

CONNECT
COGNITIVE DECLINE IN NEPHRO-NEUROLOGY

Dissemination and Communication Plan

COST Action “Cognitive decline in Nephro-Neurology:
European Cooperative Target” CONNECT- CA19127

Working Group 5 (WG5)

CA19127 | EU COST CONNECT ACTION

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1. Purpose and Scope of the Action Dissemination and Communication Plan

Fragmentation between neurological and nephrological expertise has frustrated research into the mechanism of cognitive decline secondary to kidney disease, raising several clinical, social, and ethical issues. By for the first time bringing these fields together in CONNECT we establish a novel multidisciplinary field to improve patient diagnosis and care.

The developed world is experiencing a growing number of patients with chronic kidney disease (CKD), a complex systemic and potentially fatal disease. With improved long-term life expectancy as the result of kidney replacement therapies, more attention has been given to comorbidities, including cognitive impairment. In CKD patients, both the central and peripheral nervous system are frequently affected. Eventually, this decreases quality of life and eventually causes dementia with loss of independence in everyday activities.

CONNECT aims to coordinate research on cognitive impairment in CKD. This requires exchanging clinical information between nephrologists and neurologists, and between neuroscientists and kidney physiologists, guided by big data analysts. This collaborative network will define new experimental paradigms, their translational value and, in turn, focus on new interventions in the field of cognitive impairment. Moreover, attention to emerging ethical issues will result in practical guidelines for clinicians working at the intersection of CKD and cognitive diseases.

At the core of this COST Action lie activities that bridge the gaps between these fields and prepare early-stage researchers and clinicians to start new research lines. The interdisciplinary consortium from 22 countries will focus on 1) pre-clinical research, 2) clinical trials, 3) clinical practice, 4) data management and analytics, and 5) inclusiveness and dissemination of the Action. This COST Action will alleviate disparities in CKD patient care and enable breakthrough research enabling patient diagnosis and early treatments.

The achievement of the described activities will be assured as follows:

- **Content generation:** by all the participants
- **Content management:** by WG5
- **Content repository and layout:** WG5 and Boutik
- **Content dissemination:** by all the participants, coordinated by WG5

2. Communication, Dissemination Objectives

To connect with stakeholders and research communities by:

- Sharing research results
- Stimulating new research projects
- Raising awareness of the Action topic in general public and among scientific societies
- Engaging the stakeholders
- Influencing policy making
- Exchanging ideas in clinical management
- Creating a platform for facilitating the alignment of scientific research with clinical and societal needs

This action aims to achieve, within its action duration (4 years), the following **communication objectives**:

- To manage the communication network of CONNECT
- To set up WG5 to verify the content to be communicated or disseminated and approve the target group to be addressed
- To take actions to communicate the activities and results of the project
- To participate in symposia, workshops, meetings as well as organize the Final Conference at the end of the action
- To create a dedicated website for CONNECT
- To create, in collaboration with the MC, all needed communication tools to give a visual identity to the action
- To ensure the proper communication and dissemination of the information generated by the project to relevant stakeholders and the public
- To facilitate the communication systems with the on-going action CONNECT as well as other relevant organizations in order to promote the sharing of data and knowledge

This action aims to achieve, within its action duration (4 years), the following **dissemination objectives**:

- To take actions to disseminate the activities and results of the action
- To disseminate action materials to the widest audience of the general public, to raise awareness around the action topic and create an interest among the audience
- To increase action awareness via the use of informational and promotional materials (newsletters, flyers, brochures, leaflets etc.) in workshops or conferences in which CONNECT will participate

3. Dissemination and Inclusiveness Working Group

As defined in MoU, WG5 will lead dissemination and inclusiveness activities of the CONNECT action composed by leader, co-leader, and members.

The roles of WG5:

- To manage the communication network of CONNECT
- Organize partners participations in symposia, workshops, meetings taking place at European level
- Organize targeted information sessions and a conference in the final year of the project.
- To disseminate to the widest audience of the general public to promote greater public engagement and dialogue between the scientist and society.
- To ensure the proper communication and dissemination of the information generated by the action to relevant stakeholders and the general public.

