



SPECIAL REPORT

The ERA-EDTA today and tomorrow: a progress document by the ERA-EDTA Council

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ABSTRACT

Scientific societies are increasingly seen as central to the advancement of information sharing and collaboration among scientists and clinical investigators for the progress of medical research and the promotion of education, professional competence, integrity and quality studies. To more effectively serve the practicing nephrologists and investigators dedicated to renal science, the Council of the European Renal Association and European Dialysis and Transplantation Association (ERA-EDTA) reorganized and integrated the various activities of the society into two branches, the Clinical Nephrology Governance branch and the Renal Science branch. New affordable initiatives to promote research, education and professional development and to advocate for the recognition of chronic kidney disease as a major public health issue at the European level will be put in place and/or potentiated in the new organizational frame. Educational initiatives will be espoused to Continuous Professional Development and, starting from 2019, 14 Education & Continuous Professional Development courses will be held covering the full range of knowledge areas of modern nephrology. Consolidation and development is the short- and medium-term mantra of the ERA-EDTA. The society has a rich portfolio of successful

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activities and brilliant, creative scientists among its members. Integrating the various activities of the ERA-EDTA and treasuring the expertise and wisdom of its most accomplished members will facilitate collaborative research, education and its public impact at large.

Keywords: clinical governance, ERA-EDTA, scientific associations, scientific societies

Harnessed by the growth of biomedical research, scientific associations have now entered into an era of profound transformation. New technologies and unprecedented possibilities of rapidly integrating disparate, previously irreducible, sources of information have accelerated the pace of discovery and advancement in knowledge [1]. In such a scenario, these associations shape and facilitate contacts among investigators and professionals in general, and are key to promoting research and education and to sustaining the advancement of modern professionalism. National and international scientific societies are increasingly seen as central to the advancement of information sharing and collaboration among scientists and clinical investigators for the progress of medical research and the promotion of education, professional competence, integrity and quality studies [2]. Scientific associations need to establish interactions of various sorts with society at large and maintain contacts with national and continental governmental bodies, as well as with the public. Innovation and transparency are key to the success of modern biomedical societies. However, pursuing these goals is more difficult than in the past because funding by the industry of independent research projects and of educational initiatives by medical associations has dwindled over the last decade [3].

The European Renal Association and European Dialysis and Transplant Association (ERA-EDTA) is a successful, half-century-old society that has gradually evolved to respond to the challenges posed by scientific research on renal diseases, to the need to provide high-quality education on these diseases and to establish an open channel with the institutions that fund scientific research in Europe. Under the contingent pressure of these needs, the ERA-EDTA has grown following an incremental model, i.e. by adding new activities to the existing ones. As a consequence, its internal organization has reached a high level of complexity, which increases the risk of duplicating and overlapping some activities. The Council believes that the organizational structure needs to be redesigned and better integrated. This document revolves around the progress that the Council has made over the past year to reorganize the ERA-EDTA into two main branches that may better serve our society in reaching its goals under today's budgetary constraints.

REORGANIZATION AND INTEGRATION OF THE ACTIVITIES OF THE ERA-EDTA

The ERA-EDTA has the full potential to more effectively serve the practicing nephrologists and clinical and basic scientists who form its membership. This goal can be achieved within the present level of financing by reorganizing and integrating the various activities of the society and by extending the application of Web-based meetings. New affordable initiatives to promote research, education and professional development and to advocate for the recognition of chronic kidney disease (CKD) as a major public health issue at the European level need to be put in place and/or potentiated.

Renal epidemiology and evidence-based nephrology

The ERA-EDTA Registry is a spearhead of the Society and the major promoter of epidemiology research and education in nephrology in Europe. Initially having focused on end-stage renal disease (ESRD) only, over the last two decades, the Registry has extended its area of interest from ESRD to CKD and from 2004 onwards it holds first class, itinerant and on-site educational activities that have allowed the formation of several renal epidemiologists in diverse European countries. The educational activities of the Registry have gained worldwide recognition, and the Registry has received invitations to organize courses in South America and in other non-European countries. Members of the staff of the Registry and of the Registry Committee are all respected clinical epidemiologists linked to a vast network extended to national and regional registries, thus forming a powerful resource for data collection and elaboration and for the production of large-breadth documents that may inform prevention and clinical practice. Because CKD is an epidemic phenomenon and a true public health priority, about 10 years ago the ERA-EDTA led the formation of the European Kidney Health Alliance (EKHA), an alliance involving patients' associations and kidney foundations. EKHA has successfully established stable contacts with members of the European Parliament to advance CKD in the public health agenda in Europe. Maintaining a continuous flow of epidemiologic information [4, 5] from European countries towards the Council and the EKHA is important to maximize the effectiveness of the interaction between these two entities and for lobbying with the European Parliament by EKHA. In this respect, the Registry is a natural, robust source of knowledge to be channelled to the Council and to the EKHA Board. To this scope and within the Registry realm, the Council decided to set up an advisory committee focusing on CKD and Public Health to gather and periodically update relevant information for the Council and the EKHA. Information on the dimensions and the evolution of CKD and ESRD epidemiology at European and national level as well as information on kidney care availability and quality is fundamental for the advocacy activities on CKD by the ERA-EDTA and for supporting the lobbying activity of EKHA.

