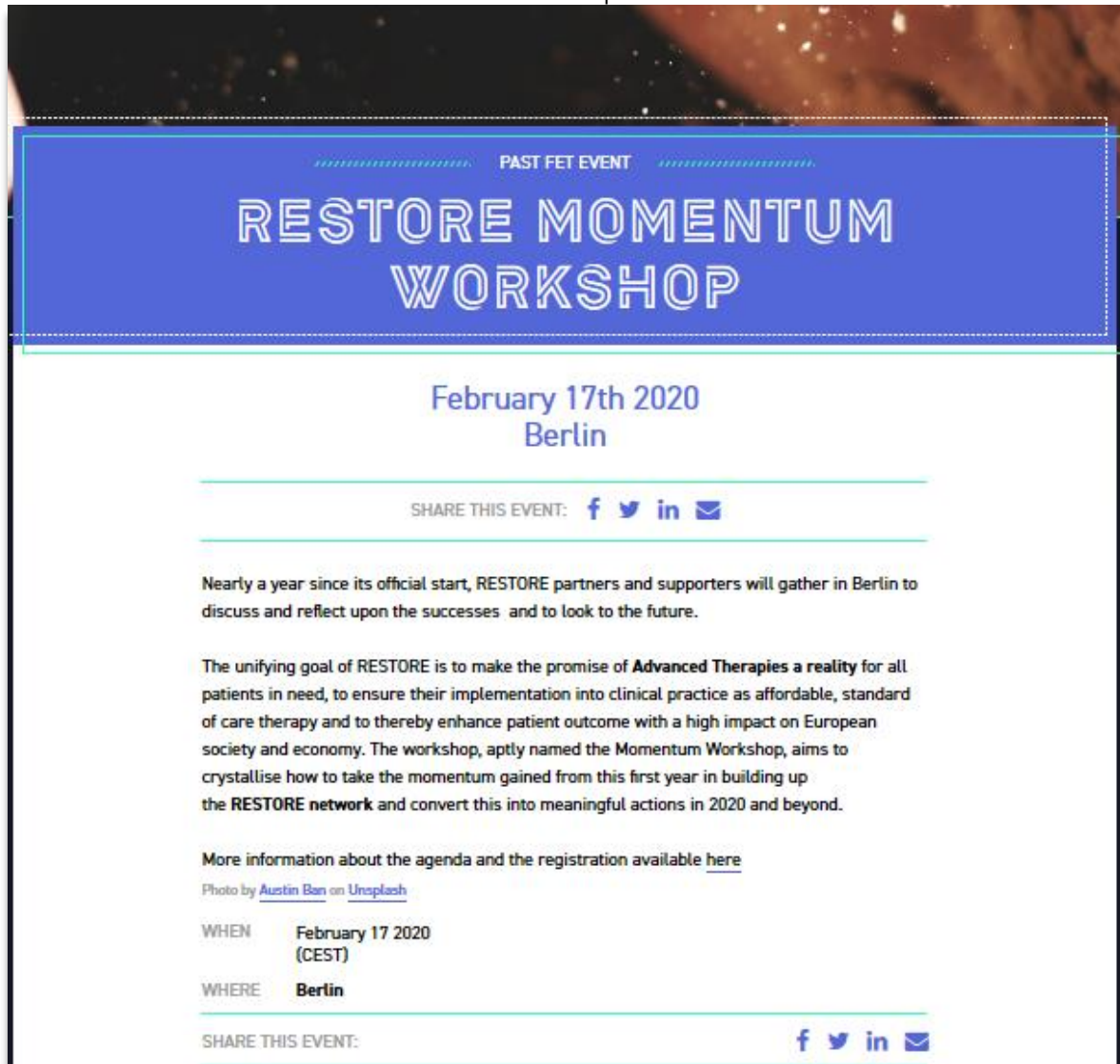
DCID & Next Generation Vaccines Days	Bergisch Gladbach, Germany	1 October 2019	Miltenyi	Andreas Dzionek	international researchers in cellular therapies	Presentation of collaboration opportunities with RESTORE
Wyss Zurich Annual Event	Zurich	3 October 2019	UZH	Slmon P. Hoerstrup	Academia, basic and applied researchers	
Tissue Engineering & Regenerative Medicine International Society – AP Chapter and 7th Asian Biomaterials Congress - TERMIS-AP + ABMC7 2019 Congress	Brisbane, Australia	13-17 October 2019	Minho	Rui Reis, Nuno Neves	SME, Industry; Academia, Venture Capitals	RESTORE in general
Meet in Italy for Life Sciences 2019	Trieste, Italy	16-18 October 2019	Innovation Acta	Cannella, Dessole	SME, Academia, Industry	RESTORE in general
Acatech board Meeting	Berlin	16 October 2019	TissUse	Uwe Marx	Acatech German National Academy of Science and Engineering	RESTORE in general
RegMed Forum	Berlin	22 October 2019	Charité	Reinke, HD Volk,	Patients, patients organizations	Zell- und Gentherapien – ein Dialog zwischen Patienten, Ärzten und Wissenschaftlern
AstraZeneca Scientist lecture	Cambridge UK	22 October 2019	TissUse	Uwe Marx	MPS overview for AstraZeneca	RESTORE in general
MPNErare	Berlin	25-27 October 2019	Charite	H.-D- Volk	Patients, patients organizations	RESTORE in general
Second Achilles Conference	Braga, Portugal	4-5 November, 2019	Minho	Rui Reis, Nuno Neves	Academia, basic and applied researchers	RESTORE in general

GDK Symposium/Biobanken: Ressource für Wissenschaft, Diagnostik und Therapie	Zurich	14-15 November 2019	UZH	Steffen Zeisberger	Academia	
ATMP workshop “Future in Medicine – Innovative Cell and Gene Therapies”	Bruxelles	3 December 2019	Miltenyi	Manal Hadenfeld	European stakeholders in science, health care and politics	Presentation of collaboration opportunities with RESTORE
Innovation Life Science meeting at EU Parliament	Bruessels	3 December 2019	TissUse	Uwe Marx	MPS and RESTORE	RESTORE in general
FDA Webex Meeting	US East and West Coast attendies	12 December 2019	TissUse	Uwe Marx	MPS and RESTORE	RESTORE in general
ReSHAPE First Annual Meeting	Berlin	23-24 January 2020	Charité	H.-D- Volk		
DIATECH Conference keynote	Leuven	27 January 2020	TissUse	Uwe Marx	MPS and RESTORE	RESTORE in general
ICTEHV	Abu Dhabi	14 February 2020	UZH	Simon P. Hoerstrup	Academia, basic and applied researchers	RESTORE in general

Collaboration with FETFX project

FETFX project (www.fetfx.eu) is an EC funded project that aims to enhance visibility and impact of FET research, using diverse communication and outreach activities. FETFX acts as a *communication hub* and it supports RESTORE communicating our activities through e-Magazines, events, workshops, newsletter and their social media channel ([Twitter](#), [Youtube](#), [LinkedIn](#)).

Examples of advertisement via FETFX website are reported here below:



The image shows a screenshot of a website event page for the 'RESTORE MOMENTUM WORKSHOP'. The page has a blue header with the text 'PAST FET EVENT' and 'RESTORE MOMENTUM WORKSHOP'. Below the header, the date and location are listed: 'February 17th 2020' and 'Berlin'. There is a section for sharing the event with social media icons for Facebook, Twitter, LinkedIn, and Email. The main text describes the workshop as a gathering for RESTORE partners and supporters to discuss successes and look to the future. It also mentions the goal of making advanced therapies a reality for all patients. At the bottom, there is a section for more information and registration, a photo credit to Austin Ban on Unsplash, and a table with event details: WHEN (February 17 2020 (CEST)) and WHERE (Berlin). There is also a second sharing section at the bottom with social media icons.

PAST FET EVENT

RESTORE MOMENTUM WORKSHOP

February 17th 2020
Berlin

SHARE THIS EVENT: [f](#) [t](#) [in](#) [✉](#)

Nearly a year since its official start, RESTORE partners and supporters will gather in Berlin to discuss and reflect upon the successes and to look to the future.

The unifying goal of RESTORE is to make the promise of **Advanced Therapies a reality** for all patients in need, to ensure their implementation into clinical practice as affordable, standard of care therapy and to thereby enhance patient outcome with a high impact on European society and economy. The workshop, aptly named the Momentum Workshop, aims to crystallise how to take the momentum gained from this first year in building up the **RESTORE network** and convert this into meaningful actions in 2020 and beyond.

More information about the agenda and the registration available [here](#)

Photo by [Austin Ban](#) on [Unsplash](#)

WHEN	February 17 2020 (CEST)
WHERE	Berlin

SHARE THIS EVENT: [f](#) [t](#) [in](#) [✉](#)

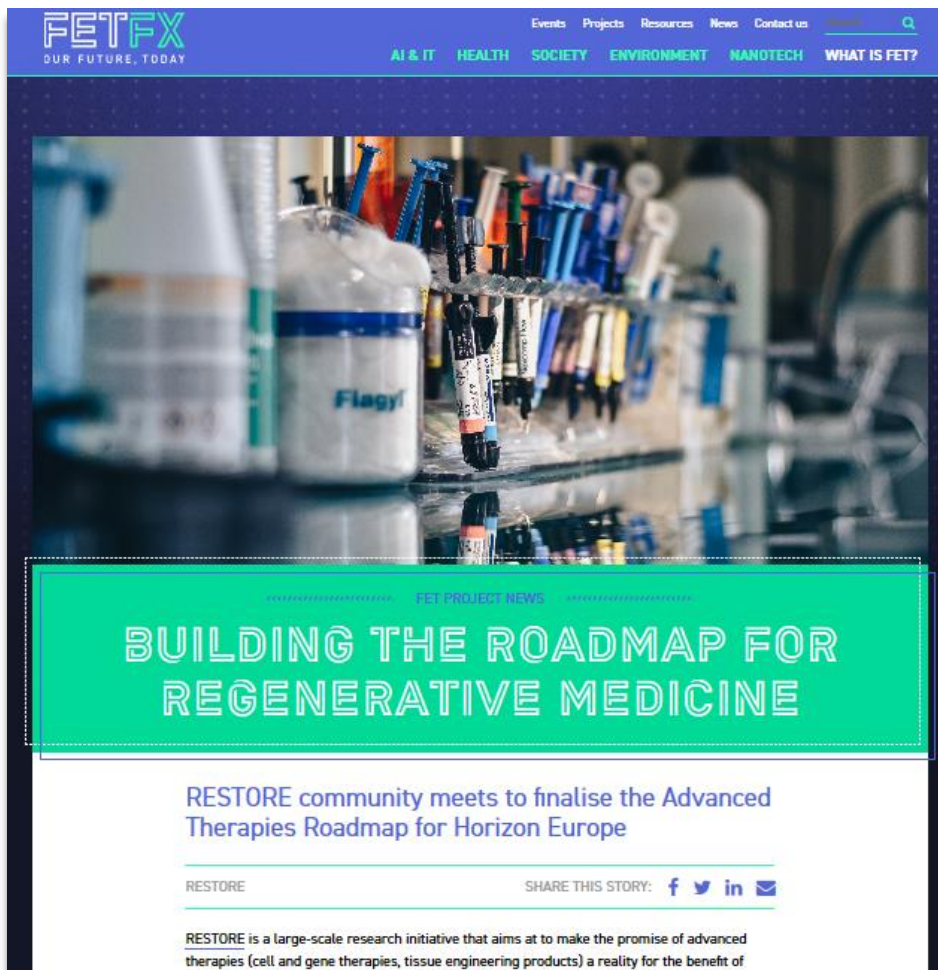


On the 17th February the RESTORE community gathered at the RESTORE Momentum Workshop to reflect on the progress made by the project in the last 12 months and how to continue fulfilling the RESTORE mission in the future.

A clear glass pitcher is shown from a high angle, containing a small number of pills. The pills are in various colors: blue, green, orange, and yellow. Some are round, while others are more elongated or have a different shape. The pitcher is placed on a highly reflective surface, which creates a clear, inverted reflection of the pitcher and its contents. The background is a plain, light color, making the glass and the pills stand out.

RESTORE AT THE EUROPEAN PARLIAMENT IN BRUSSELS

On Monday 5th December, RESTORE members and supporters attended a lunchtime meeting at the European Parliament in Brussels to speak about Advanced Therapies. The debate, organised by RESTORE and hosted by Dr Christian Ehler, highlighted the staggering and increasing health costs imposed by chronic diseases in Europe, which has both economic and



Media

For reaching out to non-scientific people, the RESTORE messages are advertised with press releases in appropriate and popular scientific journals and newspapers, and on [Youtube](#).

A [RESTORE YouTube](#) channel was launched on the occasion of the 1st ATSM and it permanently stores the talks given.

Publications

Preparation of a number of white papers based on the RESTORE roadmaps and working groups activities results is currently ongoing. The Consortium have agreed to publish the papers in an open access journal such as Frontiers in Medicine.

Position papers

Preparation of a number of position papers is currently ongoing and they will be submitted as deliverables by the end of the project period.

Newsletters

A **periodic newsletter** has been distributed to provide a means of reporting unfolding developments during the course of RESTORE. Considering the type of content, the newsletter is circulated within

the RESTORE Community to inform supporters about events, activities and about any relevant updates.

Typical stories that are included are: suitably edited versions of project press releases; announcements of progress/milestones by single beneficiaries or workgroup collaborators; reports on conferences and meetings; news of publications; personnel announcements; information about newsletter

Four issues of Newsletter have been distributed to RESTORE Community and the PDF are enclosed to the current deliverable in Annex 1- Published Material.

Survey

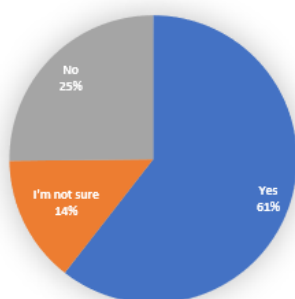
RESTORE performed a survey addressing EU citizens with the aim to investigate the grade of knowledge, awareness and interest in the Advanced Therapies among the general public. A detailed report is enclosed in Annex 1- Survey

Purpose: The purpose of the survey was to measure awareness of Advanced Therapies and attitudes towards Advanced Therapies within the population in Germany, England, Spain, France, Italy, the Netherlands, Poland and Portugal. The collected data can then be used to determine how Advanced Therapies can be further developed for the benefit of patients and society.

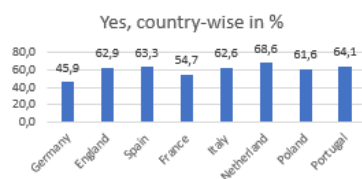
Method: A representative online panel was used. 4435 adult women and men were queried in Germany, England, Spain, France, Italy, Netherlands and Poland between December 2019 and January 2020.

Findings (Knowledge of Advanced Therapies): The majority (60,6%) of the surveyed population in Europe has heard about Advanced Theories. Percentages for individual countries range between 45,9% (Germany) and 68,6% (the Netherlands).

Knowledge: Have you ever heard of Cell Therapy and/or Gene Therapy and/or Tissue Engineering before participating in this survey?



Across all countries



In general: The younger, the richer, the higher education level:

The more knowledgeable!

Size of city does not matter, except very small villages

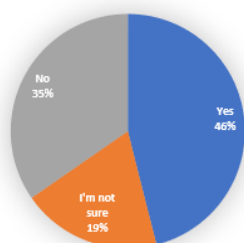


Knowledge of the current increase of Advanced Therapies offered in the market is slightly less pronounced. The majority of respondents in Europe (54,8%) are aware of the increasing supply of Advanced Therapies. In Spain, Italy, the Netherlands, Poland and Portugal the majority of people know about it. In England, France and Germany the majority does not yet know.

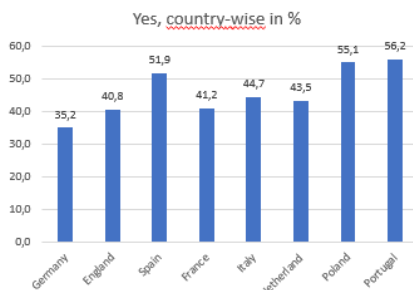
The fact that unapproved Advanced Therapies are offered is known by 46% of the surveyed population in Europe. Well-marked awareness exists in Poland (55,1%) and Portugal (56,2%). When

it comes to public warnings in the media about unapproved Advanced Therapies a clear majority of 67,6% (all countries) supports them. Only 10,6% of those surveyed think no measures should be taken. 40,2% support stricter guidelines for advertising online and offline.