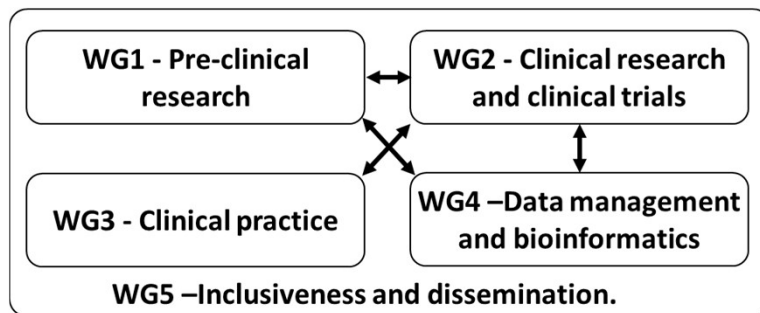


Figure 1. “WG5 Inclusiveness and dissemination” is linked to each WG

WG5 members:

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4. Dissemination Procedure

Every activity will be written in the dissemination plan. From each working group, one or two participants may be designated to feed WG5 for dissemination and communication activities. WG5 members and Science Communication Manager will work in coordination to make decisions about the texts to be published in the press and media organs.

5. Communication and Dissemination Strategy and Activities

With this communication plan, the overall communication and dissemination strategy is explained. This plan will be updated with the work to be done by the working groups and new decisions to be taken during this period.

a. Communication, Dissemination, and Inclusiveness activities:

- Structure of WG5
- Preparation of the Communication and Dissemination plan

- Development of communication tools (logo, website, newsletters, posters, and leaflets etc.) to support presentations
- Creation and maintenance of action social media accounts
- Creation of videos which will be posted on the action website and utilized to reach the public at large
- Preparation and presentation of the deliverables (Dissemination Activities Report and Assessment and the Final Dissemination Activities Report and Assessment at the end of the project)
- Distribution of press releases regarding any important objectives and phases of the project as they are reached to be distributed to all media contacts
- Distribution of electronic newsletters to target groups and members of the media
- Organization of participation in events, workshops, and international conferences

b. Key Messages:

Based on each WG activities during this 4-year-period, new key messages will be created. The main key messages are as follows:

- Healthy kidneys, healthy brain.
- It is important for clinical care to raise awareness that cognitive impairment may develop in patients with chronic kidney disease.
- It is necessary to develop a common language between nephrologists, neurologists, and geriatricians.

c. Direct Communication:

The direct foreseen actions are:

- Direct mailing (newsletter, press release)
- Direct distribution to the stakeholders, included in the MoU list, of the communication material produced (leaflets, brochures, printed versions of the newsletters, other information material prepared, invitations to action events and conferences, etc.)
- Discussions generated on the social media tools

d. Indirect Communication:

- CONNECT action website is the primary platform of communication about the activities and results of the action
- CONNECT electronic newsletter, leaflets and other information material circulated
- CONNECT accounts in social networks: Twitter, LinkedIn, Facebook, ResearchGate, Instagram, Academia,eu

6. **Impact Indicators**

- Number of participants
- Number of scientific publications
- Number of conferences, STSMs, ITC conferences, summer schools, other events
- Number of attended conferences
- Circulation of information on other websites and networks
- Number of visits and downloads from website
- Number of members and followers of social media accounts
- Feedback received over any communication or dissemination activities
- Number of press releases published and circulated
- Number of newsletters and subscribers
- Number of coverages in specialized and general media

7. **Target Groups**

The target groups involved in the communication and dissemination actions will be part of the following categories:

Scientific community

- Private/public research institutes and universities
- Hospitals
- Colleagues (nephrologist, neurologist, neuroscientist, pharmacologist, others in scientific community)