Nephrology and Public Health Advisory Committee.

This is a six-member advisory group aimed at producing periodically updated information to support public health policies aimed at fighting the CKD epidemic. Members of this committee should have in-depth knowledge and experience in epidemiology and public health and should be selected to represent homogeneous areas within Europe. The scope of this committee is to develop proposals for raising awareness on the importance of kidney diseases for public health. The committee is expected to produce a strategic document and comprehensive yearly documents focusing on the epidemiology of CKD and on existing policies aimed at timely identification of CKD and prevention at national level. This document will be published in the journals of the society and amply

diffused via the communication team and the press office.

The European Renal Best Practice (ERBP) is another successful initiative by the ERA-EDTA, which was established in 2008. ERBP stands as an independent advisory organ about Evidence-Based Medicine. As such, ERBP is insulated from external and internal influences and it is funded directly and exclusively by the ERA-EDTA, with no direct contribution from the industry. Over the last decade, ERBP has produced several successful consensus documents and clinical guidelines and gained international standing. Like the Registry, ERBP also has established educational activities. The ERA-EDTA Registry is an obvious relevant partner of ERBP and informal links between these two ERA-EDTA resources already exist. The activities of these two ERA-EDTA organs can be better integrated, from educational activities to evidence-based knowledge production activities. With the proviso that the Registry and ERBP need adequate human and financial resources and internal coordination and leadership, it seems rational that appropriate integration of their activities is established and monitored.

Taking into account the foregoing considerations, the Council decided to group the activities of the Registry and ERBP into a Clinical Nephrology Governance coordination branch of our society. The coordination of this branch will be granted by the chairman of the Registry, who will assume the role of Clinical Nephrology Governance chair. The activities of this branch, including the newly created Public Health Advisory Committee, and its major links with other ERA-EDTA committees, are shown in Figure 1.

Oversight of scientific activities and Scientific Advisory Board

In 2006, the ERA-EDTA created a special Scientific Advisory Board (SAB) whose mission is to enhance the integration of existing kidney research in Europe and to promote translational research in nephrology. The SAB has been key for the selection process and the management of the ERA-EDTA competitive research grants distributed during past years and the SAB chair has always represented this Board in the scientific committee overseeing the annual Congress. Due to limitation in financial resources, 3 years ago, the ERA-EDTA stopped issuing research grants. This *de facto* limited the range of action of SAB to the ERA-EDTA fellowships. To enhance the integration of the ERA-EDTA activities, the ERA-EDTA fellowships will be assigned to competitive research proposals by the Working Groups (WGs). In this perspective, WGs will be asked to propose to the SAB research projects they are pursuing or they intend to start. These projects will be posted in the European Nephrology Portal and linked to the Fellowships call, and young investigators submitting their candidature for an ERA-EDTA fellowship will be asked to identify the project they would like to join. Fellowships will be then awarded on the basis of the achievements and the curricula of the candidates.

Starting from 2019, the undertakings of the SAB will include the advice to the Council about all ERA-EDTA awards, from the Stanley Shaldon award for young investigators to the Senior awards that ERA-EDTA grants on an annual basis. In this respect, whenever needed, the newly established Renal Science chair (see below) will have the possibility of integrating advice by the SAB with advice by high-profile, independent international experts.

The Council believes that facilitating contacts among investigators to allow the building of large breadth, ambitious projects to be submitted to the European Commission and other

funding bodies should be set as a special mission of the ERA-EDTA. This endeavour is already strongly stimulated by the Council via an expanded role of the EKHA for the promotion of research on kidney diseases at the European level.

