



EUROPEAN KIDNEY PATIENTS FEDERATION

AGENDA 2020 - 2021



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Work Programme

2020 will be a transitional year for EKPF as we develop a new four-year Action Plan for the period from 2021 to 2024. The plan will continue to reference these key objectives in the current Action Plan:

- ✦ **EKPF Manifesto**
- ✦ **Kidney Patient Involvement and Empowerment**
- ✦ **Prevention and early Detection of CKD**
- ✦ **Choice of treatment promoting Shared Decision Making**
- ✦ **Communications and Engagement**
- ✦ **Governance**
- ✦ **Member Organization**
- ✦ **Social Needs, Protection, Inclusion with Non-Discrimination**
- ✦ **Sustainable Health Systems for All**
- ✦ **Effective and Kidney Patient Centred Research and Regulatory Frameworks.**

During 2020 we will see a refocussing of these priorities as we move towards establishing our Action Plan. The evolution of our strategic pillars set out below will enable EKPF to better purpose our Work Programme based upon a reformulated organisational purpose, mission and vision, which will be developed in partnership with our Member Organisations, supporters and network.

In setting out our Action Plan within the theme of Kidney patient perspective, voice and value we aim to make our Programme to be more accessible, providing an enhanced base to demonstrate impact.

Evolving EKPF Strategic Pillars & Existing Strategic Action Plan Goals

Within the **Kidney Patient Involvement and Empowerment**, the overall aim of EKPF's Policy and Advocacy work continues to bring to the European health policy arena the notion of the kidney patient perspective and to provide such a perspective on areas of health policy and practice relevant to Europe's 500 million citizens and most particularly the 50 million with some stage or Kidney health conditions.



In 2020 we will continue to work on legislative and policy priorities agreed with the EKPF Board and building on the outcomes of the **EKPF Manifesto** with new activity within the field of our statement as Kidney Patients representatives.

Kidney Patient Prevention and early Detection of CKD refers to raise awareness and educational activities undertaken or supported by EKPF to enhance the capacity and capability of patients and patient organisations to exercise their rightful role within the healthcare arena on a local, national and European level.

As key event regarding Prevention and early Detection we celebrate World Kidney Day, where sets out to raise awareness of the high and increasing burden of kidney diseases worldwide and the need for strategies for kidney diseases prevention and management. In addition, **endorsing EKHA (European Kidney Health Alliance)** actions in activities and prevention programs at European level.

Choice of Treatment (Shared Decision Making)

EKPF promotes that Kidney Patient should choose any Kidney Replacement Therapy (KRT) which are Trasplant, Hemodialysis at centre, Peritoneal dialysis or Home Hemodialysis and Conservative Kidney management.

Conservative kidney management (CKM) is a patient-centered package of services for patients with kidney failure who are unlikely to receive a survival and/or quality-of-life (QoL) advantage with dialysis. It rests on shared decision making, involves interventions to delay the progression of kidney failure and minimize complications (including symptom management), and incorporates advance care planning and psychosocial and family support. However, it does not include dialysis.

Moreover, EKPF promotes **increase living donor trasplantation** as important treatment option for end stage renal disease. But, living donor kidney trasplant activity has stagnated in many parts of the world.

Acceptance criteria for living donation vary, despite excellent guidelines and recommendations available in many countries. Recent reports emphasized a growing relative risk for developing renal failure in kidney donors compared to healthy non-donors. Physicians are therefore cautious to accept living kidney donors with hypertension, diabetes, HIV, and kidney stones.

With correct identification, follow-up and care, **living donation should be acknowledged as safe and effective for donor and recipient.**

Nowadays, **Home-therapies are underused in the major part of the countries.** Thus, EKPF commiment is to adapt the RRT to people lives, not the lives to the treatment.



Shared Decision Making (SDM) ensures that individuals are supported to make decisions that are right to them. It is a collaborative process through which a clinician supports a kidney patient to reach a decision about their treatment.

SDM is a process in which people who experience a change in their health work together with clinicians to select tests, treatments, management or support packages. **EKPF should promote create effective tools for SDM.**

Communications and Engagement

Effective communication is central to all aspects of the work undertaken by EKPF. The 2020 EKPF communications Plan will be developed to support each of the Action Plan in a manner that enables effective communication and engagement.

For 2020 our Workplan will additionally focus on ensuring that our communication outputs are provided in English to enable a greater number of our partners, stakeholders and the wider European Kidney patients population to be able to use.