Non-scientific community

- General public
- Civil Society/Organizations
- Patients, candidates for kidney diseases
- Associations of patients
- Policy makers at EU/national/local level (e.g., not in the first months. The first months should be arranged to know each other. Maybe one year later we may contact policy makers)
- Pharmaceutical sector, industry
- Media
- Relevant students from university and high schools

Examples of organizations that will be reached are:

Research, Industry and Policy

- European Renal Association
<https://www.era-online.org/en/>
- Federation of European Neuroscience Societies (FENS)
<https://www.fens.org/>
- European Congress of Neuropsychopharmacology (ECNP)
<https://www.ecnp.eu/>
- International Society of Nephrology
<https://www.theisn.org/>

- American Society of Nephrology
<https://www.asn-online.org/>
- The Asian Pacific Society of Nephrology
<https://apsneph.org/web/index.html>
- Society For Neuroscience (SfN)
<https://www.sfn.org/>
- American Academy of Neurology
<https://www.aan.com/>
- European Academy of Neurology
<https://www.ean.org/>
- The International Society for Cerebral Blood Flow and Metabolism (ISCBFM)
<https://www.iscbfm.org/>
- The International Neuroethics Society
<https://www.neuroethicssociety.org/>
- The International Brain Initiative
<https://www.internationalbraininitiative.org/>

Associations

- Patient Associations for Nephrology
- Patient Association for Neurology

8. Action Communication and Dissemination Tools

Professional design company Boutik designed the concept, logo, and the website. Website was launched as an important outcome of the first grant period. Domain name is www.connectcost.eu

This strengthens the shared identity of the partners and improves recognition and visibility of the Action. Website will be active for the duration of the action and two additional years. It enables internal communication through e-mails, dissemination of scientific results and communication with different stakeholders. The website is updated regularly by WG5 and Boutik who has access to edit the content.

Tools for sharing ideas and results:

Channel	Tool	Tasks
Online	Website	All info
	LinkedIn, ResearchGate, Twitter, Facebook, Instagram, Academia.eu	News, calls, general dissemination videos (trailers/animations) Posts and interactions with related social media accounts weekly (e.g., COST, COST Academy, NDT etc.)
	Webinars	Sharing available knowledge, collaborations with other projects
	Scientific journals	Scientific papers, reviews
Events	Workshops, symposiums, summer schools, STSM, ITC conferences	Achieving new knowledge, collaborations in the network
	Conferences	Posters, presentations, workshops At least 2 by partnering with for instance the ERA, SfN and the National Nephrology meetings (e.g., the Italian Society of Nephrology)
	Public lectures and science festivals	Yearly public lectures in countries of COST Action participants, always in the language of the respective country. This will be achieved by teaming up with national science festivals (e.g., Bergamoscienza in IT, Weekend of Science in NL, Berlin Science Week in DE)
Print	Scientific printed journals, flyers, newsletters, press- release	Dissemination at conferences Newsletters at least 2x per year
	Brochures	2 brochures: one for patients and one for policy makers and healthcare payers. Brochures will be distributed through the European and the national nephrology societies at annual meetings

a. Action Logo

Boutik has created CONNECT logo to describe the key messages of the Action. Key words were given “nephrology-neurology connection, kidney-brain, kidney-dementia”

b. Action Website

The action domain name is www.connectcost.eu

The public area of the website contains:

- A presentation of the action, its objectives, the partners
- An introduction to the scientific topics and the background research activity of CONNECT action
- Short, introductory videos explaining the action and providing a visual aid for the website (these videos are provided at a later stage of the action to disseminate the action results)
- A page with the main news coming from all the action countries, including those coming from the contacts established during the action
- A page with details on the events organized by the action, both the dissemination events and the Final Conference
- A page with access to the electronic newsletters to be published twice per year. Stakeholders and interested researchers/others will be able to download relevant information whenever they need it
- A page with useful links to EU COST website, public bodies working in the action topics in EU countries and other websites relevant to the action objectives and goals
- Link to similar COST Action websites and eventually other ERA initiatives
- Other pages such as Sitemap and Contact us, whenever necessary and with a relevant format
- Links to the action’s ResearchGate, LinkedIn and other social media channels
- A regularly updated calendar or timeline demonstrating the ongoing work projects and past developments
- A page listing all partners that will highlight each organization, their role within CONNECT and their work
- Media corner that will include all communication materials that will be of interest to media such as press releases, action logo, leaflet, posters, news, newsletters etc.