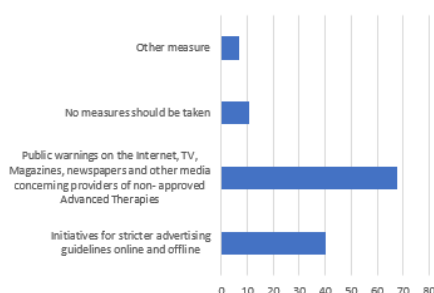
There also are private clinics that offer non-approved Advanced Therapies to patients. Have you heard about this?



Across all countries

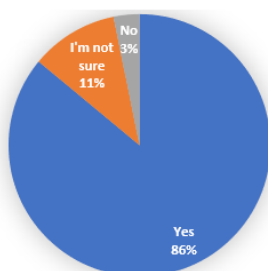


And what should we do about it?

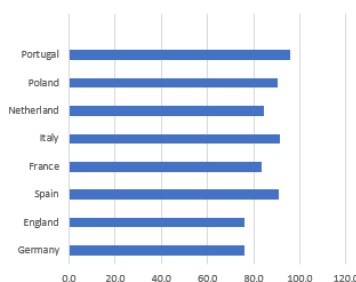


Findings (Research and Development): The clear majority of participants expressed support for using EU- and state-funding to help finance medical innovations. 61,3% of participants from all countries expressed strong and definite support (“Yes, definitely”) while a further 24,8% percent expressed milder support (“Yes, maybe”) which adds up to 86,1% of the questioned population. Values for individual countries range from 72,2% of respondents in support (England and Germany) to 95,7% in support (Portugal). The overall support for using EU- and state-funding is almost as strong when the funding would be used specifically for innovative technologies or materials: 83,5% of participants in all countries did answer either “Yes, definitely” or “Yes, maybe”.

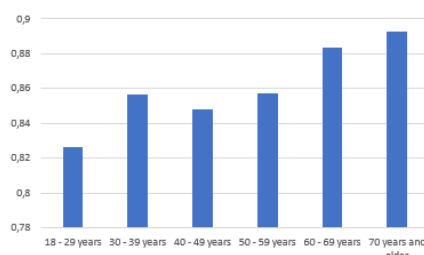
Do you think EU- and state-funding should be invested in the development of future medical innovations?



Across all countries

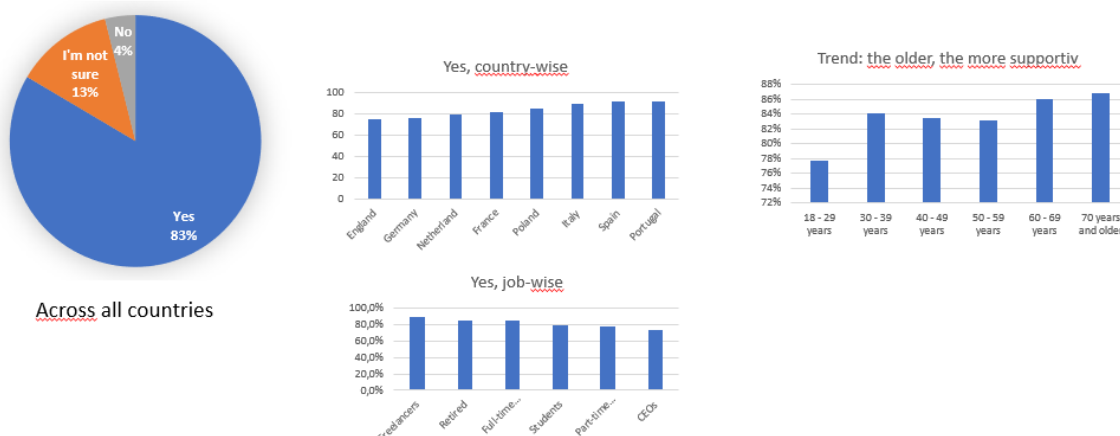


Yes, country-wise in %



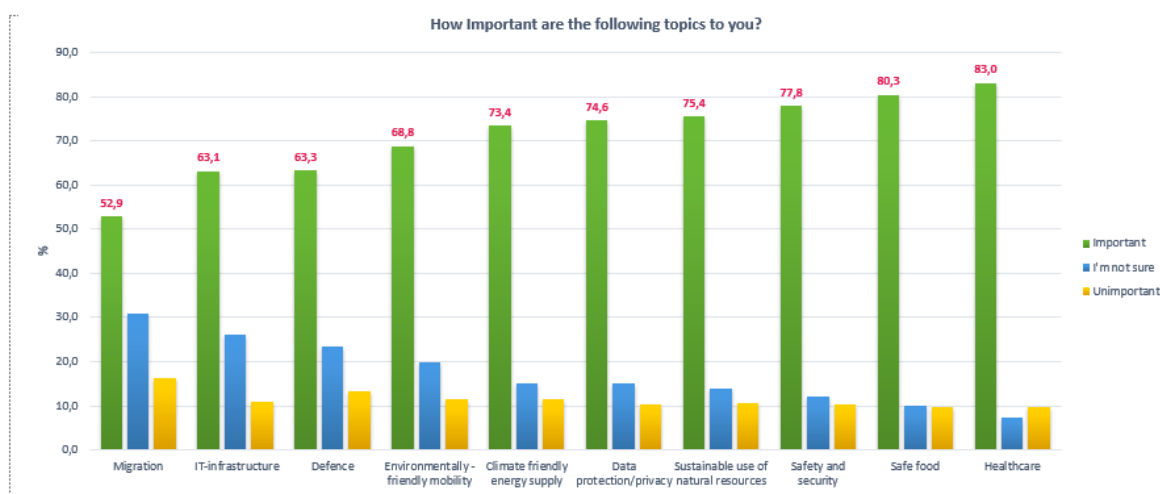
Trend: the older, the more supportiv!

Should EU and Member States fund enabling technologies for Advanced Therapies?



Participants in all countries rated healthcare the number one most important topic rating it at 1,6 out of 5 (1 being very important, 5 being unimportant). Next on the list are safe food (1,7), safety and security (1,8), data protection/privacy (1,9), sustainable use of natural resources (1,9), climate friendly energy supply (2,0), environmentally friendly mobility (2,1), IT-infrastructure (2,2), defense (2,2) and migration (2,4).

Importance of big political issues



Findings (Affordability and Reimbursement): In total 61,8% of participants in all countries agreed that the state should pay very high prices for treatments that have been shown to be effective in the short term (up to two years), even though information for the long-term benefit of these drugs is still lacking. Results for individual countries in that respect ranged from 48,1% of respondents in agreement (Germany) to 79,7% (Portugal).

The majority of the surveyed population expressed strong ("Yes, definitely"; 35,4%) or mild ("Yes, maybe"; 37,6%) support for the claim that cross-border health care is ideal when it comes to the treatment of rare medical conditions. This adds up to 73% of the surveyed population in Europe being in support. In every single country surveyed, the majority of the population support this. On the question of whether health insurers should cover non-medical costs (such as cost of travel and accommodation) if medical treatment is administered abroad most people in the surveyed countries (70,5%) do think that by law health insurers should have to cover this type of non-medical cost. Results for individual countries range from 56% (England) to 82,6% (Portugal).

Key aspects which the data show:

1. Health-care is the number one issue for the population when it comes to big issues in politics (environment, IT-infrastructure, privacy, migration, ...) according to the survey.
2. The majority of the European population is aware of Advanced Therapies and considers them a useful and very promising approach.
3. The majority of the surveyed population wants EU- and state-funding to be invested into Advanced Therapies.

Actions to be Taken: The survey shows that it is the will of the surveyed European population that EU- and state-funding should be used to support Advanced Therapies. Further applications for EU-funding for Advanced Therapies should thus be made since it reflects the explicit interests of the European people.

The survey has currently been extended to additional 5 countries (Sweden, Denmark, Romania, Czech Republic and Lithuania) and the results are expected to be available by the end of April 2020.

Requirements of dissemination and Communication material

Any dissemination of results (in any form, including electronic)

- i. display the EU emblem, or
- ii. include the acknowledgements of the EC for H2020 funding
- iii. almost all data generated during this phase will be eligible for gold/green level open access (dependent on the journal where the position papers will be published)

Annex 1- Published Material



Health by Advanced Therapies

Advanced therapies are one of the most recent and significant advances in medicine. They include gene and cell therapies and tissue-engineering approaches to not only treat disease symptoms, but to potentially provide a cure for otherwise incurable chronic diseases.

A growing number of these advanced therapies are now reaching patients, transforming not just the lives of people afflicted with chronic diseases, but the lives of their families too. However, to make these innovative therapeutic strategies available to millions of patients, there are multiple challenges to overcome, from conceptual and technical hurdles through to special manufacturing issues and new payment models.

We at **RESTORE** want to make these treatments options available to patients as a standard of care across Europe. We believe that Europe provides an optimal scientific ecosystem for such a large and concerted interdisciplinary effort, with excellent science, sound infrastructure and diverse funding opportunities.

RESTORE is a network of over 300 research institutes, companies, consortia and non-profit organizations from Europe and beyond, which is managed by ten European partners and coordinated by the BCRT and BeCAT in Berlin. We are working on the "Advanced Therapies Roadmap for Horizon Europe" to make the vision of bringing Advanced Therapies to patients around the world a reality, and to build a European infrastructure to support and enable this vision.

For more information,
for to get involved, you can follow us on



twitter.com/RESTOREhorizon



www.facebook.com/RESTOREhorizon



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and tag us @RESTOREhorizon

www.restore-horizon.eu



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 820292.



BIH Regeneration
BIH Center for Regenerative Therapies (BCRT)



Forschung Aktuell

09.05.2019

Forschungsinitiative RESTORE startet erfolgreich in Berlin

[Zurück zur Übersicht](#)

[Startseite](#) > [Forschung](#) > [Forschung Aktuell](#) > [Pressemitteilung](#)





Prof. (Professor) Dr. Hans-Dieter Volk und Prof. (Professor) Dr. Petra Reinke von der Charité führen in die Veranstaltung ein. Foto: Wiebke Peitz/Charité

Vom 6. bis zum 7. Mai haben sich über 200 Beteiligte des RESTORE-Konsortiums in Berlin getroffen, um gemeinschaftlich und interdisziplinär einen Plan zur Weiterentwicklung ihrer europaweiten Forschungsinitiative zu neuartigen Therapien – den sogenannten Advanced Therapies – zu erarbeiten. Die Europäische Kommission unterstützt das Vorhaben mit einer Million Euro und hat den Verbund eingeladen, das Konzept auszubauen, um Europa im Bereich der Advanced Therapies an die Spitze zu bringen. RESTORE steht unter der Leitung des BIH (Berlin Institute of Health) Centrums für Regenerative Therapien (BCRT (Berlin-Brandenburg Center of Regenerative Therapies)), eines gemeinsam von der Charité – Universitätsmedizin Berlin und dem Berlin Institute of Health (BIH (Berlin Institute of Health)) getragenen interdisziplinären Translationszentrums.

Um die Strategie von RESTORE weiter voranzutreiben, gründeten sich während der Auftaktveranstaltung 17 Gruppen nach spezifischen Themen und nahmen ihre Arbeit auf. Diese Form der Zusammenarbeit und die aktive Teilnahme aller Beteiligten stellten sicher, dass wichtige und unterschiedliche Formen von Wissen in das Projekt einfließen. „Unsere sehr offene Strategie hat sich als Erfolg erwiesen. Es haben sich etwa 55 Teilnehmende pro Gruppe beteiligt und unser Netzwerk aus Unterstützern ist nun auf mehr als 300 Forschungsinstitute, Unternehmen, Patientenorganisationen und Initiativen angewachsen“, bekräftigt Prof. (Professor) Dr. Hans-Dieter Volk das gute Gelingen der Veranstaltung. Prof. (Professor) Volk ist Koordinator von RESTORE, Leiter des Instituts für Medizinische Immunologie der Charité, Sprecher des BIH (Berlin Institute of Health) Centrums für Regenerative Therapien sowie am Berlin Center of Advanced Therapies (BeCAT) der Charité tätig.

Wichtige Aspekte, Ideen und Dialoge, die bei dem Zusammentreffen in Berlin entstanden sind, hat eine Künstlerin visuell festgehalten. Die Zusammenfassung ist hier zu sehen: [Link zur Grafik](#) .

Die nächste große Veranstaltung des RESTORE-Konsortiums – das 1st Advanced Therapy Science Meeting – wird vom 25. bis zum 26. November in Berlin stattfinden.

Links

[RESTORE Forschungsinitiative](#)

[Pressemitteilung zu RESTORE vom 14.02.2019](#)

[1st Advanced Therapy Science Meeting](#)

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FET PROJECT NEWS (<http://www.fetfx.eu/news/?cat=fet-project-news>)

BUILDING THE ROADMAP FOR REGENERATIVE MEDICINE

RESTORE community meets to finalise the Advanced Therapies Roadmap for Horizon Europe

RESTORE

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RESTORE (<http://www.fetfx.eu/project/restore/>) is a large-scale research initiative that aims at to make the promise of advanced therapies (cell and gene therapies, tissue engineering products) a reality for the benefit of patients and society, making Europe a spearhead in the application of advanced therapies.

Two months after the official launch, the RESTORE core partners and supporters gathered in Berlin to flesh out the details of the "Advanced Therapies Roadmap for Horizon Europe", its mission to create a pipeline of "made in Europe" advanced therapy products over the next 10 years.

At the kick-off, RESTORE founders presented the main fields RESTORE plans to be active in: manufacturing, preclinical and clinical development, regulatory, market access, economics and ethics of advanced therapies. About 200 supporters from academia, industry and patient advocacy groups participated in the two-day event and joined a total of 17 working groups that commenced their discussions to identify challenges and roadblocks slowing down progress in the field.

After the event, discussions moved online where the community is debating putative solutions and jointly developing a community-driven strategy that will propose a suitable configuration and sustainable funding for RESTORE.

This unusual bottom-up approach was favoured by the organisers for two reasons. First, due to the ambition of the mission, there is a need to bring in people and expertise from the entire European Union and beyond. Second, there are many – albeit scattered – successes and best-practice cases around advanced therapies that can be leveraged and built upon.

The organisers were also proud to report that the RESTORE community continues to grow, currently with more than 300 supporters from academic institutions, companies, initiatives and patient organisations.

RESTORE has received funding from the European Union's Horizon 2020 research and innovation FET programme (<https://ec.europa.eu/programmes/horizon2020/en/h2020-section/future-and-emerging-technologies>) under grant agreement No 820292.

Photo by [Ibrahim Boran](https://unsplash.com/@ibrahimboran?utm_source=unsplash&utm_medium=referral&utm_content=creditCopyText) (https://unsplash.com/@ibrahimboran?utm_source=unsplash&utm_medium=referral&utm_content=creditCopyText) on [Unsplash](https://unsplash.com/search/photos/medicine?utm_source=unsplash&utm_medium=referral&utm_content=creditCopyText) (https://unsplash.com/search/photos/medicine?utm_source=unsplash&utm_medium=referral&utm_content=creditCopyText)

July 17th, 2019

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(<http://www.fetfx.eu/news/the-evmanifesto-released/>)

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RESTORE Momentum Workshop

A moment to reflect on the future of the RESTORE mission

March, 5th 2020 FET PROJECT NEWS
(<http://www.fetfx.eu/news/restore-momentum-workshop/>)



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About FETFX project (<http://www.fetfx.eu/about-fetfx-project/>)

– Privacy policy (http://www.fetfx.eu/wp-content/uploads/2019/01/FETFX_Fondazione_iCons_Projects_Privacy_Notice_23012019.pdf)



This project has received funding from the European Union's Horizon 2020 FET Programme under grant agreement No. 824753.