In 2020 EKPF will focus on continuing delivery of high-quality communications products.

EKPF will focus its communications effort in:

- **Developing a new EKPF website** in order to better align it to the current organisational strategy as well as to improve its accessibility www.ekpf.eu
- An Impact Statement publishing our **EKPF Manifesto**
- **COVID-19 Resource point**
- **European Map membership** with all EKPF members
- **Videos** to be uploaded on our section EKPF TV.

Governance

Effective governance is core to everything we do at EKPF. Since our inception we have continually worked to improve the way in which we operate EKPF, and are committed to **transparency** and **independence** in all aspects of our work in accordance with our actions and resources for working with funding partners. In keeping in line with our commitment to transparency, all financials pertaining to EKPF are available on our website.

During 2020 we will seek to utilise, further develop and enhance the way in which we are governed and the way in which we operate. Principal areas include:

- **THE 2020/21 ANNUAL GENERAL MEETING**
will focus on our action plan and publish our EKPF Manifesto
- **CONSOLIDATION OF THE NEW EKPF EXECUTIVE BOARD**
investing in team development activities aimed at helping to ensure that the EKPF Board and are best able to work together.



Member Organisations

EKPF members are at the core of everything we do. They are the legitimacy of EKPF, and they shape the strategy and the priority of our organisation. EKPF's membership has grown considerably to 24 members in 2020.

Our objective is to welcome all legitimate Kidney patients organisations to reinforce our collective disease and geographical representativeness.

To achieve this objective, in 2020 we will undertake the following actions:

.- Contacts with potential new members: EKPF will constantly update the map/list of potential members, based on the 2020 EKPF membership mapping.

.- Supporting emerging national coalitions: national coalitions play a crucial role in monitoring understanding and reacting to, as well as influencing national health policies. They are a vital partner in cascading messages to the grassroots. Strengthening their capacities adds value for the targeted countries and for EKPF. In 2020, EKPF will continue to support national coalitions through training and exchange of best practices.

.- EKPF aims at both gaining new members and to enhance the engagement of existing ones. We will continue to improve our tools to promote interactions between the EKPF Executive and EKPF members, with the objective of being as clear, efficient and inclusive as possible in our internal communications.



Patient Perspective

Traditionally termed policy and advocacy, our Kidney Patient Perspective work covers domains central to ensuring that European health policy and practice meaningfully account for the patient perspective.

During 2020 we will continue with a range of existing work streams, instigate others having discontinued those which are no longer a priority or where their activities have come to a natural end.

There will be a focus on building on the outputs from our EKPF Action Plan and Manifesto, with an activity programme being developed during January 2020 and January 2021.

Engagement Framework

With a new European Parliament and a new European Commission, EKPF will continue to build our network from which we are able to represent our Members and the wider European Kidney Patient community.

✦ EUROPEAN PARLIAMENT

EKPF should have a strong profile in the European Parliament through EKHA (European Kidney Health Alliance) and EPF (European Patients Forum), which we continue to strengthen and build upon, focussing in particular to involving new MEPs and developing an engagement strategy closely with the new Parliament.

Policy Activities

For 2020 and 2021 we will continue our focus on certain core areas, introduce new areas and conclude or set others aside. Our programme will focus on the following policy areas:

✦ PATIENT SAFETY

We will re-launch our work on patient safety following the adoption of a WHO resolution on patient safety in 2018 and the establishment of an official Patient Safety Day (17th September)

Building on the outcomes of the EKPF Action Plan, our work will focus on advocacy for greater recognition of the important role of patients and family members in the area of safety and on providing information and education on patient safety topics, such as healthcare-associated infections.



ANTIMICROBIAL RESISTANCE

Given the far-reaching implications of antimicrobial resistance for healthcare and especially for patients, EKPF will continue to address AMR as part of our policy and information and communication activities, developing a fact sheet on AMR.

We will aim to further develop our collaboration with the ECDC and WHO and continue as a stakeholder partner in the EU Joint Action.

✦ QUALITY OF CARE

Building on work done to date we will continue to engage with policymakers, international organisations such as WHO and OECD, and with other stakeholders to improve quality of care. Engagement with discussions around value-based healthcare, patient-centredness, patients' priorities, and patients' involvement.

✦ SOCIAL NEEDS, PROTECTION, INCLUSION WITH NON-DISCRIMINATION

Building on our work on non-discrimination in healthcare, education and employment, we will consult with our membership to identify patients' priorities in this area where further advocacy is needed, e.g. in terms of social support and rights.