The private area (accessible only to action partners, COST, the WG leaders and the WG Members) contains:

- A common storing space for partners including work packages, deliverables, reports, other official documents for action management purposes
- The draft versions of the reports and deliverables for consortium accessibility
- An e-mail functionality enabling the sending of e-mails to pre-defined groups; info@connectcost.eu

Visual materials such as pictures and video recordings collected from partners will be used for the website (GDPR is a concern in case of personal data).

c. Action Leaflet and Brochures

This will be discussed in further periods. 2 brochures: one for patients and one for policy makers and healthcare payers. Brochures will be distributed through the European and the national nephrology societies at annual meetings.

d. Flyers for Project Activities

This will be discussed in further periods.

e. Action Electronic Newsletter

The action newsletter will be prepared in a suitable format to be sent by electronic e-mail to all registered subscribers, targeted organizations, composed by public and scientists and to contacts collected among the partners. During Covid-19 pandemic, every material will be electronic. It will also be able to be published in print after the pandemic.

- Newsletters will be sent by e-mail showing the titles of the main subjects and a few lines, linking to the website.
- Newsletters will also be available as a downloadable PDF document from the website.
- Newsletters will be published at least twice a year containing information on the action and on action activities to keep the audience informed about the results achieved and expected, news on activities, and action accomplishments.
- Newsletters will gather all the news published on the website all year long.
- Short and updated news will be published more often on the public website, following partners' participation in conferences, publication of partners' abstracts, eventual prizes and awards received by the partners, and other interesting information related to project achievements or partners' activities.
- All partners are requested to keep in contact with the WG5 and send updates and news at any time, when submitting an abstract, when receiving a slot for a presentation in a conference, poster presentation, etc.
- Partners are also requested to communicate in their papers and abstract the name of the action CONNECT the logo and the fact that the action is funded by EU COST.
- WG5 in the phase of preparation of the newsletter will ask to all partners for their input to produce the content.
- As the newsletter will be based on contributions from the partners, if no contributions arrive, the newsletter will be postponed until relevant news can be included.
- Pictures or short videos collected in the partner's laboratories will be used to match with the paper-based material.
- The WG5 will look at other existing newsletters in the similar field in Europe and will select those that could be most interesting and worthwhile to be

contacted in order to share information and include news from the CONNECT action.

f. Press Releases

All Press Releases will be originally written in English, and it will be the partners' responsibility to translate these releases into their local languages if the information is relevant to any local audiences, particular to their region or if the CONNECT action would particularly benefit from sharing the press release with local media.

- Scientific Partners are requested to provide technical material and important discoveries as they occur so that they may be included in the Press Releases.
- Press Releases will also be posted in the "Media" section of the action website in English, for further accessibility for media or any other interested parties.

g. Action PowerPoint template

The PowerPoint template will be an internal tool available for use by any of the action partners as a visual aid reflecting the themes and message sent by the CONNECT action. COST ppt templates are available.

h. Social Media and other online tools

- ❖ LinkedIn
- ❖ ResearchGate
- ❖ Twitter (journalists)
- ❖ Facebook (patients, associations)
- ❖ Instagram (visual)
- ❖ Academia.eu

- WG5 will update CONNECT social media pages regularly and grow the CONNECT network in the social media
- Links to the ResearchGate, LinkedIn, Twitter, Instagram, Facebook, and other accounts will be included on the action website, as well as a section with a live Twitter feed, showing the on-going news of CONNECT
- News of particular significance will also be posted in the "News" section of the official action website, but daily news may all be found on the social media sites
- Feedback will be received and monitored on the project social media outlets which will then be considered for future use.
- Photos and videos used for other dissemination activities may also be posted on the social media sites, particularly photographs of events and workshops in which CONNECT participates.
- All participants will be invited to "like" the social media accounts, join the LinkedIn group and follow the CONNECT action so that they may remain updated on the news posted by the WG5.