GENEVIEVE BELL

RESTORE 1st Advanced Therapies Science Meeting

25th-26th November 2019, Berlin

RESTORE-Health by Advanced Therapies invites you to join the **First Advanced Therapies Science Meeting (ATSM)**, an EACCME[®] accredited event, which will be held at the Maritim Hotel, Stauffenbergstraße in Berlin from the 25th - 26th November 2019.

Advanced Therapies are one of the most recent and significant advances in medicine. They include gene and cell therapies and tissue-engineering approaches to not only treat disease symptoms, but to potentially provide a cure for otherwise incurable chronic diseases. **RESTORE** aims to ensure that these regenerative therapies are implemented as a standard of care across Europe and beyond. The **1st ATSM** will bring together experts from industry, patient organisations and academia to discuss the challenges within the field of Advanced Therapies and to drive forward a concerted interdisciplinary effort, making use of the excellent science, infrastructure and funding landscape within Europe, to make regenerative therapies a reality for all.

RESTORE is coordinated by Prof. Dr. Hans-Dieter Volk, Spokesperson for the BIH Center for Regenerative Therapies (BCRT) and his team, "Advanced Therapies are a potential game changer in health care, aiming to shift our focus from chronic treatment of disease to regeneration of health.", says Prof. Volk. He adds, "We are determined to translate promising research findings into safe therapies, and we are working across disciplines and national borders in order to achieve this goal. The **1st Advanced Therapies Science Meeting** provides the opportunity for participation in discussions on the still numerous obstacles in the way of implementing these promising therapies in routine clinical care."

Advanced Therapies, also known as "**living**" **drugs**, are a disruptive innovation, i.e. an innovation that will change the paradigm of clinical drug development in the future. For some patients these regenerative therapies are already a reality, unfortunately for most patients this is not yet the case. The motivation behind **RESTORE** is to accelerate the availability of these "**living**" **drugs** to **all** those in need by supporting collaboration throughout the transdisciplinary network required during drug development and by helping to overcoming regulatory, scientific and technological roadblocks that stand in the way of such a trailblazing change.

"We are immensely grateful to all our supporters and to the EU for backing **RESTORE** and the **1st ATSM**, allowing us to share and evolve our vision for the future of Advanced Therapies." says Prof Volk. **RESTORE** is a Europe-wide large-scale research initiative, backed by an international and transdisciplinary community comprised of industrial partners, research institutions and hospitals.

The packed two-day **1st ATSM programme** will include talks from Nobel Prize winner **Ada Yonath** (Director of Weizmann Institute of Science, Israel), **Michele De Luca** (University of Modena, Italy), **Timothy O'Brien** (National University of Ireland, Galway, Ireland), **Maksim Mamonkin** (Baylor College of Medicine, USA), **Manuela Gomes** (University of Minho, Portugal) and many many more!

For more information about **RESTORE** and the **1st ATSM**, to view the meeting programme or to register, please visit our website:

<https://www.restore-horizon.eu/1atsm-home/>

You can also follow us on [Twitter](#), [LinkedIn](#) and [Facebook](#) and tag us **@RESTOREhorizon**

RESTORE partners comprise the Charité Universitätsmedizin Berlin and Berlin Institute of Health (Germany), the University of Zurich (Switzerland), Cell and Gene Therapy Catapult (United Kingdom), TissUse GmbH (Germany), Pluristem Ltd (Israel), Miltenyi Biotec GmbH (Germany), INSERM – Institut National de la Santé et de la Recherche (France), Innovation Acta S.r.l. (Italy), Fondazione Telethon Milan (Italy), and the University of Minho (Portugal).



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 820292.



1st ADVANCED THERAPIES SCIENCE MEETING

25th-26th November 2019 - Berlin, Germany

The **RESTORE 1st Advanced Therapies Science Meeting** took place in Berlin from the 25th - 26th November 2019.

Speakers and participants, from across Europe and beyond, congregated to take part in discussions highlighting the challenges facing Advanced Therapies and to hear about the latest advances from basic research and preclinical models to manufacturing processes, clinical trials, ethics, economics, regulatory issues and clinical implementation.

The focus of the **1st ATSM** was on Advanced Therapies, one of the most recent and significant advances in medicine. They include cell, gene and tissue engineering therapies to not only treat disease symptoms, but to potentially provide a cure for otherwise incurable chronic diseases. Advanced Therapies, also known as “living drugs”, are a disruptive medical innovation, i.e. an innovation that is changing healthcare and the way drugs are developed and used in clinical routines.



Prof Hans-Dieter Volk opened proceedings with an inspiring presentation on the aims and vision of the large-scale research initiative **RESTORE**.

RESTORE aims to accelerate the availability of “living drugs” to all those in need by supporting collaboration throughout the transdisciplinary network required during the entire drug development trajectory, from inception to implementation and by helping to overcome regulatory, scientific and technological roadblocks that stand in the way of such a trailblazing change.

On day 1, we heard how the knowledge gleaned from foundational research is being used to identify new targets and indications for the development of novel Advanced Therapies. We also heard about new developments in the preclinical testing of Advanced Therapies, such as organ-on-a-chip systems, which are more suitable than traditional animal models. The third part of the day was dedicated to innovation in manufacturing technologies and how it may disrupt the entire field of Advanced Therapies and pave the way for reproducible, high-grade “living drug” products using current manufacturing structures.

We were truly honoured to have Nobel Prize winner Ada Yonath open day 2. She talked about her research into the ribosome and the opportunities her findings have provided for overcoming antibiotic resistance. Her talk on the translation of findings from foundational research into meaningful healthcare products bridged the topics discussed on day 1 to those discussed on day 2, bringing Advanced Therapies into the clinic. We heard about the unique regulatory challenges associated with authorising Advanced Therapies and the new reimbursement models required to pay for them. The issues of ethics, big data and public engagement surrounding Advanced Therapies were covered in a special focus session, which highlighted how machine learning could be applied to clinical development how ethics can be used to advance research and about the dangers of the dissemination of inaccurate information to the public.



Across the two days, a stunning array of topics, visionary research approaches and success stories in Advanced Therapy development were discussed, as well as the challenges that their widespread implementation still faces. Bringing together the whole of the Advanced Therapies community is part of what **RESTORE** is about. It was truly motivational to see and hear from so many people sharing a common goal: to ensure that ATMPs are implemented as a standard of care across Europe and beyond.

We are grateful to everyone who took part and made the 1st ATSM a success!

www.restore-horizon.eu

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This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 820292.



5th December 2019

European Parliament
Brussels

Dr. Christian Ehler MEP



Health by Advanced Therapies

Pursuing FET Flagship in Horizon Europe: Strategic Planning on Living Drugs by RESTORE

On Monday 5th December, RESTORE members and supporters attended a lunchtime meeting at the European Parliament in Brussels to speak about Advanced Therapies. The debate, organised by RESTORE and hosted by MEP Dr Christian Ehler, highlighted the staggering and increasing health costs imposed by chronic diseases in Europe, which has both economic and societal impact. Prof Hans-Dieter Volk (BCRT, Charité) cautioned that, whilst Advanced Therapies are already a reality, huge barriers remain to their sustainable and widespread distribution across Europe.



However, it is not all doom and gloom, Advanced Therapies hold real promises as curative treatments for chronic diseases and with the concerted action of RESTORE, its supporters, and the backing of EU initiatives the goal of affordable and accessible Advanced Therapies for everyone in Europe becomes ever more achievable. A key aim of RESTORE is to generate a sustainable ecosystem combining all aspects of Advanced Therapeutic development to accelerate innovation at scientific, technical, logistical and economic levels. Guillaume Fusai (responsible for EU affairs at INSERM) acknowledged the importance of RESTORE in generating such a hub, which combines industry, hospitals and research to advance and fast-track the translation of basic research to the clinic.



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 820292.

The pharmaceutical industry has recognised the new challenges and opportunities of Advanced Therapies noted Ivana Cattaneo (Public Affairs Director for the European Region, Novartis Oncology), adding that "All along the whole trajectory from discovery to access, there is a need for all stakeholders to engage and collaborate in a different way." Zami Aberman (executive chairperson of the Israeli company, Pluristem) suggested that emerging technologies "have the potential to significantly impact Europe's ecosystem by providing cost-effective therapies to many unmet medical conditions and generate advanced research centres and biopharma companies that will use advance tools such as AI and machine learning to improve patients' health while reducing costs for healthcare systems."



During these discussions, it is important not to forget the patients, the people for whom these therapies can transform their lives. Prof Petra Reinke (BeCAT, Charité) presented the potential of regulatory T cell (Treg) therapies to change the lives of transplant patients by reshaping the immune balance. The current norm after transplantation is a regimen of 20-30 pills a day, every day for the rest of your life. The debate heard directly from one of the first patients to ever receive Treg therapy about just how life changing these Advanced Therapies can be, "I take just one pill per day and am now able to lead a pretty much normal life." Karolina

Hanslik from the European Organisation for Rare Diseases (EURORDIS) highlighted that there is hope for new treatment options, and possible cures, for people living with rare diseases. Since there are numerous challenges to bringing the Advanced Therapies to the patients, the rare diseases' community expects to be supported by European institutions, national governments, researchers, clinicians and the initiatives such as RESTORE to have access to the most effective, innovative treatments.

The mission of RESTORE is not just to raise awareness of the hurdles standing in the way of Advanced Therapies, but also to provide potential solutions to overcome them. In this regard, the RESTORE position paper (which can be read [here](#)) outlines recommendations to the EU and to all those involved in Advanced Therapy research for ensuring the future of accessible and affordable Advanced Therapeutics too all those in need.

Finding cures for the incurable

Advanced therapies are no longer the stuff of science fiction. **Martin Banks** reports on the regenerative therapies often referred to as “living drugs” and the hurdles currently impeding their availability in Europe

The increasing prevalence of chronic diseases in Europe represents a high social and economic burden. Direct healthcare costs soared by 50 percent during the last decade and reached €1.5tn in 2017 - a staggering 9.6 percent of Europe's GDP. This was one of the main messages to emerge from a debate in the European Parliament on advanced therapies. The event was organised by RESTORE, a project seeking to promote implementation of advanced therapies which is partly funded by the EU's Horizon 2020 programme. Hosting the event, German EPP member Christian Ehler highlighted the economic costs involved in achieving excellence in science, technology and innovation. While putting forward several “instruments” designed to reduce the administrative burden for researchers and SMEs, he pointed to current budgetary constraints at Member State level and also the need to provide affordable medicine.

Hans-Dieter Volk of the Berlin Institute of Health said that advanced therapies “hold the promise of not just treating disease symptoms but providing cures for previously incurable diseases.” Such regenerative therapies are already a reality, he told the audience, but cautioned that “affordability and accessibility” remain “huge barriers” to their widespread and sustainable availability in Europe.

“We now need concerted action to make these advanced therapies ac-



“We now need concerted action to make these advanced therapies accessible to all in need by addressing scientific, technical, logistical and economic roadblocks”

Hans-Dieter Volk

cessible to all in need by addressing scientific, technical, logistical and economic roadblocks,” Volk said. To do this, he suggested that a European Research Area on Advanced Therapies could be setup, as well as a dedicated EU-funding programme for advanced therapies that integrate innovative elements, disruptive research and breakthrough innovations. He acknowledged RESTORE's efforts to create a sustainable European “eco system” and predicted that advanced therapies had the potential to “have a major impact on patients and society.” Another keynote speaker, Mir-Farzin Mashreghi, group leader of the “Therapeutic Gene Regulation” group at the German Rheumatism Research Centre, noted that advanced therapies require the knowledge of the “molecular identity of each single cell”, either

driving or regulating the pathogenesis of chronic diseases. “Such information is essential for the selection of cells which qualify as living drugs. Single-cell sequencing technologies are key for understanding the real cellular composition of chronic diseases and are game changers, not only for therapies aiming to cure chronic diseases but also for therapy response.”

As current therapies rarely cure, but merely fight symptoms, lifelong treatment is required, the debate was told. But this can result in potential adverse effects, limited quality of life and increased costs. Higher health costs or restricting access to new therapies “to a few wealthy patients” are not solutions, it was said. Guillaume Fusai, who is responsible for EU affairs at INSERM, a French public scientific and technological institute, also paid

 Sponsored event by

tribute to RESTORE, saying it is a “unique European hub to accelerate innovation.” He said that by advancing knowledge about life and disease, treatment innovation and public health research, such expertise will boost the development of advanced therapies and living drugs. “By mixing industrials, hospitals and research organisations RESTORE will speed up innovation and new patient treatments.” The debate also heard directly from a young patient who had suffered chronic kidney failure but, as a result of the advanced therapy treatment she had received and the kidney donation from her mother, is now well on the road to recovery. She said, “I take just one pill per day and am now able to lead a pretty much normal life.”

Petra Reinke, a professor of internal medicine, nephrology and transplantation, said, “Currently, we need lifelong therapy and, in the case of transplant patients, 20 to 30 pills per day, 365 days per year, for years and years. Most of these are for treating side effects.”

She added, “Reshaping the immune balance by the single application of regulatory T cells gives patients a new life as demonstrated here with our patient: one of the first transplant patients worldwide to receive the therapy. These are the cases and people who motivate us as physicians.” Ivana Cattaneo, public affairs director for the European Region at Novartis Oncology, said that the pharmaceutical industry “recognises the challenges and opportunities of advanced therapies, whose complexity requires new models of collaboration.” She added, “All along the whole trajectory from discovery to access, there is a need for all stakeholders to engage and collaborate in a different way.”

Also contributing to the debate was Zami Aberman, executive chairman of the Israeli company, Pluristem, who predicted that emerging technologies will enable advanced therapies to become cost-effective drugs which would help millions of patients in need. “These technologies have the

potential to significantly impact Europe’s ecosystem by providing cost-effective therapies to many unmet medical conditions and generate advanced research centres and biopharma companies that will use advanced tools such as AI and machine learning to improve patients’ health while reducing costs for healthcare systems.” The debate also heard from Karolina Hanslik, of the health NGO EURODIS, who said that in Europe an estimated one in 2,000 people suffer from a rare disease - about five percent of the population. She said the majority of these people living with a rare disease has “delayed or no access at all” to the medicine they need. “Often the necessary medicine simply does not exist.” She concluded with the message that the rare diseases community “expects to be supported by the EU institutions, national governments, manufacturers and clinicians,” adding, “Our ambition is to increase by three to five times the approval of new rare disease therapies.” ★



“Reshaping the immune balance by the single application of regulatory T cells gives patients a new life as demonstrated here with our patient”

Petra Reinke



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 820292.



RESTORE MOMENTUM - 17th February 2020

Mercure Hotel MOA - Stephanstraße 41, 10559 Berlin - Germany

The **RESTORE Momentum Workshop**, which took place on **17th February 2020 in Berlin**, brought together the RESTORE community to reflect on the progress made in the last 12 months and how to continue fulfilling the RESTORE mission in the future. There were thought provoking talks from patient advocates, Bettina Ryll (MPNE), Karolina Hanslik (EURORDIS) and Sabine Dupont (IDF-Europe), on how to make the patient voice heard among the many players in the ATMP development pipeline and the importance of clear communication between all stakeholders.