Sustainable Healthcare Systems for All

Access and inclusivity will continue to be a core priority also in 2020. Priority areas will include:

✦ ACCESS TO HEALTHCARE

EKPF will continue to focus on access to healthcare from the patients' perspective based on our work to date, including the definition of access, and in consultation.

We will aim to collect further patients' evidence on access barriers in collaboration with other stakeholders where relevant, and address these barriers using policy instruments such as the European Semester, the UN Sustainable Development Goals, and the European Pillar of Social Rights.

✦ PROJECTS



Artificial Inteligence for Kidney

Call Information Call Identifier: SC1-BHC-06-2020 Topic: Digital diagnostics – developing tools for supporting clinical decisions by integrating various diagnostic data RIA – Research and Innovation Action EU Funding: 8 to 15M Euros (total 40M€) Closes: 7th April 2020

<https://ec.europa.eu/info/funding-tenders/opportunities/portal/screen/opportunities/topic-details/sc1-bhc-06-2020>

Introduction:

Cardiovascular disease (CV) is the main cause of morbidity and mortality in the general population. The approach to identifying cardiovascular risk or mortality recommended by the Clinical Guidelines is based on known risk factors that are included in most predictive models but presents significant limitations in clinical practice. An essential part of the population escapes their identification or receives unnecessary preventive treatment. In parallel, chronic kidney disease (CKD) and especially hemodialysis, which is an epidemiological problem, is closely related to cardiovascular risk and both potentiate each other, leading to high CV pathology and mortality.

CV and mortality risk models implicitly assume that each risk factor is linearly related to events, oversimplifying what are really complex relationships that would include a huge amount of risk factors, which would also have non-linear relationships. Therefore, approaches that incorporate multiple risk factors and that identify real relationships are needed. Machine-learning (ML) offers an alternative. It is based on computational methods that detect complex and non-linear interactions between variables and identify latent variables that are unlikely to be directly observed. There is no validated experience in the study of these risk factors in the CKD. On the other hand, the evolution of chronic kidney disease has other associated risk factors that generate multiple complications that make it difficult to predict both the progression of the disease itself and the appearance of such complications. ML could also offer the development of predictive models of the course of the disease. The objective of the project is to develop advanced analytical tools (e.g. ML algorithms based on neural networks) that will integrate various data sources and could establish risk predictive models of the evolution of CKD, CV disease and mortality to increase precision of diagnostic and clinical decision making. Entity: Fundació Parc Taulí (FPT) is an entity created in order to promote and manage the biomedical teaching, training, and research by healthcare professionals from the Consorci Corporació Sanitària Parc Taulí (CSPT). AS a strategic objective, FPT provides researchers with facilities for basic research, assistance in search of funds for scientific and medical research, as well as valorises the technology and research results generated by the CCSPT professionals and transfers them to the society by transforming the medical scientific findings into useful products. FPT's Clinical and Computational Nephrology Group proposes to create and coordinate a H2020 proposal into the development of advanced analytical tools for treatment of CKD and CV.



Participant organisation name

- 1 (Coordinator) Corporacio sanitaria Parc Tauli de Sabadell, Barcelona (CSPT) Spain
- 2 Universitat Autònoma de Barcelona (UAB) Spain
- 3 DXC Technology Spain
- 4 Mario Negri Institute Italy
- 5 University of Bergamo, Biomedical Engineering Italy
- 6 University of Patras (UPAT). Department of Electrical and Computer Engineering Greece
- 7 Universitat Internacional de Catalunya (UIC) Spain
- 8 Port d'Informació Científica Spain
- 9 Bergamo Hospital, Nephrology Unit Italy
- 10 Wrocław Medical University Poland
- 12 Belgrade Serbia
- 13 Uppsala University Sweden

EKPF ensures the effective dissemination in the AIKIDNEY consortium, boasting 13 partners, made up as associated members countries of patient organisations (members of EKPF), hospitals, Universities, Institutes that aims to co-create a framework enabling sustainable, ethical, meaningful and systematic patient engagement in AI , Big Data and Machine learning to prevent CardioVascular Disease.



VASCULAR ACCESS MANUAL FOR PEOPLE WITH KIDNEY DISEASE

It is well known, Vascular Access is crucial in kidney disease and hemodialysis treatments.