Below are some networks on LinkedIn that can be potentially used to disseminate CONNECT news and results, attract potential members to CONNECT LinkedIn group and to receive possible feedbacks later on:

[European Renal Association-\(ERA\)](#)

(7000 members)

[Federation of European Neuroscience Societies - FENS](#)

(6009 members)

[European College of Neuropsychopharmacology \(ECNP\)](#)

(2363 members)

[Society For Neuroscience \(SfN\)](#)

(50062 members)

[International Society of Nephrology](#)

(7131 members)

[American Society of Nephrology](#)

(5257 members)

[American Academy of Neurology](#)

(15359 members)

[European Academy of Neurology](#)

(1535 members)

i. Action Videos

- 1-3 min animation videos have been created by two professional companies, Riva Illustrations (France) and Darvideo Animation Studio (Ukraine), to introduce the goal of the action to reach wide audience. Key message was defined as “Healthy Kidneys, Healthy Brain”. Animated videos will be available later in the action to continue communicating with the general public.

j. Traditional Media/Press

- Newspapers (in local languages, MC members may be in contact with local newspapers)

9. Plan for the Publication of Scientific and Peer-Reviewed Papers

Increasing collaborations during the action and publishing scientific papers from joint projects is one of the main objectives of CONNECT action. New collaborations will be formed throughout the action and studies for new publications will continue. In the first grant period the following six manuscripts are accepted in a top journal NDT:

Nephrology Dialysis Transplantation (NDT) Special Issue (*in-press*)

- Pepin M, Wiecek A et al. Cognitive disorders in patients with chronic kidney disease: specificities of clinical assessment
- Bikbov B., Hafez G et al. Albuminuria as a risk factor for mild cognitive impairment and dementia –what is the evidence?
- Wagner C, Unwin R et al. Acidosis and cognitive and motor impairments in patients with kidney disease

- Viggiano D, Capasso G. et al. Brain dysfunction in distal tubulo-interstitial kidney diseases
- Wanner C, Zoccali C. et al. Neuropeptide Y as a risk factor in CKD: is it time for clinical trials?
- Liabeuf S, Massy Z, et al. Chronic kidney disease and neurological disorders: are uremic toxins the missing piece of the puzzle?

10. Participation in Workshops and Conferences

Yearly public lectures in countries of COST Action participants, always in the language of the respective country. This will be achieved by teaming up with national science festivals (e.g., Bergamoscienza in IT, Weekend of Science in NL, Berlin Science Week in DE).

Starting from the second year of the action, at least one summer school is planned per year.

11. Exploitation of COST action results and outcomes: Intellectual Property

IP management during dissemination activities:

- A participant shall not include in any dissemination activity another participant's result or Background IP without obtaining prior written approval unless these have already been published (and then with proper reference).
- If a participant wishes to produce a publication or a presentation in relation to the COST Action that may contain another participant's result or Background IP, he/she must contact the MC, which shall be responsible for the coordination of an appropriate procedure.

12. Final Conference and the Calendar of WG5

Final conference will be in 2024.

The milestones of WG5	Year 1				Year 2				Year 3				Year 4			
Kickoff meeting	■															
Action website online		■														
Organize satellite events with current conferences and meetings							■									■
Brain-kidney joint research agenda published				■			■									■
Brain-kidney COST Action international conference												■				
Interdisciplinary summer schools							■					■				■

References

Detailed information about the Action research topic and COST rules can be found in MoU and at the following links:

www.cost.eu

www.connectcost.eu