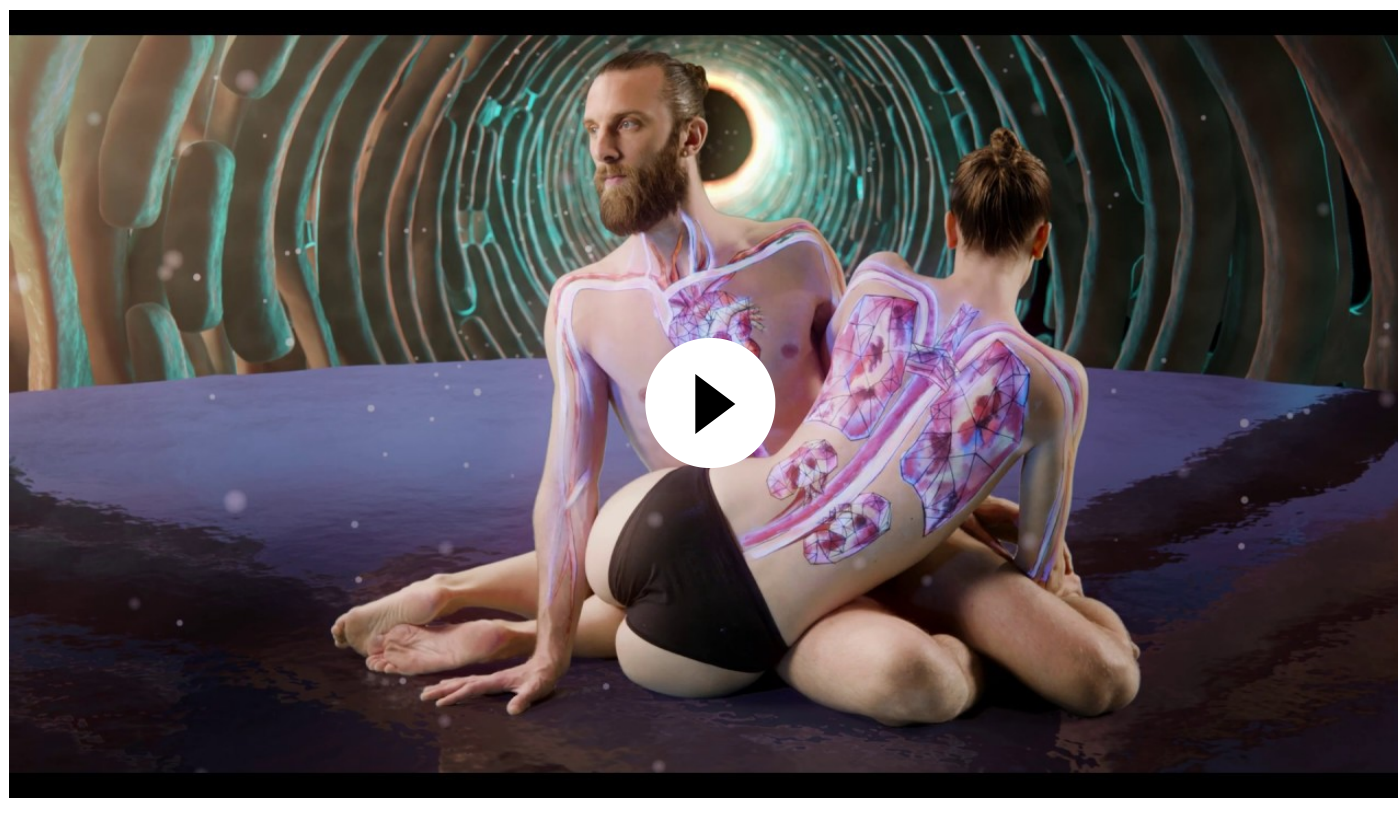
The importance of clear communication and well-defined procedural guidelines was a theme throughout the day. From the talk of Toni Cathomen (Universitätsklinikum Freiburg), we learnt about the need for clear guidelines and assays for the detection of off target effects of CRISPR/Cas9 products. Similarly, Hildegard Büning (Hanover Medical School) talked about the many barriers for AAV reaching their full potential in gene therapy methods, including the need for defined genotoxicity testing and measures for transduction efficiency and accuracy. Johan Van Eldere, speaking on behalf of EUHA, highlighted the requirement for a new model of communication and cooperation between university treatment centres for CAR T cell therapies. Whilst Stephen Sullivan (GaiT) stressed the importance of standardisation both in the language used to describe different requirements during ATMP development and the quality control methods used for different products. Clear-cut guidelines were again a focus in the talk by Ulrike Köhl (Frauenhofer IZI), in which she stressed the importance of up to date staff training and coherence of this training and information transfer between institutes about manufacturing processes for ATMPs.

A joint survey by CARAT and RESTORE, presented by Michel Apel (Miltényi) is investigating the views of professionals on ethical, regulatory and technological obstacles for the translation of Advanced Therapies. The results are still coming in (if you want to participate please click [here](#)), but already trends are emerging about areas in which more information and clarity is required.

Finally, more than 80% of European citizens support the idea that EU member states should be funding innovation and enabling technologies for Advanced Therapies (preliminary results from survey by RESTORE, presented by Gady Goldsobel). A strong indication to the politicians that healthcare is important to EU citizens and should not be neglected in future budget plans. Perhaps information that is not currently being communicated between the general public and the political sphere and an area where RESTORE hopes to close this communication gap.

The issue of bringing Advanced Therapies to the market is a tricky one. There are a huge number of technical, scientific and economic barriers that must be overcome in order to make Advanced Therapy Medicinal Products (ATMPs) available to all those in need. As was evident from the discussions between speakers and audience members, breaking down these barriers will be no mean feat. However, this is the mission RESTORE set out to fulfil just under 1 year ago, to make the promise of Advanced Therapies a reality for all patients in need to ensure their implementation into clinical practice as affordable, standard of care therapy and to thereby enhance patient outcome with a high impact on European society and economy. RESTORE coordinator, Hans-Dieter Volk (Charité Universitätsmedizin Berlin) summarised the event in his closing remarks "with the enthusiasm and backing of the RESTORE community, we continue to learn and evolve and so will continue to build up a European ecosystem to bolster innovation, communication and translation within the complex realm of Advanced Therapies".





Dear RESTORE partners and supporters,

We are delighted to share the first issue of our RESTORE newsletter, which will keep you up to date with all the latest news from the RESTORE community! You will find it filled with information regarding upcoming and previous events, calls for proposals in the field of Advanced Therapies, upcoming deadlines for our Working Groups and much more!

We always welcome your comments and ideas for the Newsletter - don't hesitate to send us a message and please feel free to share the RESTORE Newsletter with interested colleagues!

Sincerely,
Mareen and Gady on behalf of the coordinator

REVIEW



RESTORE Kick-Off Event

May 6th-7th 2019, Mercure Hotel MOA, Stephanstraße 41, 10559 Berlin, Germany

RESTORE's preparatory phase was officially launched at the Kick-Off Event by discussions, presentations and networking between 200 representatives of supporters and partners. By further consolidating the specific Working Groups, we took first steps of formulating "The Advanced Therapies Roadmap for Horizon Europe". This strategy will include clear deliverables over the medium-term in pursuit of an ambitious long-term vision for 2030: A range of Advanced Therapy products on the market, having an impact in clinical routine, providing transformative patient benefit and being economically sustainable.



Federation of Clinical Immunology Societies Annual Meeting

June 18th-21st, Boston (USA)

The Annual Meeting of the Federation of Clinical Immunology Societies (FOCIS

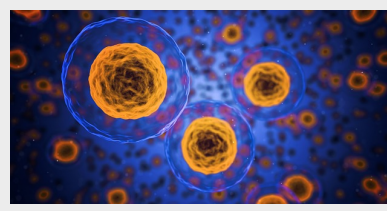
<http://www.focisnet.org/meetings/focis-2019/>) is the definitive global meeting in translational immunology and brings together leading researchers and clinicians to present and discuss the latest breakthroughs in immune-mediated diseases. RESTORE Health by Advanced Therapies hosted a lunch session on 20 June 2019, where RESTORE partners presented the backbone of the Advanced Therapies Roadmap and discussed specific points like the preclinical evaluation of advanced therapies, innovative technologies for GMP, gene therapy of primary immunodeficiencies and next-generation regulatory T cell therapy.

DEADLINES



Working Groups

The leads and co-leads of the working groups are currently revising the Working Group Outlines, discussing open points and re-opening the revised drafts for further comments by supporters; see the [RESTORE website](#) for more detail. The drafts will be closed on July 3rd for final revision by leads and co-leads.



Calls Innovative Medicines Initiative (IMI)

The two IMI2 calls „Supporting the development of engineered T cells“ and “Accelerating research & innovation for advanced therapy medicinal products” are open. Please find more information [here](#). RESTORE Partners and supporters are preparing to take part in both calls.

EVENTS



1st Advanced Therapies Science Meeting

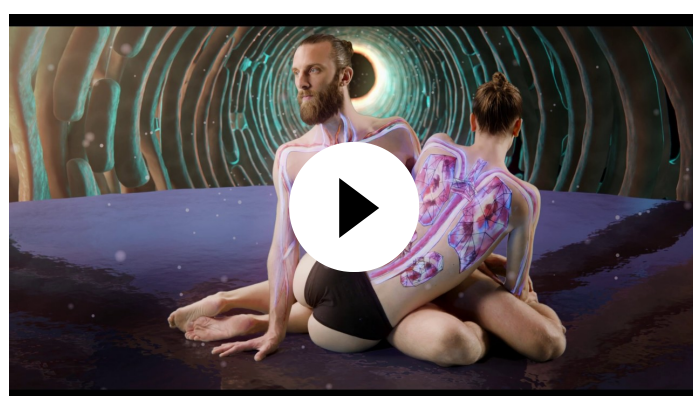
25-26 November 2019 | Berlin

The 1st Advanced Therapies Science Meeting (<https://www.restore-horizon.eu/1atsm-home/#>) will be held in autumn this year.

What are the research challenges that will smash the current roadblocks and allow the development of curative treatments leading to the wider adoption of Advanced Therapies in clinical routine? Join the conversation on Foundational Research discussing new targets and indications, Preclinical Models and Technologies with a focus on human-on-a-chip, Manufacturing Technologies, Clinical Implementation, Regulatory Science and Clinical Trials. Selected Keynote Speakers include Tal Dvir (Tel Aviv University, Tissue Engineering and RegMed, Israel), Antonella Mott (University of Trento, Italy), Clinoa Rooney (Pediatrics-Hem-Onc Cell & Gene, Baylor College of Medicine, Houston, TX, USA), Eric Shifru (University of California, San Francisco, CA, USA) and Ada E. Yonath (Weizmann Institute of Science, Israel).

You are warmly invited to submit your abstract by 15 July 2019 [right here](#), meeting registration will open mid-July 2019.

NEWS



RESTORE Video

A first video about Advanced Therapies and RESTORE is now publicly available; it illustrates the achievements and potential of Advanced Therapy Medicinal Products for patients with severe chronic diseases in comparison to conventional drugs and also the transformational vision of RESTORE to cure diseases rather than just treating symptoms.



Raising awareness

Raising awareness for Advanced Therapies is a key objective of RESTORE, we all are working hard to put and keep the topic on the agenda of policy makers and the public at large. Please do follow RESTORE on [Twitter](#) and [Facebook](#) for updates (and much more) and feel free to share.



Patient information

We are currently preparing an information section on the RESTORE website for patients, families and patient advocacy groups. This section will include information about Advanced Therapies, RESTORE, a contact form and weblinks. We kindly ask for your support in providing relevant information with regard to national registries for clinical trials and patient organisations (Oncology and Hematology, Cardiovascular Diseases, Diseases of the central nervous system, Musculoskeletal Diseases, Endocrine, Metabolic and Genetic Disorders, Ophthalmology, Dermatology, Infectious Diseases, Gastroenterology, Genitourinary Disorders, Respiratory Diseases) in your region and country so we can support patients in their specific search for information and assistance. Please contact us info@restore-horizon.eu.



RESTORE

Dear RESTORE partners and supporters,

Welcome to the second issue of the RESTORE newsletter. You will find information on the latest events, both past and upcoming, as well as news and calls for proposals. We hope you enjoy it, do not hesitate to send us a message and please feel free to share the RESTORE newsletter with interested colleagues!

You can unsubscribe by clicking the link at the bottom of the newsletter

Sincerely,
Nicola, on behalf of the coordinator

info@restore-horizon.eu

REVIEW



RESTORE F2F

September 16th 2019, Catapult HQ, Guy's Hospital, London, UK

Members of the RESTORE core team met in London to discuss the progress, updates and future of RESTORE, including the Advanced Therapies Roadmap 2030.



Phacilitate: Leaders Europe Event

17th -18th September 2019, London, UK

Members of RESTORE, including Zami Aberman, Petra Reinke and Hans-Dieter Volk, attended the Phacilitate: Leaders Europe Event, which brings together the entire ATMP ecosystem to promote opportunities provided by the EU market. RESTORE partners participated in round table and panel discussions.

Italian Infrastructure for Regenerative Medicine (IRMI)

30th September 2019, Bologna, Italy

Prof. Hans Dieter Volk presented RESTORE during the final event of the national IRMI project, an Italian initiative, which aimed to create the infrastructure to facilitate exchange of knowledge between different disciplines. This kind of infrastructure is crucial for the advancement of regenerative therapies and medicinal products.

DEADLINES



Horizon 2020

CSA

H2020-SC1-HO-19-2020

Reliable and accessible information on cell and gene-based therapies

This Horizon 2020 coordination and support action (CSA) is open for applications. You can find more information [here](#). The deadline for applications is 7th April 2020.



Future IMI topics

Calls planned for early 2020

To allow maximum time for applicants to form consortia and prepare proposals, the IMI regularly publishes information on potential future topics in advance of the official call launch.

The following relevant topics are under consideration:

Facilitating the translation of advanced therapies to patients in Europe

- Optimising patient access to new therapies for rare diseases.

Big data, digital health, clinical trials and regulatory research

- Data lakes

Oncology

- Prospective real-world clinical implementation of liquid biopsies
- Tumour plasticity

More details on these proposed future topics of interest can be found [here](#)

46th ESAO Congress: Smartificial devices for our future



September 3rd-7th 2019, Hannover, Germany

Prof. Hans Dieter Volk presented RESTORE during the tissue-engineering symposium at the annual European Society for Artificial Organs (ESAO) congress (www.esao2019.org). This congress provides a unique opportunity to foster interdisciplinary collaborations in engineering, biological, medical and physical sciences, with the aim of promoting advances in science and technology for human health.

EVENTS



The 1st ATSM is taking place from November 25th-26th 2019, at the Maritim Hotel, Stauffenbergstraße 26, 10785 Berlin, Germany.

If you want to take part in discussions highlighting the challenges facing Advanced Therapies from basic research and preclinical models to manufacturing processes, ethics, economics, regulatory issues and clinical implementation then [register now!](#)

During a packed two-day [programme](#), participants from science, industry and patient organisations will gather to consider the developments in Advanced Therapy research, the state of the art and future challenges for implementing Advanced Therapies as a standard of care in clinical settings. Sessions will range from foundational research, new targets and indications and preclinical models and technologies (especially organ-on-chip) to manufacturing technologies, clinical implementation, regulatory science and clinical trials, as well as big data and the ethical issues raised by emerging technologies and innovation. Selected keynote speakers include Michele De Luca (University of Modena, Italy), Tal Dvir (Tel Aviv University, Tissue Engineering and RegMed, Israel), Manuela Gomes (University of Minho, Portugal), Antonella Motta (University of Trento, Italy) Ada Yonath (Weizmann Institute of Science, Israel) and many, many more!

For the full programme and details of the keynote speakers visit our website: <https://www.restore-horizon.eu/1atsm-home/>

Registration closes on the 31st October 2019. Do not miss this opportunity take part in developing a new integrative, innovative and curative pan-European ecosystem for the future. Register [here!](#)

The 1st ATSM has been accredited by the Ärztekammer Berlin. German physicians can obtain up to 12 CME over 2 days.

An application has been made for EACCME® accreditation of this meeting.

Italian Infrastructure for Regenerative Medicine (IRMI)



October 22nd 2019, Berlin

The annual RegMed forum (<https://regmed-forum-2019-zell.b2match.io/home>) will be held this year on October 22nd in Berlin. The RegMed forum meets yearly to discuss the most recent developments in regenerative medicine. This year the focus on the exchanges between patients, physicians and scientists on the development and risks of, as well as the opportunities afforded by, novel cell and gene therapies. Such topics will be discussed in the areas of rare diseases, immunotherapy cancer, immune diseases, tissue engineering and endogenous regeneration. Speakers include Petra Reinke (BeCAT, Berlin), Jörn-Sven Kühl (University Hospital Leipzig), Sybille Landwehr-Kenzel (Charité, Berlin), Nathalie Maureen Otto (Charité, Berlin), Boris Schmitt (German Heart Center, Berlin), Joachim Sproß (National Society of Muscular Diseases, Freiburg), Tobias Winkler (BCRT, Berlin) and Ditta Zobor (University Hospital Tübingen)

The meeting is jointly organised by Cluster Health Capital, RESTORE, the BIH Center for Regenerative Therapies (BCRT) and the Berlin Centre for Advanced Therapies (BeCAT). You can register [here](#) until October 21st 2019. The conference language is German and participation is free.