The creation of several successful WGs has been a fundamental step for facilitating the production of large scientific projects and, apart from WG projects directly funded by the ERA-EDTA in past years, some new WG projects [e.g. a project by the European Dialysis (EUDIAL) WG] have already received adequate external funding by the European Commission or other funding bodies. In the variegated WG scenario involving scientists with disparate interests and priorities, careful oversight and streamlining of the WG activities is essential for the same WG setting internal and external collaborations. An ordered set-up aimed at maximizing efficiency and avoiding duplications is essential in this delicate organizational phase. Furthermore, the several educational activities, including those started by the WG, which flourished both within and outside the Annual Congress need to be declined into appropriate formats and be incorporated into a comprehensive frame covering the full range of the knowledge areas covered by nephrology. In this respect, duplications and inadequacies exist and these should be rectified.

To streamline and consolidate the scientific activities of the Society, the Council has already made key organizational steps.

The role of SAB has been extended to the oversight of the activities of WG and to the conception and coordination of ambitious projects of translational nephrology to be submitted to European Commission and other funding bodies.

The scientific activities, including the SAB, are now grouped into a Renal Science Coordination and Administration branch (see Figure 1 also showing the links of this branch with other committees). A high-profile coordination role overseeing these activities and bridging the Council, SAB, educational activities and the Scientific Committee of the Annual Congress, as well as the related administrative activities, is central to this reorganization. The role of Renal Science coordinator will incorporate the chairmanship of the Administrative office.

This chair will be key for launching a new ERA-EDTA event, the ERA-EDTA Education and Scientific Interaction Day, an event with the double scope of creating an opportunity for face-to-face meetings among investigators of the WG to spur internal and external collaborations and for enlarging the educational portfolio of the ERA-EDTA. This new event may also facilitate contacts between all interested members of the ERA-EDTA and the leadership of WG.

In concert with the SAB, the Renal Science chair will supervise and benchmark the WG activities and will propose criteria for setting a time span and a turnover of the same WG.

In this new organizational set-up, both the Clinical Science and Renal Science chairs will join forces to optimize the integration and collaboration within and between clinically- and basic sciences-oriented WG and will produce a joint document describing their annual action plan. Both chairs will become *ex officio*, non-voting members of the SAB.

Furthermore, to facilitate cross-fertilization of clinical and basic science, a yearly WEBINAR covering themes bridging basic and renal science will be jointly organized by the chairs of the two research branches of the ERA-EDTA.

Education & Continuous Professional Development

For the last 20 years, the ERA-EDTA has funded a rich programme of educational courses, most of which have been externalized at country level to investigators that proposed a

