2019 - 2024

EKPF
EUROPEAN KIDNEY
PATIENTS' FEDERATION

CEAPIR

Action Plan

How we can achieve our challenges

Action Plan 2019-2024

01 **Primary Topics**
The topics were agreed during the previous meetings cover the key areas of action needed to improve care for people with kidney diseases.

02 **Goals**
There are goals per priority area depending on the topic. The goals were formulated in a SMART way.

03 **Actions**
Design of actions to achieve the objectives. Initially, those that are implemented in 2019 are proposed, budgeting them.

04 **Schedule**
Programing actions with defined tasks and participants, as well as defining deadlines and evaluation.

05 **Evaluation**
Programming of outcomes analysis systems to implement timely correction measures and dissemination of results.

EKPF
EUROPEAN KIDNEY
PATIENTS' FEDERATION
CEAPIR

01. Primary Topics

Prevention and Early Detection
- Focus on high risk groups
- Promote healthy habits
- Decrease incidence of CKD

Choice of Treatment
- Information for all possible treatments
- Adapted learning styles.
- Real choice (SDM)

Increasing Access Transplantation
- Promote access in all Countries
- Education and information general population
- Overcome living donation barriers
- Promote best practices
- Support for the EKHA goals

Treatment Reimbursement Strategies
- Adequate reimbursement policies
- Funding models whithout barrier for shared decision making.
- Reimbursement strategies cover new models of RRT

Self-caring and patient empowerment
- Promote access in all Countries
- Education and information general population
- Overcome living donation barriers
- Promote best practices
- Support for the EKHA goals

Promoting the Research in Kidney Diseases
- Introduce renal research in EU priorities
- Promote PROMs and PREMs in clinical trials
- Demand patient vision in research design

Social Needs, Protection and Societal Participation
- Increase in social services
- Improve access to employment
- Information for social aspects adapted to people with CKD
- Patients have time to consult with their families and be trained in time