NEWS



The patient information section on the RESTORE website is now available!

This section provides information for patients, families and patient advocacy groups about RESTORE and Advanced Therapies. It contains various web links to other useful websites related to Advanced Therapies and a contact form for those wishing to contact RESTORE directly. Click [here](#) to visit the patient area.



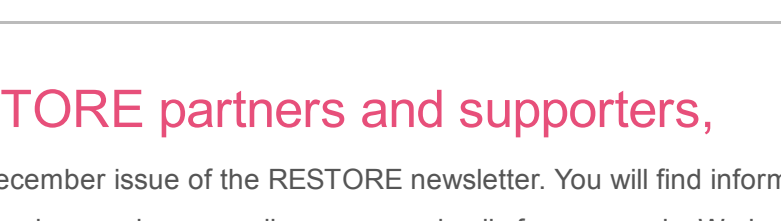
EBISC survey

European Bank for induced pluripotent Stem Cells (EBISC) wants your opinion! This IMI supported project provides a non-for-profit human induced pluripotent stem cell (iPSC) bank for use by researchers across academia and industry. They are running a survey until the end of October 2019 to ensure they continue to offer relevant products and services to the scientific community. If you would like to take part click [here](#)



Raising awareness

Please continue to raise awareness about Advanced Therapies. This is a key RESTORE objective. We are working hard to maintain an awareness of Advanced Therapies in the public sphere, as well as on the radar of policy makers. Please follow RESTORE on [Twitter](#) and [Facebook](#), as well as via [LinkedIn](#), for updates and information. Tag us @RESTOREhorizon and feel free to share!



Dear RESTORE partners and supporters,

Welcome to the December issue of the RESTORE newsletter. You will find information on the latest events, both past and upcoming, as well as news and calls for proposals. We hope you enjoy it, do not hesitate to send us a message and please feel free to share the RESTORE newsletter with interested colleagues!

You can unsubscribe by clicking the link at the bottom of the newsletter

We wish you a very merry holiday season and good fortune for the New Year,

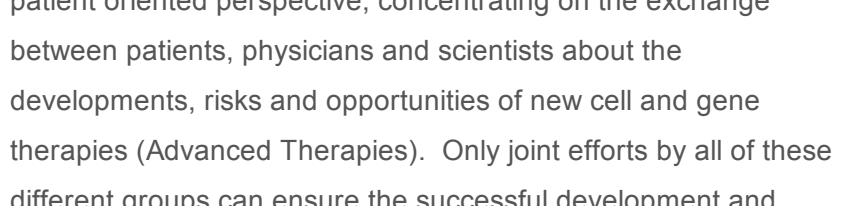
Sincerely,
Nicola, on behalf of the coordinator

info@restore-horizon.eu

REVIEW

RegMed Forum 2019

October 22nd 2019



The RegMed Forum has met annually since 2014 to discuss the progress made and the highlights in regenerative medicine. Speakers and participants are traditionally members of the scientific community from both academia and industry, but the event is also open to the public. This year the pan-European large-scale research initiative, RESTORE, joined the event as an organiser, thus the focus of the forum was shifted towards a more patient oriented perspective, concentrating on the exchange between patients, physicians and scientists about the developments, risks and opportunities of new cell and gene therapies (Advanced Therapies). Only joint efforts by all of these different groups can ensure the successful development and clinical implementation of this new class of therapies.

The 2019 RegMed forum, which took place in Berlin on October 22nd, was hosted by Prof. Petra Reinke (BeCAT, BCRT, RESTORE) and offered an exciting programme where case studies from various indications in the following areas, immune diseases, cancer, musculoskeletal system, cardiovascular system and rare diseases, were presented by physicians, scientists, patient organisations and patients. This provided a broad perspective, including the lived experience of being on the receiving end of Advanced Therapies, and basis for discussion of the development and risks involved in cell and gene therapy. In the final hour, a panel of experts discussed both with the audience and among themselves, the general themes and patient related aspects of Advanced Therapies, to round off an interesting and informative day.

This was a joint event organized by BeCAT (Berlin Center for Advanced Therapies), BCRT (BIH Center for Regenerative Therapies), RESTORE, Charité, BIH (Berlin Institute of Health) and Cluster Health Capital.

1st Advanced Therapies Science Meeting

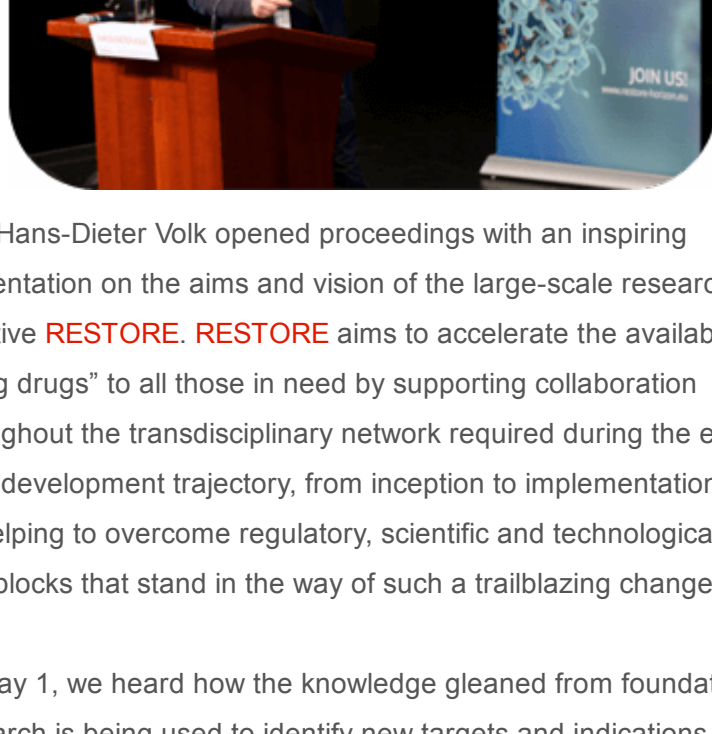
25th -26th November 2019, Berlin, Germany



The RESTORE 1st Advanced Therapies Science Meeting took place in Berlin from the 25th - 26th November 2019.

Speakers and participants, from across Europe and beyond, congregated to take part in discussions highlighting the challenges facing Advanced Therapies and to hear about the latest advances from basic research and preclinical models to manufacturing processes, clinical trials, ethics, economics, regulatory issues and clinical implementation.

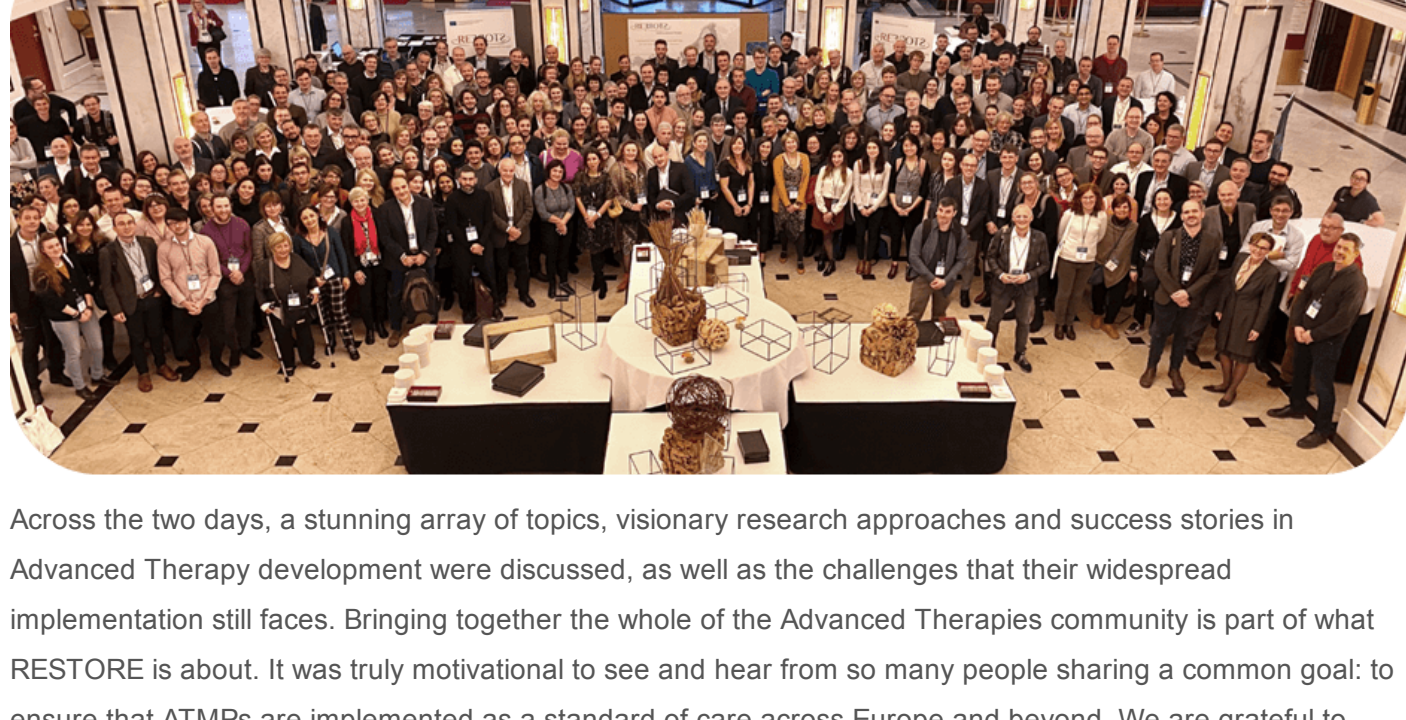
The focus of the 1st ATSM was on Advanced Therapies, one of the most recent and significant advances in medicine. They include cell, gene and tissue engineering therapies to not only treat disease symptoms, but to potentially provide a cure for otherwise incurable chronic diseases. Advanced Therapies, also known as "living drugs", are a disruptive medical innovation, i.e. an innovation that is changing healthcare and the way drugs are developed and used in clinical routines.



Prof Hans-Dieter Volk opened proceedings with an inspiring presentation on the aims and vision of the large-scale research initiative RESTORE. RESTORE aims to accelerate the availability of "living drugs" to all those in need by supporting collaboration throughout the transdisciplinary network required during the entire drug development trajectory, from inception to implementation and by helping to overcome regulatory, scientific and technological roadblocks that stand in the way of such a trailblazing change.

On day 1, we heard how the knowledge gleaned from foundational research is being used to identify new targets and indications for the development of novel Advanced Therapies. We also heard about new developments in the preclinical testing of Advanced Therapies, such as organ-on-a-chip systems, which are more suitable than traditional animal models. The third part of the day was dedicated to innovation in manufacturing technologies and how it may disrupt the entire field of Advanced Therapies and pave the way for reproducible, high-grade "living drug" products using current manufacturing structures.

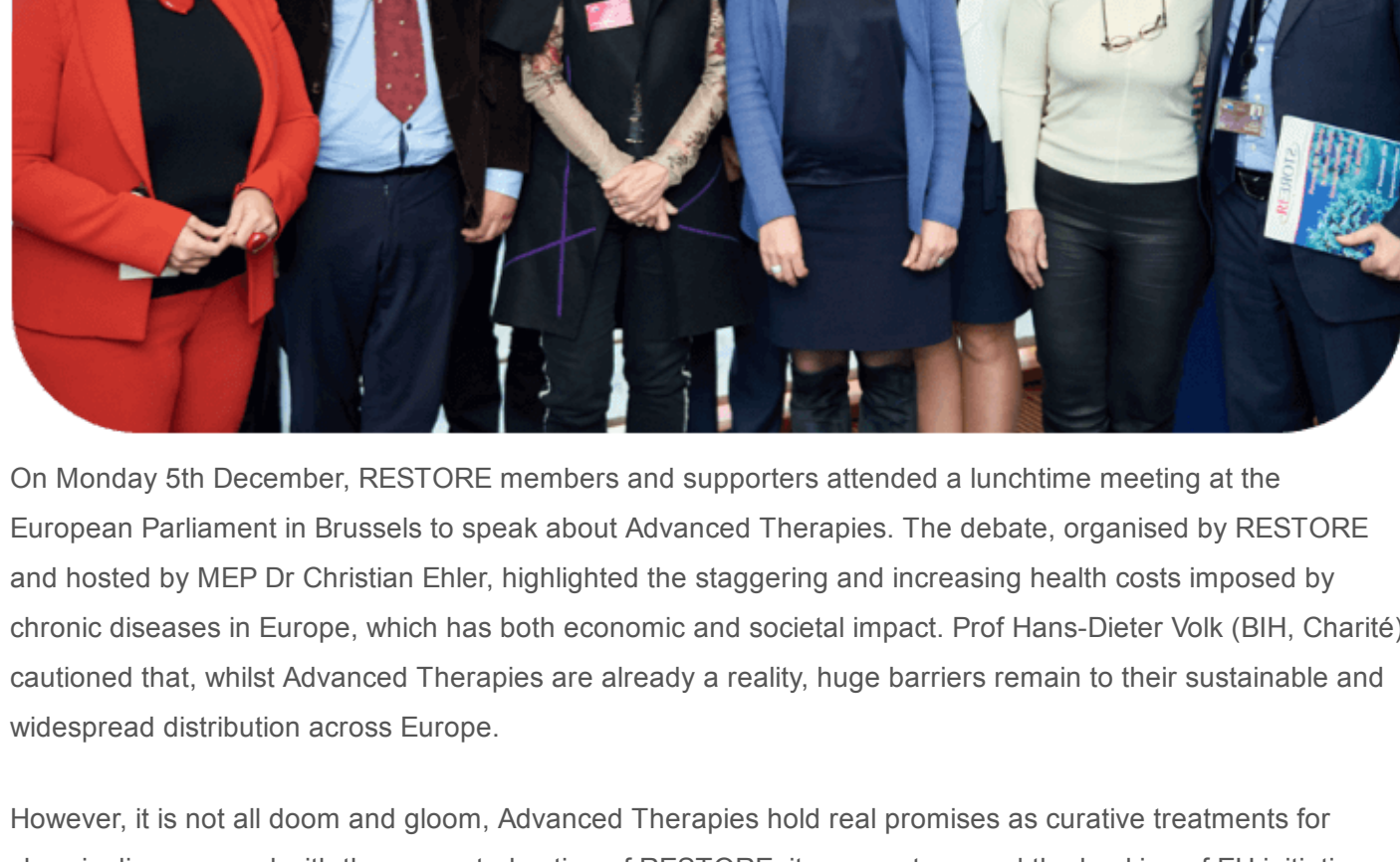
We were truly honoured to have Nobel Prize winner Ada Yonath open day 2. She talked about her research into the ribosome and the opportunities her findings have provided for overcoming antibiotic resistance. Her talk on the translation of findings from foundational research into meaningful healthcare products bridged the topics discussed on day 1 to those discussed on day 2, bringing Advanced Therapies into the clinic. We heard about the unique regulatory challenges associated with authorising Advanced Therapies and the new reimbursement models required to pay for them. The issues of ethics, big data and public engagement surrounding Advanced Therapies were covered in a special focus session, which highlighted how machine learning could be applied to clinical development how ethics can be used to advance research and about the dangers of the dissemination of inaccurate information to the public.



Across the two days, a stunning array of topics, visionary research approaches and success stories in Advanced Therapy development were discussed, as well as the challenges that their widespread implementation still faces. Bringing together the whole of the Advanced Therapies community is part of what RESTORE is about. It was truly motivational to see and hear from so many people sharing a common goal: to ensure that ATMPs are implemented as a standard of care across Europe and beyond. We are grateful to everyone who took part and made the 1st ATSM a success!