Last 2017, The Spanish Society of Nephrology has published the Guidelines of Vascular Access (VA) for Hemodialysis for health professionals (see attached). Nowadays, is state of the art related to VA, one of the best international guidelines of VA with a lot of reviews and publications.

In Spain, They decided 2 years ago to resume and adapt the technical language of the VA clinical guidelines for professionals for people with kidney diseases, and create a Manual of Vascular Access for kidney patients (In Spanish), aiming to facilitate the importance of VA in quality of life and survival of people. This Manual of VA has been revised by a multidisciplinary team with Nephrologists, Nurses, Radiologists, Surgeons and Kidney Patients.

EKPF will endorse and translate to English the first Manual of VA for kidney patients in Europe. It would be our first project as entity. Spanish kidney patient's association (ALCER) with GEMAV and ADER have done the adaptation for Spanish kidney patients, but we would translate it in English, to spread it across Europe and worldwide. In addition, the Manual of VA has 9 original videos for better understanding.



PANACEA (imProving clinical mANagement of pAtients with CKD using rEal-world dAta)

The PANACEA project aims to improve the identification and clinical management of chronic kidney disease (CKD) using Real-World Data (RWD) from European healthcare, registries and cohorts. PANACEA will use this wide range of RWD to map the patient trajectory from primary to specialist care in different health settings, and investigate key aspects such as multi-morbidity, drug safety and patients' quality of life, using both standard statistical and machine learning (ML) methods.



CORDIAL (Clinical validatiOn of a continuous flow peRitoneal Dialysis system dIaLysate regeneration)

Goal of the project is to validate a novel system for continuous flow PD in an FIH trial and crossover clinical trial. Proof of concept of safety and efficacy has been obtained in extensive in vitro and in vivo (in rodents, pigs) evaluation. Preclinical research has been completed. Prototype systems have been tested in pigs and are ready for use. Patient selection and recruitment plans have been set-up with input from patients and patient organisations.



Conclusions

EKPF is very proud of our Agenda as a document that sets out our ambition and purpose in a readily accessible form. We use it for communication with our Executive Board, Organisational Members, Supporters and stakeholder network.

We also use it internally to develop our projects and goals, to manage and report on activities that we undertake. It is therefore a living document, which is likely to undergo revision and adaptation at an operational level throughout the year. Yet it remains the central plan that connects our Action Plan to our operations and then onto our evaluation and review process.

We thank you very much for taking the time to read through our Action Plan and for the Contribution that you have made directly and indirectly to support its development.

If you have further thoughts or reflections, then please do not hesitate to get in touch.



EKPF 2020 KEY EVENTS

Please note this schedule is tentative and does not include all events

| March | Place |
|---|-------------------------|
| EKHA Forum 2 nd and 3 rd | Brussels |
| World Kidney Day 12 th | All countries |
| April | |
| EPF General Assembly 25 th | Video |
| May | |
| EKPF Executive Board meeting 6 th | Video |
| June | |
| EKPF Executive Board Meeting 10 th | Video |
| World Kidney Cancer Day 18 th | All countries |
| July | |
| EKPF Executive Board Meeting 8 th | Video |
| September | |
| Atypical Hemolytic Uremic Syndrome Day 24 th | All countries |
| EKPF Executive meeting | Video |
| Patient Safety Day 17 th | All countries |
| ADPKD World days 26 th and 27 th | All countries |
| October | |
| EKPF General Assembly 1 st and 2 nd | Schiphol (Amsterdam) |
| European Day for Organ Donation and Trasplantation 10 th | All countries |
| December | |
| EKPF Executive meeting | Video |



EKPF 2021 KEY EVENTS

Please note this schedule is tentative and does not include all events

| March | Place |
|---|---------------|
| EKHA Forum | Brussels |
| World Kidney Day 11 th | All countries |
| April | |
| EPF General Assembly | Brussels |
| May | |
| EKPF Executive meeting | Video |
| June | |
| EKPF Executive Meeting | Video |
| World Kidney Cancer Day 18 th | All countries |
| August | |
| ESOT 29 TH | Milan |
| September | |
| Atypical Hemolytic Uremic Syndrome Day 24 th | All countries |
| EKPF Executive meeting | Video |
| Patient Safety Day 17 th | All countries |
| ADPKD World days 26 th and 27 th | All countries |
| October | |
| EKPF General Assembly | To be Defined |
| European Day for Organ Donation and Trasplantation 10 th | All countries |
| December | |
| EKPF Executive meeting | Video |