02. Goals

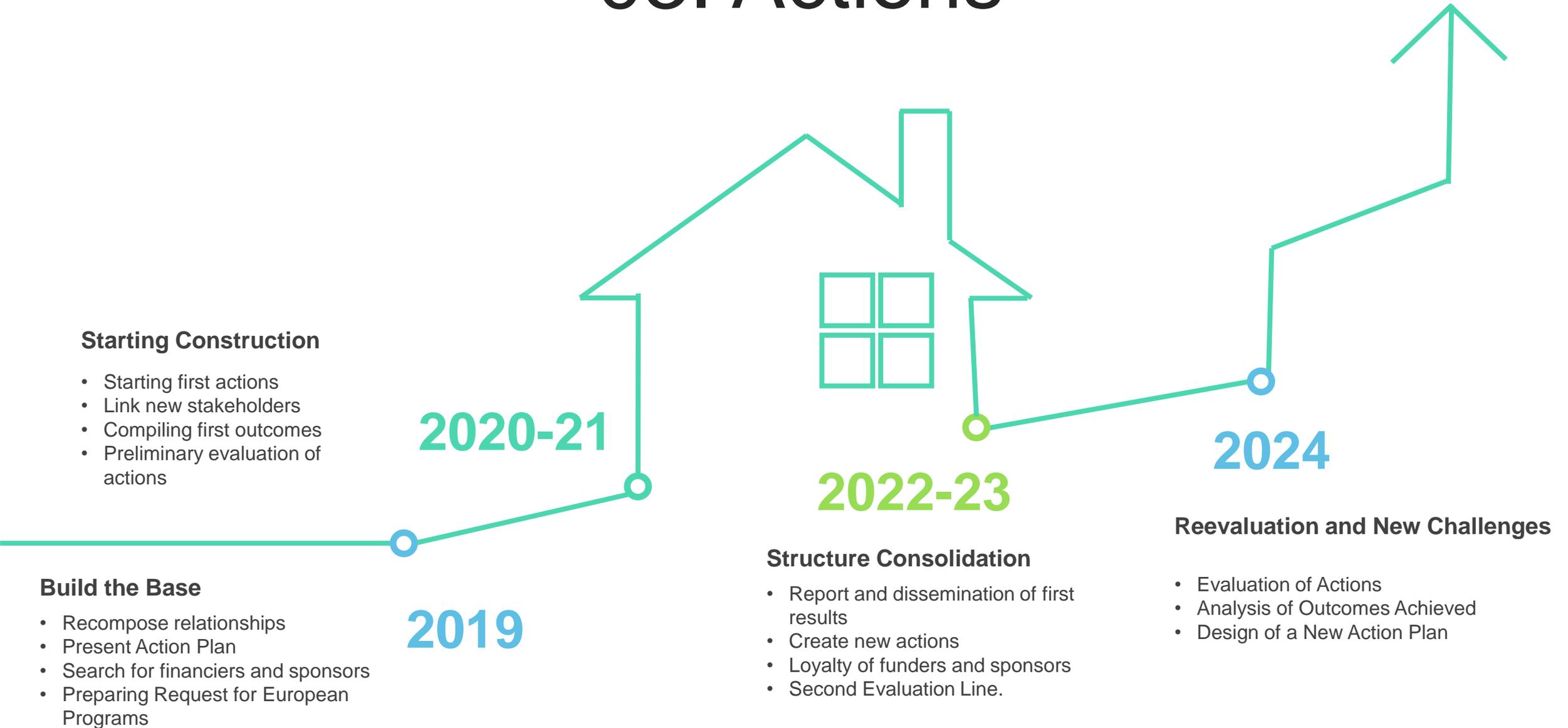| SMART Definition	Prevention and early detection	Choice of treatment	Increasing access to transplantation
Specific	Focus on CKD in high risk groups and measurement and registration of kidney function	The principles of SDM summarized in 'Ask 3 questions' are all over Europe introduced and used http://personcentredcare.health.org.uk/resources/ask-3-questions-materials	Start an ERA-EDTA registry on living and post mortem kidney donation and transplantation together with QoL scores; also include the waiting time and pre-emptive transplantation as indicators of how accessible transplantation is, to set a model/goal for best practice.
Measurable	The inflow of new CKD patients slow down or reduces (item for ERA-EDTA to register Europe wide)	In every country a large scale campaign on SDM and ask 3 questions in hospitals	The set up of this registry and the compliance of every country to deliver the data is the key to change. The survey now (EDITH) is a good starting point but not enough. Continuity is important.
Acceptable	Prevention is a very cost-effective way to lower the overall health costs;acceptance is also needed by GP's as gatekeepers	SDM as a concept is worldwide accepted. There is limited experience with implementation. This broader acceptance is needed before we can talk about all the options in Kidney Replacement Therapy (RRT)	ERA-EDTA already have a good registry and good connections to all European countries. There is now the EDITH project: *Aim of this survey is to learn from your experience in providing dialysis, kidney transplantation and comprehensive conservative management, including potential barriers and facilitators for these treatments.* EKPF is via Marc Murphy already involved in the EDITH project but a more extensive and bilateral contact is needed. It's already pending.
Realistic	Focus on high risk groups (elderly, diabetics, high blood pressure, obesity)	The UK and The Netherlands proved that it's possible with the wright stakeholders to introduce it and start implementation	
Time specific	Within 5 years kidney function is every year measured for high risk groups and known by patient and GP	The introduction and implementation will take 10 years, so let us focus on the introduction in every European country in the next 5 years	The EDITH project is for a period of 2017-2020

02. Goals

SMART Definition	Self-care and patient Empowerment	Treatment Reimbursement Strategies	Social needs, protection and Societal Participation
Specific	Exchange of good programs	Collect data on RRT reimbursement strategies and accessibility for CKD patients on a European level	Collect data on CKD patients participation in payed jobs
Measurable	At least from 4 countries good examples of programs they use	Develop a model/structure to compare the different RRT and the different countries	Develop a model/structure to compare the participation rate in the different countries
Acceptable	It's already done in some countries and we can support and learn from each other	It can be difficult to collect these data. What are the real costs? What is the difference between the real costs and the reimbursement for the different modalities? Are these figures public? Let's us ask MEP's to make a real issue of this.	Report: "*communication from the commission to the European parliament, the council, the European economic and social committee and the committee of the regions European disability strategy 2010-2020: a renewed commitment to a barrier-free Europe*" In this document: *This Strategy focuses on eliminating barriers9 . The Commission has identified eight main areas for action: Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health, and External Action.*
Realistic	It can be a part of the EKPF website if we host and maintain it in a proper way	If we can collect some data to convince the MEP's to start an investigation by the EP or to motivate for instance the European Consumers Organization to do this https://www.beuc.eu/	Only for CKD patients this issue is not realistic to get it on the agenda.
Time specific	Within 2 years there must be a prototype	This research topic will take time, at least three years	This a long term challenge, with actions that will produce outcomess later than the period 2019-2024