RESTORE at the European Parliament in Brussels

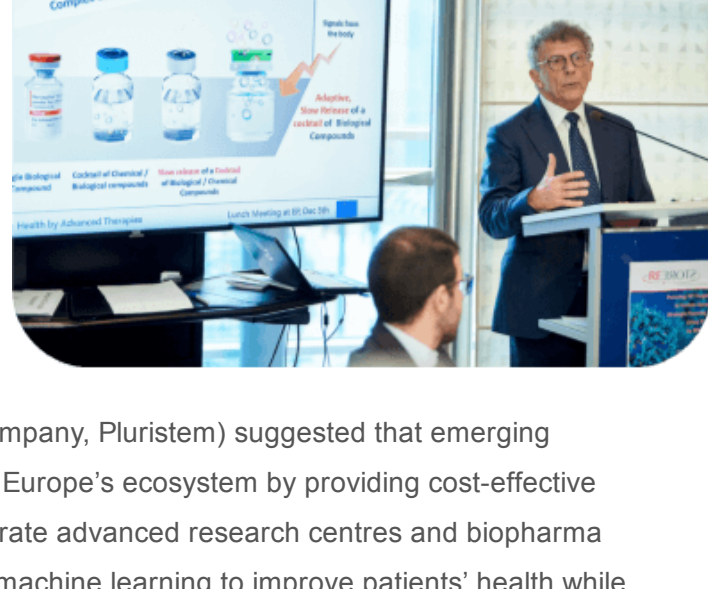
5th December 2019, European Parliament Brussels, Belgium



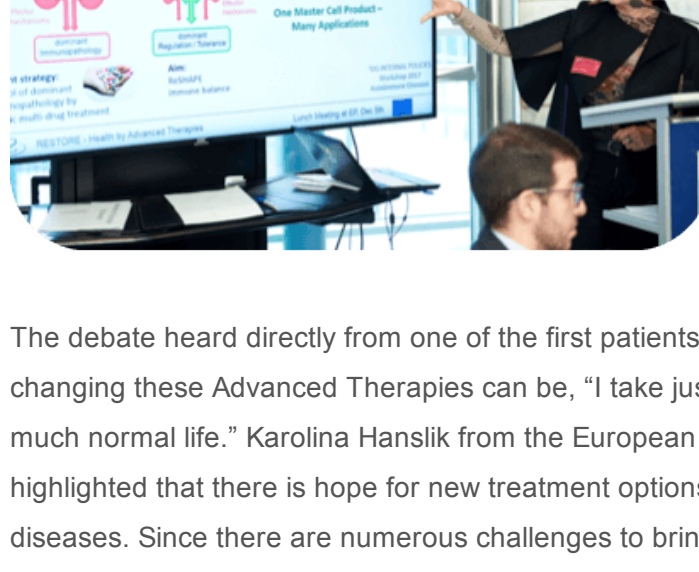
On Monday 5th December, RESTORE members and supporters attended a lunchtime meeting at the European Parliament in Brussels to speak about Advanced Therapies. The debate, organised by RESTORE and hosted by MEP Dr Christian Ehler, highlighted the staggering and increasing health costs imposed by chronic diseases in Europe, which has both economic and societal impact. Prof Hans-Dieter Volk (BIH, Charité) cautioned that, whilst Advanced Therapies are already a reality, huge barriers remain to their sustainable and widespread distribution across Europe.

However, it is not all doom and gloom, Advanced Therapies hold real promises as curative treatments for chronic diseases and with the concerted action of RESTORE, its supporters, and the backing of EU initiatives the goal of affordable and accessible Advanced Therapies for everyone in Europe becomes ever more achievable. A key aim of RESTORE is to generate a sustainable ecosystem combining all aspects of Advanced Therapeutic development to accelerate innovation at scientific, technical, logistical and economic levels. Guillaume Fusai (responsible for EU affairs at INSERM) acknowledged the importance of RESTORE in generating such a hub, which combines industry, hospitals and research to advance and fast-track the translation of basic research to the clinic.

The pharmaceutical industry has recognised the new challenges and opportunities of Advanced Therapies noted Ivana Cattaneo (Public Affairs Director for the European Region, Novartis Oncology), adding that "All along the whole trajectory from discovery to access, there is a need for all stakeholders to engage and collaborate in a different way."



Zami Technologies (executive chairperson of the Israeli company, Pluristem) suggested that emerging technologies "have the potential to significantly impact Europe's ecosystem by providing cost-effective therapies to many unmet medical conditions and generate advanced research centres and biopharma companies that will use advance tools such as AI and machine learning to improve patients' health while reducing costs for healthcare systems."



During these discussions, it is important not to forget the patients, the people for whom these therapies can transform their lives. Prof Petra Reinke (BeCAT, Charité) presented the potential of regulatory T cell (Treg) therapies to change the lives of transplant patients by reshaping the immune balance. The current norm after transplantation is a regimen of 20-30 pills a day, every day for the rest of your life.

The debate heard directly from one of the first patients to ever receive Treg therapy about just how life changing these Advanced Therapies can be, "I take just one pill per day and am now able to lead a pretty much normal life." Karolina Hanslik from the European Organisation for Rare Diseases (EURORDIS) highlighted that there is hope for new treatment options, and possible cures, for people living with rare diseases. Since there are numerous challenges to bringing the Advanced Therapies to the patients, the rare diseases' community expects to be supported by European institutions, national governments, researchers, clinicians and the initiatives such as RESTORE to have access to the most effective, innovative treatments.

The mission of RESTORE is not just to raise awareness of the hurdles standing in the way of Advanced Therapies, but also to provide potential solutions to overcome them. In this regard, the RESTORE position paper (which can be read [here](https://www.restore-horizon.eu/position-paper)) outlines recommendations to the EU and to all those involved in Advanced Therapy research for ensuring the future of accessible and affordable Advanced Therapeutics to all those in need.

EVENTS



RESTORE Momentum Workshop

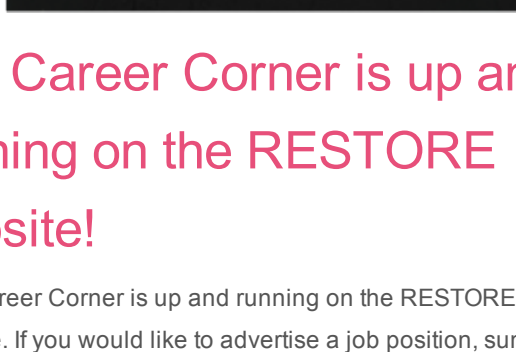
February 17th 2020, Hotel Moa, Berlin

On the 17th February RESTORE invites all supporters and partners to a workshop to reflect on all that RESTORE has achieved in the past year AND to look to the future and keep the momentum going to bring affordable Advanced Therapies to all patients in need.

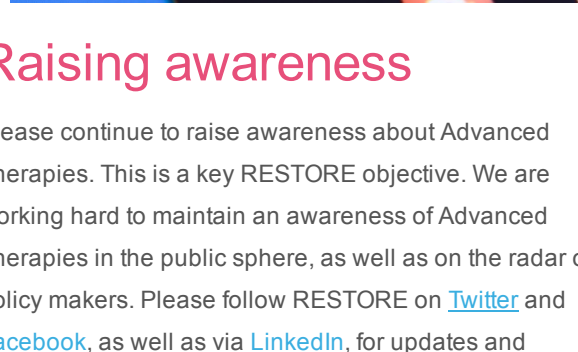
Save the date and keep your eyes peeled for more information coming soon.

Please visit our website for news and updates: <https://www.restore-horizon.eu/momentum-workshop/>

NEWS



The Career Corner is up and running on the RESTORE website. If you would like to advertise a job position, summer schools, upcoming conferences etc in the area of Advanced Therapies, then please use the RESTORE Career Corner to reach an ATMP oriented audience. Posting the advertisement is easy, simply fill in the [online form](https://www.restore-horizon.eu/career-corner), press submit and after being reviewed by the RESTORE team, your ad will be posted on the RESTORE website.



Raising awareness

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RESTORE

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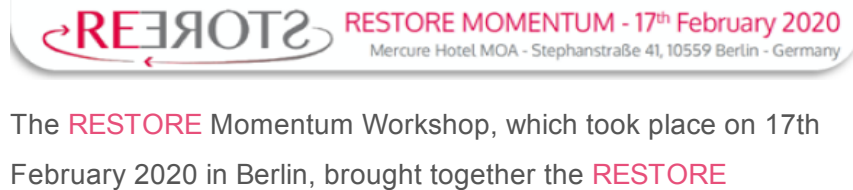
Sincerely,
Nicola, on behalf of the coordinator

info@restore-horizon.eu

REVIEW

RESTORE Momentum Workshop

February 17th 2020, Mercure Hotel Moa, Berlin



The **RESTORE** Momentum Workshop, which took place on 17th February 2020 in Berlin, brought together the **RESTORE** community to reflect on the progress made in the last 12 months and how to



continue fulfilling the **RESTORE** mission in the future. There were thought provoking talks from patient advocates, Bettina Ryll (MPNE), Karolina Hanslik (EURORDIS) and Sabine Dupont (IDF-Europe), on how to make the patient voice heard among the many players in the ATMP development pipeline and the importance of clear communication between all stakeholders.

The importance of clear communication and well-defined procedural guidelines was a theme throughout the day. From the talk of Toni Cathomen (Universitätsklinikum Freiburg), we learnt about the need for clear guidelines and assays for the detection of off target effects of CRISPR/Cas9 products. Similarly, Hildegard Büning (Hanover Medical School) talked about the many barriers for AAV reaching their full potential in gene therapy methods, including the need for defined genotoxicity testing and measures for transduction efficiency and accuracy. Johan Van Eldere, speaking on behalf of EUHA, highlighted the requirement for a new model of communication and cooperation between university treatment centres for CAR T cell therapies. Whilst Stephen Sullivan (GAIT) stressed the importance of standardisation both in the language used to describe different requirements during ATMP development and the quality control methods used for different products. Clear-cut guidelines were again a focus in the talk by Ulrike Köhl (Frauenhofer IZI), in which she stressed the importance of up to date staff training and coherence of this training and information transfer between institutes about manufacturing processes for ATMPs.

A joint survey by CARAT and **RESTORE**, presented by Michel Apel (Miltényi) is investigating the views of professionals on ethical, regulatory and technological obstacles for the translation of Advanced Therapies. The results are still coming in (if you want to participate please click [here](#)), but already trends are emerging about areas in which more information and clarity is required.

Finally, more than 80% of European citizens support the idea that EU member states should be funding innovation and enabling technologies for Advanced Therapies (preliminary results from survey by **RESTORE**, presented by Gady Goldsobel, Charité Universitätsmedizin Berlin).



A strong indication to the politicians that healthcare is important to EU citizens and should not be neglected in future budget plans. Perhaps information that is not currently being communicated between the general public and the political sphere and an area where **RESTORE** hopes to close this communication gap.

The issue of bringing Advanced Therapies to the market is a tricky one.

There are a huge number of technical, scientific and economic barriers that must be overcome in order to make Advanced Therapy Medicinal Products (ATMPs) available to all those in need. As was evident from the discussions between speakers and audience members, breaking down these barriers will be no mean feat. However, this is the mission **RESTORE** set out to fulfil just under 1 year ago, to make the promise of Advanced Therapies a reality for all patients in need to ensure their implementation into clinical practice as affordable, standard of care therapy and to thereby enhance patient outcome with a high impact on European society and economy. **RESTORE** coordinator, Hans-Dieter Volk (Charité Universitätsmedizin Berlin) summarised the event in his closing remarks "with the enthusiasm and backing of the **RESTORE** community, we continue to learn and evolve and so will continue to build up a European ecosystem to bolster innovation, communication and translation within the complex realm of Advanced Therapies".

Prolongation for RESTORE!

At the beginning of February 2020, **RESTORE** was officially granted a 2 month, cost-neutral, prolongation. There was so much helpful and interesting feedback from the 1st Advanced Therapy Science Meeting and from the **RESTORE** meeting at the European Parliament that **RESTORE** decided to ask for an extension, to allow more time to incorporate this feedback into various strategy papers that will be written by **RESTORE** partners and supporters and published in the coming months.

A joint CARAT and RESTORE survey

The EU initiative CARAT and **RESTORE** are conducting a joint survey within our research networks to identify the most important technological, regulatory, clinical and ethical hurdles for translation of CAR T and ATMP into clinical application.



The short anonymous survey includes just 12 questions and will take roughly 7 minutes to complete. We would be very grateful if you took the time to fill in your answers, as the gathered information will be extremely helpful for our discussions with regulatory bodies and to design targeted support measures for better translation of ATMPs.

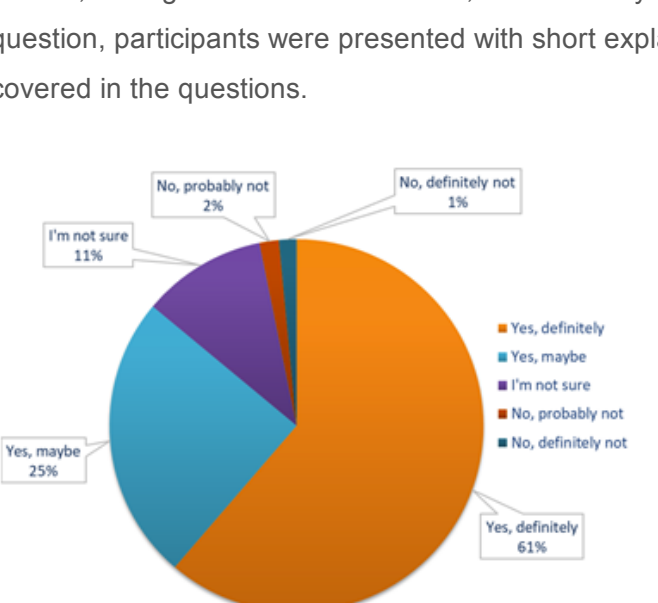
Click the link below to start the survey.
https://www.surveymonkey.de/r/CARAT_RESTORE_Survey

On behalf of the CARAT and **RESTORE** teams, thank you in advance for your participation!

A sneak peek into the Restore EU Citizens Survey



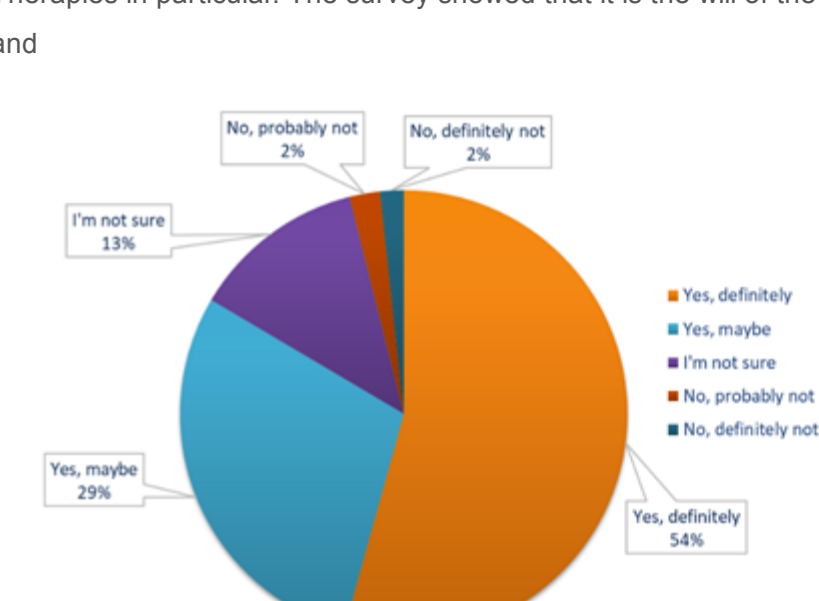
The **RESTORE** European citizens survey, which was rolled out across Germany, France, UK, Italy, Spain, Poland, Portugal and the Netherlands, was taken by more than 500 individuals from each country. For each question, participants were presented with short explanations in layman's terms that related to the topics covered in the questions.



The cost of health-care is increasing due to the ageing population. As we get older, we are at an increased risk of becoming chronically ill, and therefore a rise in the average age of the population is accompanied by higher spending on healthcare. Innovations in medicine could help to counteract this trend of rising expenditure. Two promising approaches are early detection of diseases in their early, still treatable stages and better therapies, such as Advanced Therapies that can potentially cure diseases.

Do you think EU- and state-funding should be invested in the development of these kinds of future medical innovations?