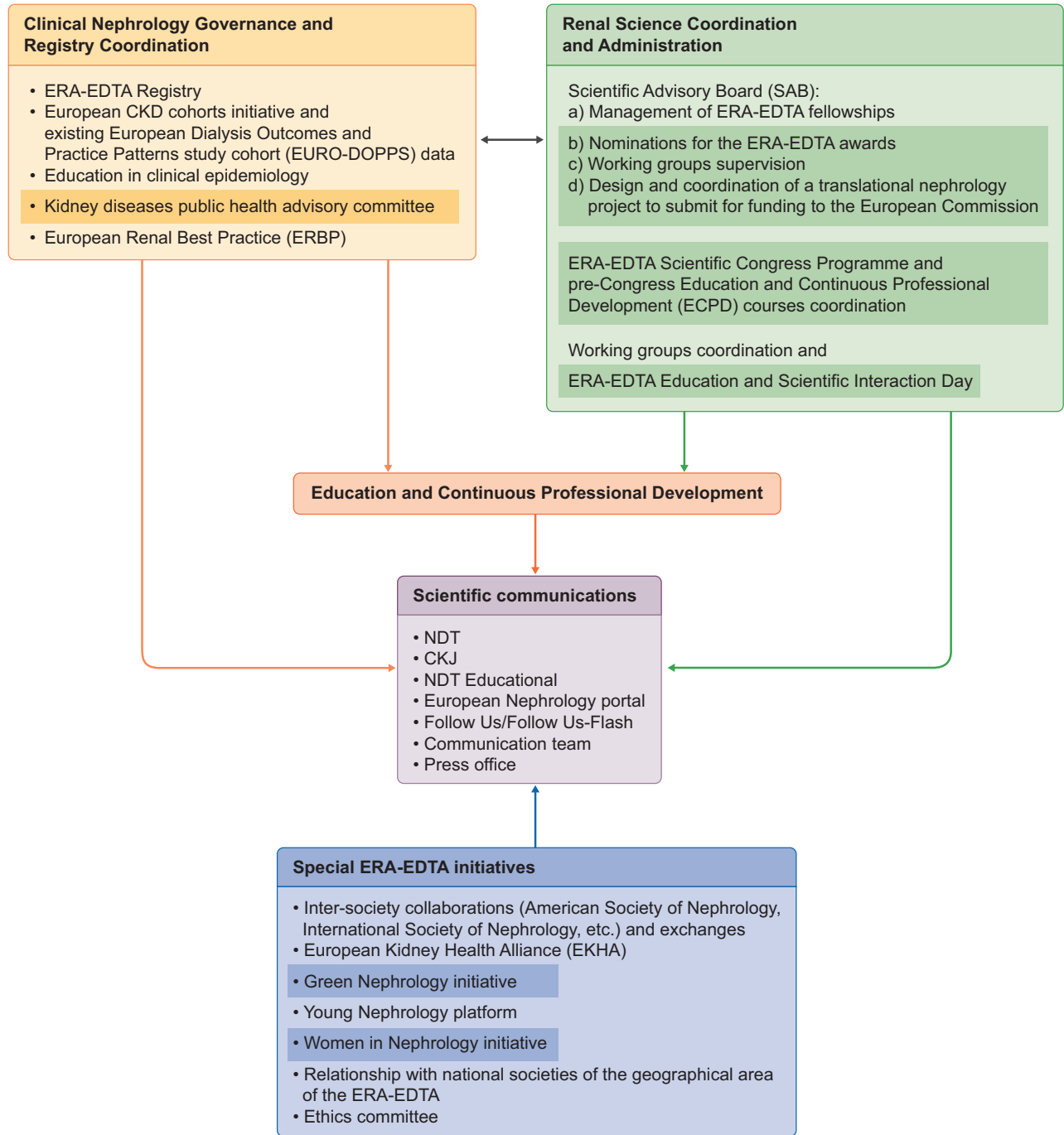


FIGURE 1: The figure shows the new organizational structure of the ERA-EDTA. Homogenous activities are grouped into two branches, the Clinical Nephrology Governance and the Renal Science branch. These two branches will have a strong relationship with the new Education and Continuous Professional Development Committee and with the Scientific Communications team and the press office. EURODOPPS (ERA-EDTA collaboration with DOPPS) is limited to the initial wave of data collection of this collaboration. International relationships, the Ethics Committee and Special ERA-EDTA initiatives, including the Women in Nephrology initiatives and the Green Nephrology Initiatives are directly managed by the ERA-EDTA Council. The new and/or the re-allocated activities are enclosed in rectangles.

programme approved by the Council. Educational initiatives will be now espoused to Continuous Professional Development initiatives and the Education committee is renamed the Education & Continuous Professional Development (ECPD) committee. The programme of ECPD courses will be restructured and simplified, and directly managed by the Society. The first day of the Annual Congress will be dedicated to ECPD courses that will replace courses previously run by the WG. The new

educational activity—branded as ECPD courses—will prioritize themes of fundamental relevance for preparing nephrologists to the challenges posed by the new ‘omic’ technologies and by precision medicine (1: Course on Basic and Transitional Nephrology) and will contemplate yearly updates in all major areas of nephrology (2: CKD; 3: Diabetes, Hypertension and Cardiovascular Disease in CKD; 4: Primary and Secondary Glomerulonephritis, Vasculitis and Auto-immune Diseases; 5:

Bone Mineral Disorders in CKD; 6: Haemodialysis; 7: Peritoneal Dialysis; 8: Transplantation; 9: Genetic Diseases and Rare Diseases; 10: AKI; 11: Electrolytes and Urolithiasis; 12: Nephropathology). These courses will be built up according to a standard format (A: background knowledge recapitulation; B: new studies published during the 2 years preceding the meeting; C: main areas where new studies are needed or are being performed; D: summing up). An additional course on Clinical Epidemiology & Biostatistics, directly run by the ERA-EDTA Registry, will be held along with the other courses. Whenever pertinent, these courses will include a Renal Consult lecture/interaction. All in all, there will be 13 courses, each lasting 4–6 hours. The programme of these courses will be prepared by the courses chairs and co-chairs selected and nominated by the Council on a list of names proposed by the ECPD coordinator and the Renal Science and Clinical Nephrology Governance chairs.