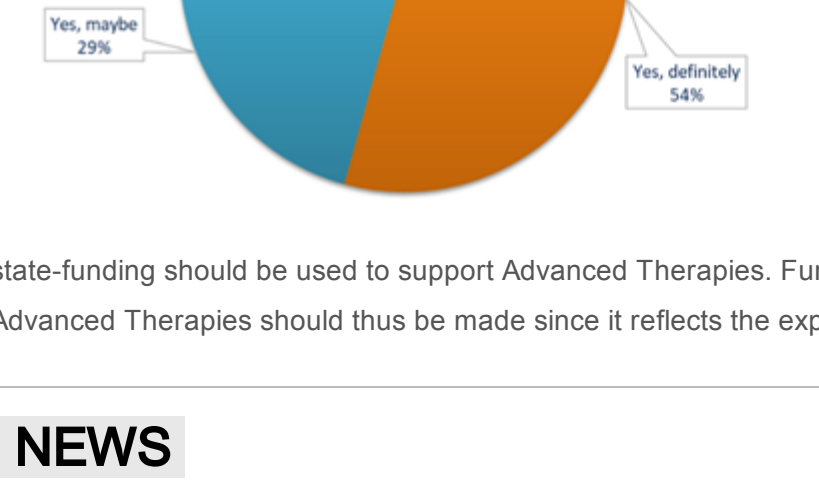
In line with these results, the majority of the surveyed population wants EU- and state-funding to be invested into innovation in healthcare in general and in technologies that will accelerate R&D of Advanced Therapies in particular. The survey showed that it is the will of the surveyed European population that EU- and



Advanced Therapies and the associated technology and materials are relatively new and therefore they are often not yet very efficient and quite expensive. Development of better and more efficient materials and technologies might lead to better and less expensive Advanced Therapies.

Do you think that EU- and state funding should be used to support the development of better and more efficient technologies and materials?

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NEWS



The Career Corner is up and running on the RESTORE website!

- If you would like to advertise a job position, summer schools, upcoming conferences etc in the area of Advanced Therapies, then please use the **RESTORE** Career Corner to reach an ATMP oriented audience. Posting the advertisement is easy, simply fill in the [online form](#), press submit and after being reviewed by the **RESTORE** team, your ad will be posted on the **RESTORE** website.



Raising awareness

Please continue to raise awareness about Advanced Therapies. This is a key **RESTORE** objective. We are working hard to maintain an awareness of Advanced Therapies in the public sphere, as well as on the radar of policy makers. Please follow **RESTORE** on [Twitter](#) and [Facebook](#), as well as via [LinkedIn](#), for updates and information. Tag us @RESTOREHorizon and feel free to share!

Survey EU Citizens

EU Survey - Who

- 8 countries – DE, FR, UK, IT, ES, PL, PT, NL

- >500 adult citizens from each country



- Age and gender sampled according to frequency in the population

EU Survey – What?

- Knowledge about Advanced Therapies
- Opinions on funding, R&D, reimbursement, importance of healthcare



EU Survey – How?

- Method – online survey
- A short explanation before each question
in layman's terms

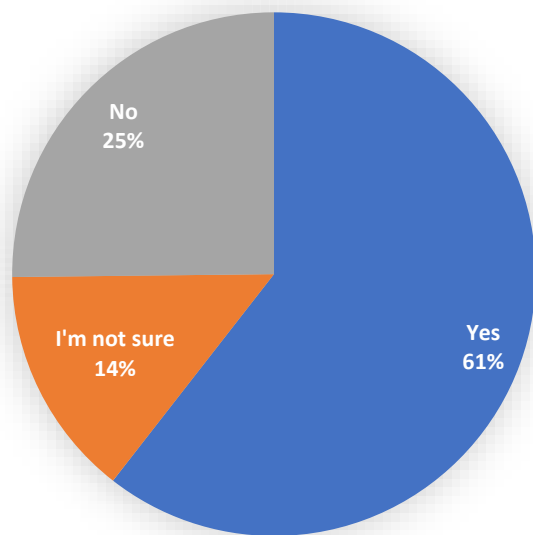
“Advanced Therapies” is a collective term for cell, gene and tissue engineering therapies.

Gene therapy involves the replacement of a faulty gene by a healthy copy. In this way diseases caused by a faulty gene can be treated or even cured.

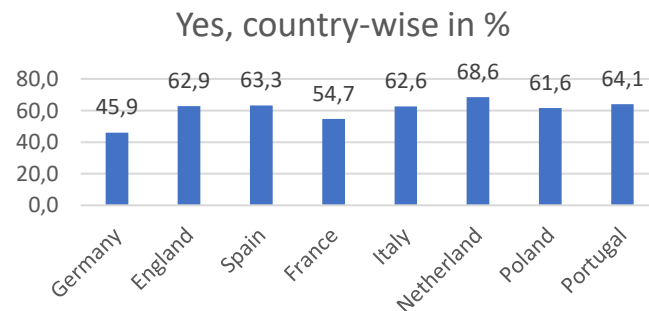
In cell therapy, certain cells are obtained from humans, modified and multiplied in order to use them therapeutically.

...

Knowledge: Have you ever heard of Cell Therapy and/or Gene Therapy and/or Tissue Engineering before participating in this survey?



Across all countries



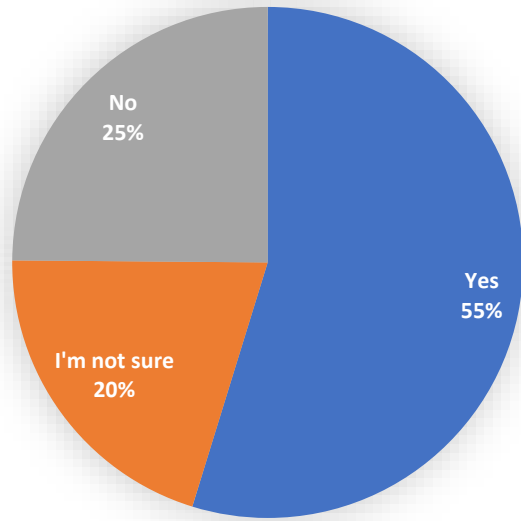
In general: The younger, the richer, the higher education level:

The more knowledgeable!

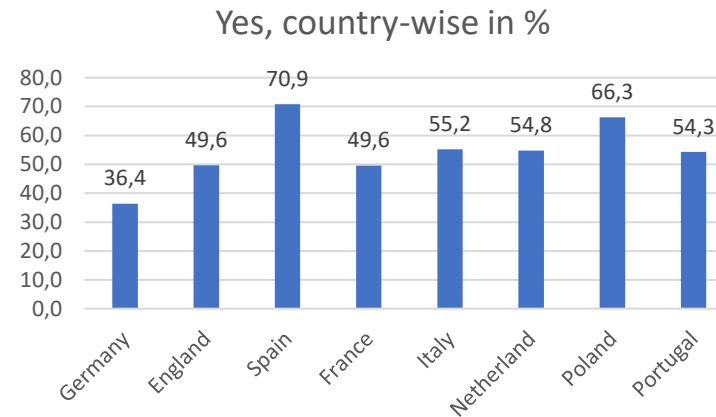
Size of city does not matter, except very small villages



Have you heard that recently more and more clinical trials of advanced therapies are being conducted or that more Advanced Therapies are being approved and thus made available to patients?



Across all countries



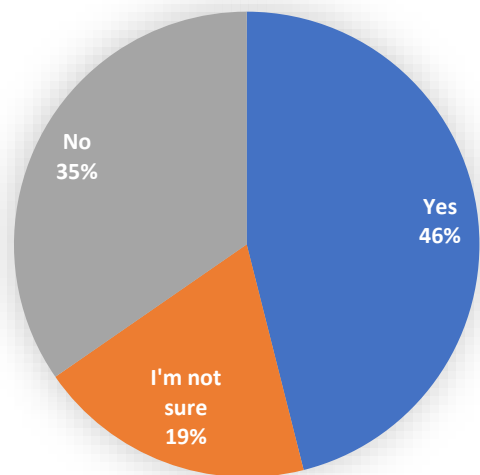
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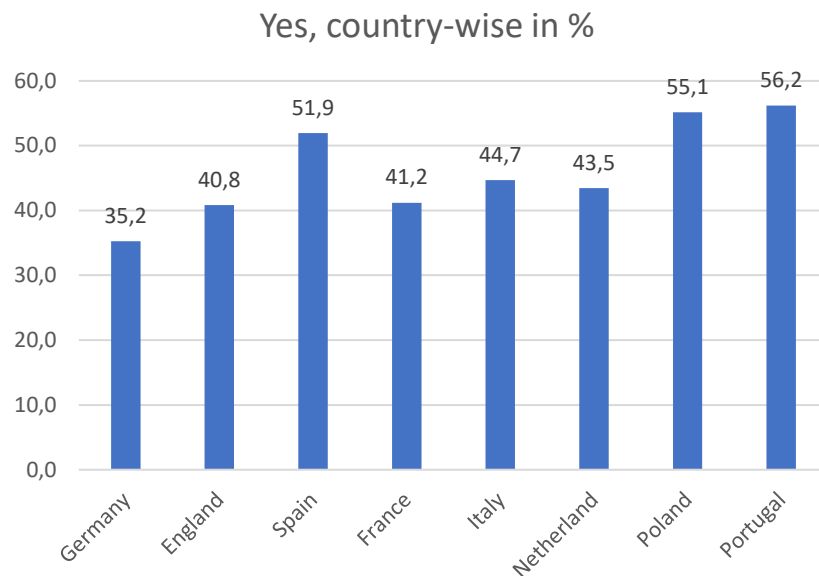
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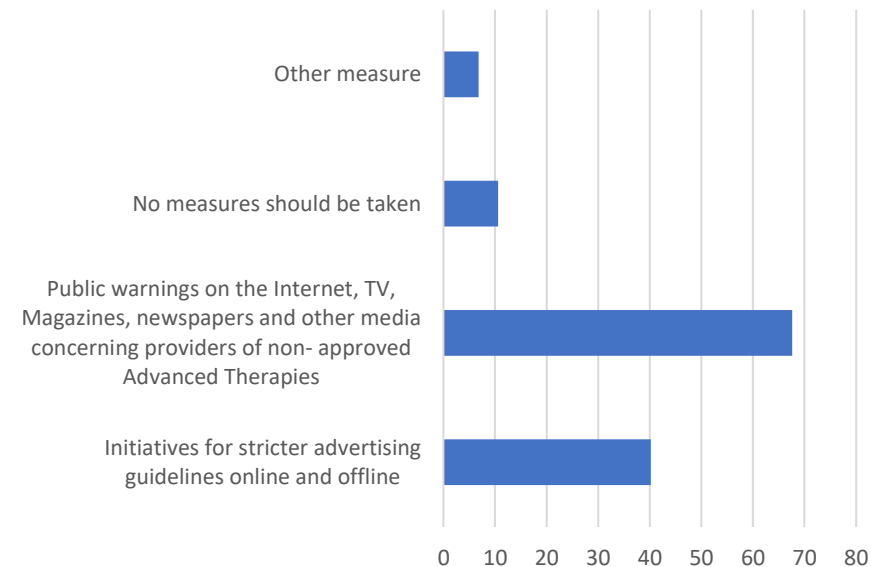
There also are private clinics that offer non-approved Advanced Therapies to patients. Have you heard about this?



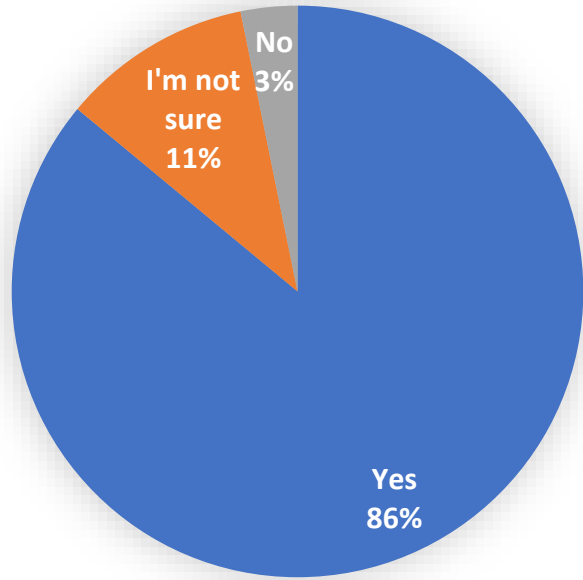
Across all countries



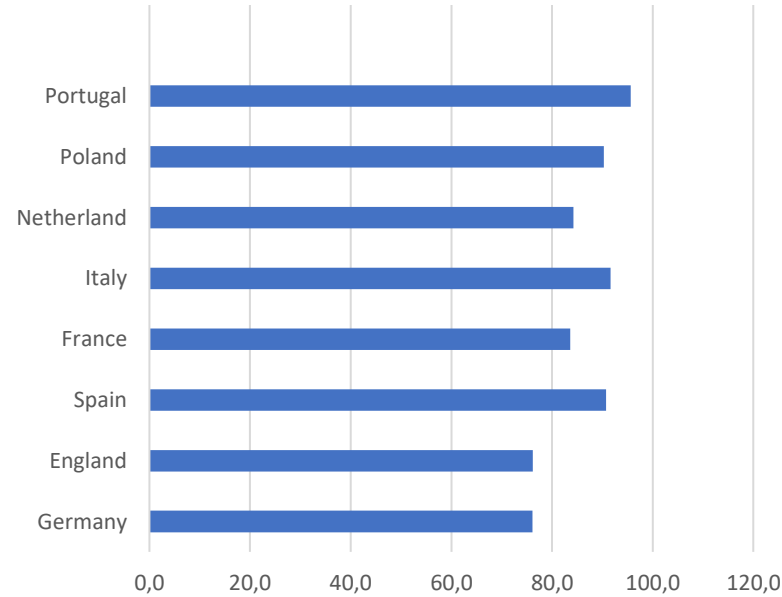
And what should we do about it?



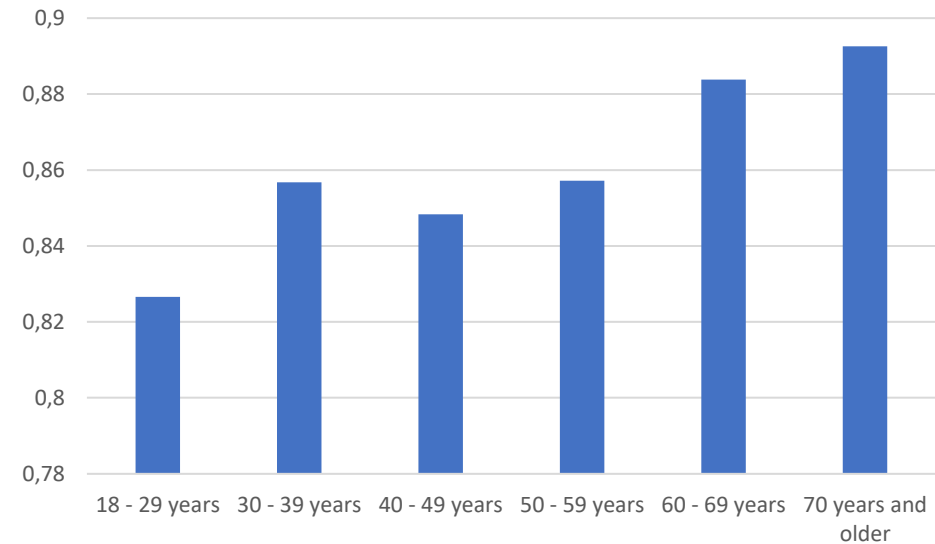
Do you think EU- and state-funding should be invested in the development of future medical innovations?



Across all countries

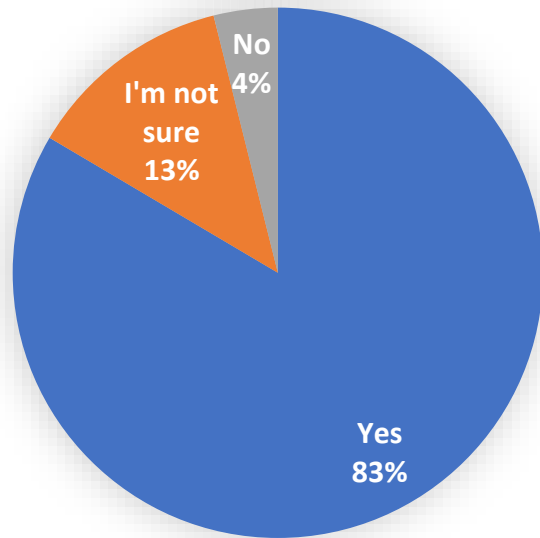


Yes, country-wise in %



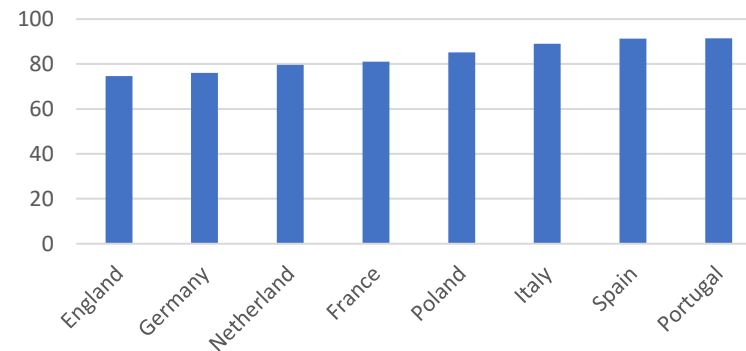
Trend: the older, the more supportiv!

Should EU and Member States fund enabling technologies for Advanced Therapies?

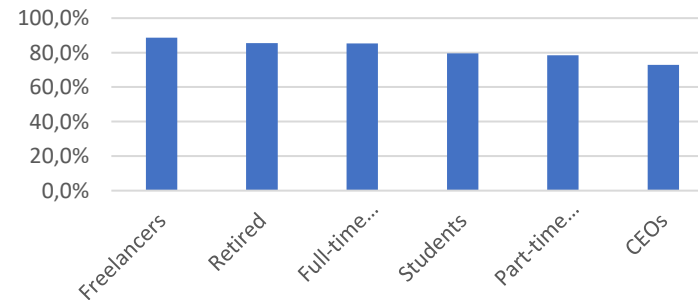


Across all countries

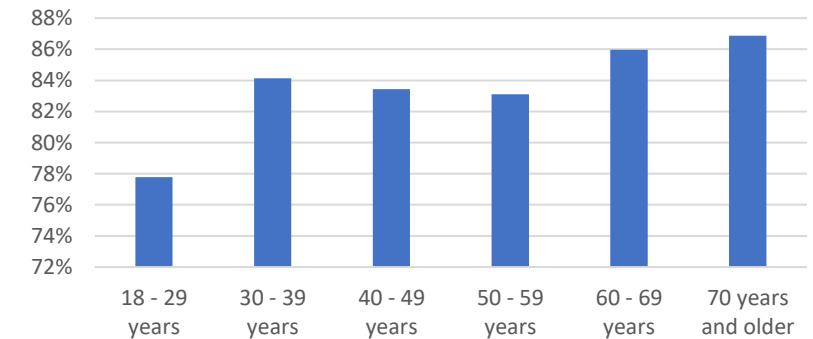
Yes, country-wise



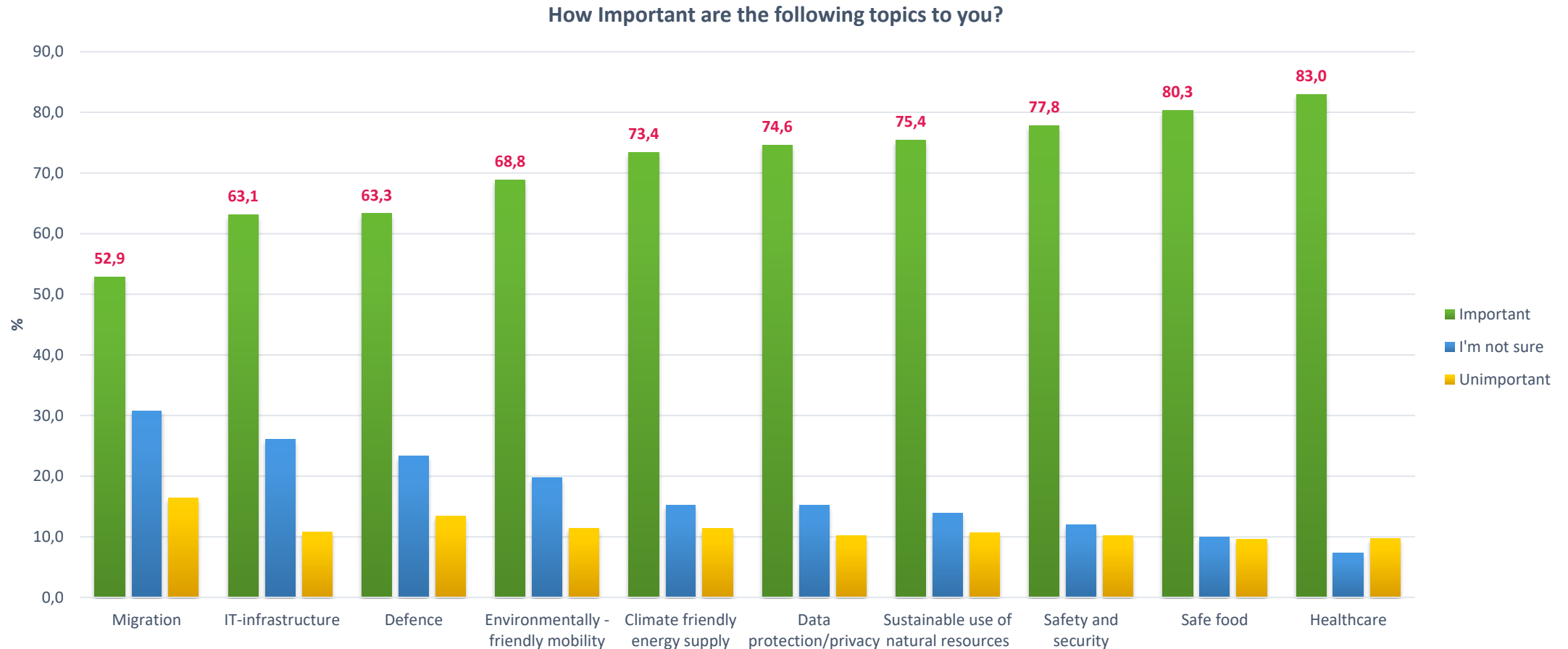
Yes, job-wise



Trend: the older, the more supportiv

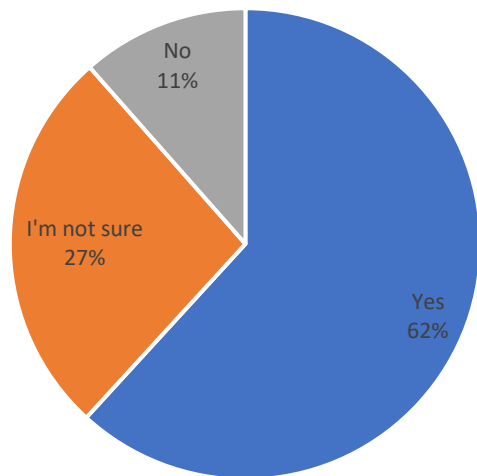


Importance of big political issues

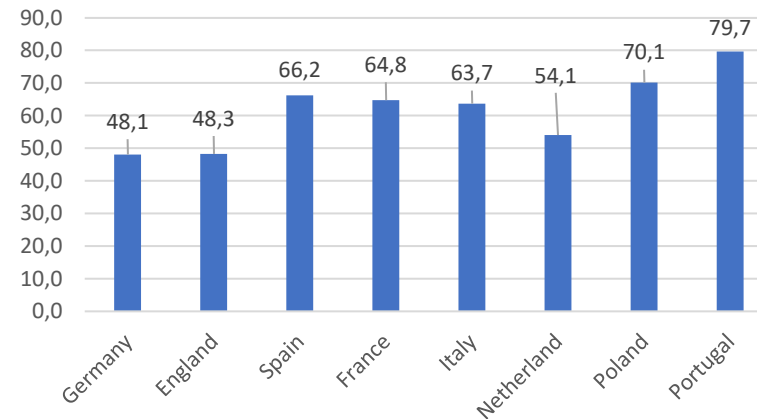


Should the state pay for very expensive therapies although evidence for long-term benefit has not been shown yet?

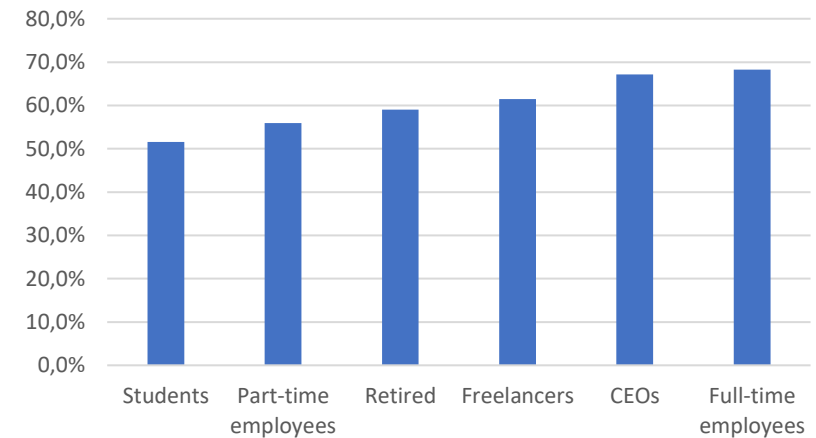
Across all countries



Yes, country wise

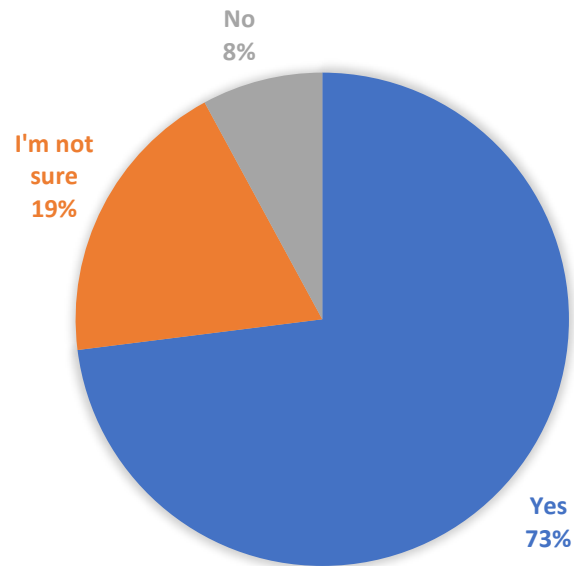


Yes. Emploament status related

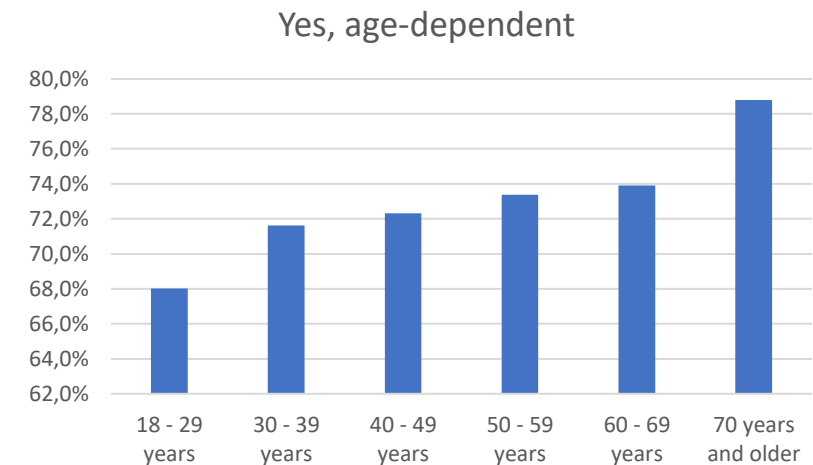
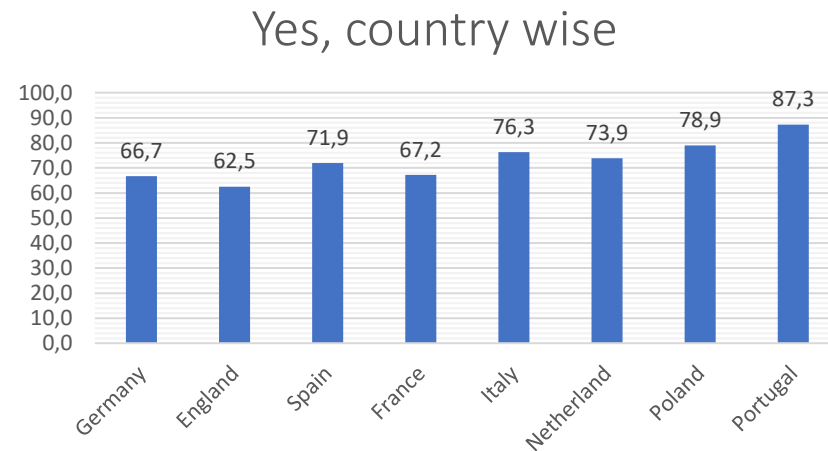


Across all countries

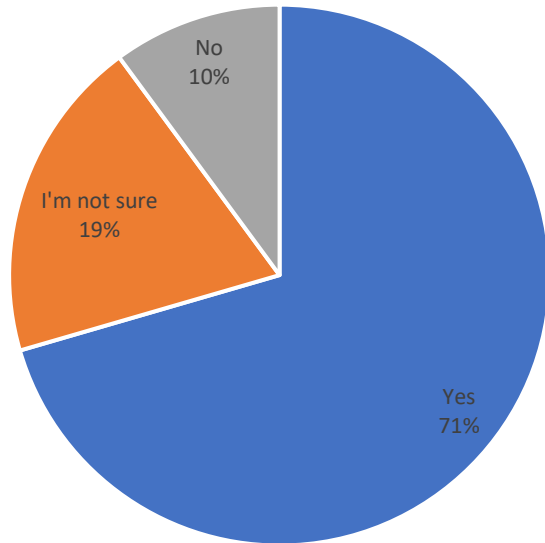
Do you agree that, in the case of rare diseases, cross-border health care, i.e. potentially travelling abroad, is the best way to provide the most beneficial treatment for patients?



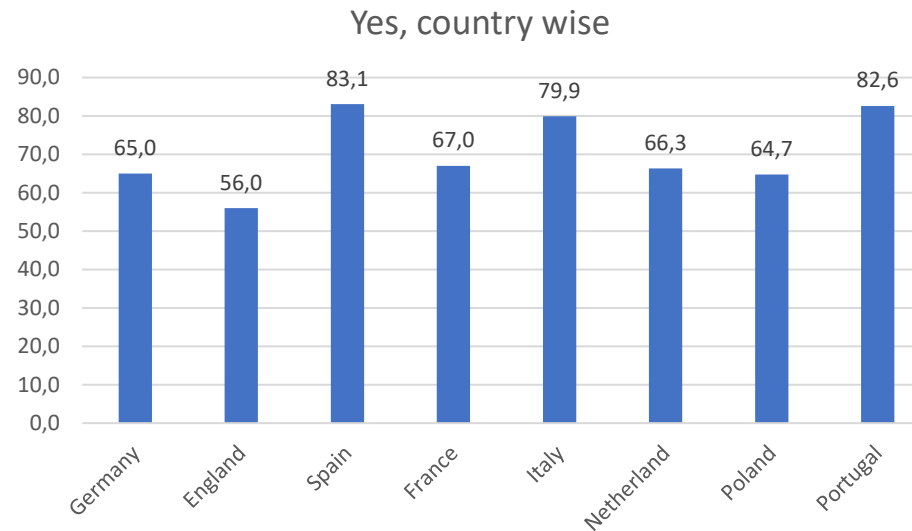
Across all countries



Should non-medical costs be covered in cross border healthcare?



Across all countries



Summary

- There is room for improvement in communication about Advanced Therapies
- Most citizens support reimbursement of Advanced Therapies, more support cross-boarder healthcare
- Healthcare is #1 political topic for the European citizen
- Vast majority support public funding of innovation in healthcare
- Vast majority support investment in enabling technologies
- Differences between countries

Thank you