Each course will be filmed and uploaded into the European Nephrology Portal to allow distance learning. Furthermore, the ECPD coordinator will also contact the national societies' chairs to collect information about particular educational needs that can be addressed in Web-based meetings, to be preferentially held in coincidence of congresses of national societies.

To help increase the attractiveness of nephrology to medical students, the Committee will develop a Web-based platform dedicated to medical students to explain the nephrology working scenario and the career and research opportunities. The scenario can be illustrated at the macro-level (Europe) and detailed at the country level. The Web platform will try to attract young students interested in periodic information about nephrology, and an agile, compact, attractive newsletter will be crafted twice a year for these students.

Finally, the coordinator of this committee will be instrumental for the building of an innovative project for Continuous Medical Education in Nephrology to be submitted to the European Commission for funding.

Scientific communications

In 2013, the Council created the communication team, which incorporated NDT, CKJ, NDT Educational, Follow Us and the Press Office. This team, led by the Press Office Chief of our society, has established robust communication channels with all ERA-EDTA organs (see Figure 1) and efficiently produces reports describing the scientific outputs and the achievements of the ERA-EDTA for members of the Association and for the public in general.

In addition to these standard activities, the scientific communication Team will organize a yearly course on 'Education to Scientific Communication' (good medical writing and effective speaking at meetings).

Special ERA-EDTA Advisory Boards and initiatives

These will be under the direct control and supervision of the Council and will include the relationship with other scientific societies (American Society of Nephrology, International Society of Nephrology and other international and national societies) and the Ethics Committee.

Young Nephrology Platform. This platform was started in 2014, thanks to the efforts by the previous ERA-EDTA President, Andrzej Wiecek. The Council decided to further expand this initiative by increasing the involvement of young investigators in

the scientific activities (WG) and in the Annual Congress programme. The WG boards will be enriched by the presence of young nephrologists with a specific interest on the research themes of the same WG. By acting as auditors or as effective members of these boards, young nephrologists may facilitate the involvement of other young colleagues to advance the WG projects. Feasible scientific projects proposed by young nephrologists will be encouraged and supported by the WG chairs. Furthermore, the Young Nephrology Platform (YNP) Board will propose the names of six young nephrologists to be included into the symposia and mini-lectures of the Annual Congress. The same board will prepare and update every year a list of the best 20 young nephrologists in Europe (indicating their main area of expertise) based on publications, academic achievements and scientific awards. After the approval by the Council, this list will be transmitted to the Scientific Committee of the Annual Congress with the specific recommendation to involve as much as possible valuable young nephrologists into the Congress programme.

Women in Nephrology. Women represent a substantial part of the nephrology workforce and over one-third of the ERA-EDTA membership. Among the YNP, over half are women. However, women face peculiar problems in the working environment in medicine [6] and remain insufficiently involved in the activities of our Society. The scope of this initiative is to heighten the contribution of women to the ERA-EDTA undertakings and to increase their involvement and visibility at all levels. By establishing an inclusive policy for the Council and other bodies of our society, national societies will be specifically invited to promote women with adequate curricula as candidates to the Council and other organs of the ERA-EDTA. Furthermore, the Council will pay particular attention to having an adequate representation of women as speakers at the Annual Congress and at other scientific and educational activities of the ERA-EDTA.

Green Nephrology initiative. Healthcare and the environment have a two-way relationship. The environment may adversely affect human health and, in turn, global health care activities may affect the environment. It has been estimated that between 5% and 10% of the global greenhouse gas emissions derive from healthcare activities, including healthcare activities directly connected with nephrology. As expanded in a recent editorial by Blankestijn *et al.* [7], the ERA-EDTA will form a task force to create awareness among ERA-EDTA members of the environmental challenges that we have the ethical obligation to face in the nephrology scenario.

CONCLUDING REMARKS

The ERA-EDTA is the third largest nephrology society on a world scale. Its boundaries reach far beyond the European borders, and it is perceived as a strong, cohesive association in continuous growth, in terms of both membership and the quality of its many activities and initiatives. Consolidation and development should be the mantra of the ERA-EDTA in the short- and medium-term. The society has a rich portfolio of successful activities and brilliant, creative scientists among its members. Integrating the various activities of the ERA-EDTA and treasuring the expertise and wisdom of its most accomplished members will facilitate collaborative research, education and its public impact at large.

The ERA-EDTA is a successful society, and in years of tight budgetary control, it will continue to grow and will serve its

large membership in the European continent and beyond even better in the future.

CONFLICT OF INTEREST STATEMENT

None declared.

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