02. Goals

SMART Definition	Promoting the Research in Kidney Diseases
Specific	Include research on kidney diseases among EU priority programs
Measurable	Number of EU-funded research in the field of kidney diseases. Number of countries with research patient training program Number of investigations including PROMS and PREMS among their results measurements
Acceptable	Achieve al least a working group with the societies involved (preferably EKHA) to put pressure on it at EU Level At least 4 countries working to train renal patients to offer their perspective in the design of clinical trials.
Realistic	Join the Patients´ Academy (EUPATI) to train kidney patients. Join EKHA to demand funding for research at EU level
Time specific	Within 5 years there must be appropriate to achieve

03. Actions

Starting Construction

- Starting first actions
- Link new stakeholders
- Compiling first outcomes
- Preliminary evaluation of actions

2020-21

2019

Build the Base

- Recompose relationships
- Present Action Plan
- Search for financiers and sponsors
- Preparing Request for European Programs

2022-23

Structure Consolidation

- Report and dissemination of first results
- Create new actions
- Loyalty of funders and sponsors
- Second Evaluation Line.

2024

Reevaluation and New Challenges

- Evaluation of Actions
- Analysis of Outcomes Achieved
- Design of a New Action Plan

03. Actions

01 Prevention and Early Detection

Internal coordination
This is maybe more an issue for Kidney/health Foundations, for instance the DKF. Ask them to coordinate and report to the EKPF and EKHA.

Ask them to give an overview of programs in the different countries that already exist and that every country can use to put pressure on this topic.

External stakeholders
Kidney and other healthcare foundations; Ministries of health; EU program on healthy aging (http://www.healthyageing.eu/?q=european-policies-and-initiatives); EKHA

02 Choice of Treatment

Internal coordination
One of the leading countries in SDM; connecting to EPF and the EU MEP's

External stakeholders
Ministries of health; federation of patient organisation; federation of medical specialists; European Patient Federation

03 Increasing Access Transplantation

Internal coordination
One of the countries that can benefit most from increasing access to transplantation, probably together with The Netherlands because ERA-EDTA is located in Amsterdam.

External stakeholders
EKHA; the individual parliaments in every country; European reports on organ donation

(https://www.nierstichting.nl/media/filer_public/72/cd/72cd8d9a-7c7f-46b5-b98d-10c6e7d5fa0f/201705-nierstichting_rapportorgaandonatie_int.pdf – in Dutch)

ERA-EDTA and the EDITH project

03. Actions

04
Self-caring and Patient Empowerment

Internal coordination
The secretary of the EKPF looks for resources to build a platform or sees how to collaborate with the EPF for exchanging good practices and for money to translate these programs in English and other European languages.

External stakeholders
EPF (http://www.eu-patient.eu/campaign/access-to-healthcare/5-areas-of-actions/); industry for kidney specific subjects;

05
Treatment Reimbursement Strategies

Internal coordination
Report of the barriers produced by the reimbursement strategies in the different countries and promotion of European directives that promote equal rights

External stakeholders
http://www.eu-patient.eu/campaign/access-to-healthcare/
http://www.eu-patient.eu/About-EPF/workinggroups/working-group-on-access-to-healthcare/

06
Social Needs, Protection and Societal Participation

Internal coordination
Social Protection Report in the EKPF countries, share projects and good practices.

Apply for European funds to promote programs that meet social needs or correct deficits

External stakeholders
http://www.eu-patient.eu/
http://www.edf-feph.org/employment

03. Actions

07

Promoting the Research in Kidney Diseases

Internal coordination

The secretary of the EKPF looks for resources to build a platform or sees how to collaborate with the EPF for exchanging good practices and for money to translate these programs in English and other European languages.

External stakeholders

EKHA, to implement join actions http://ekha.eu/policy/eu-policy-areas/kidney-health/

EUPATI, to obtain their support in training, and to promote PROMs and PREMs (www.eupati.eu)
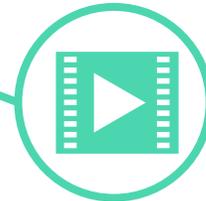
03. Actions 2019
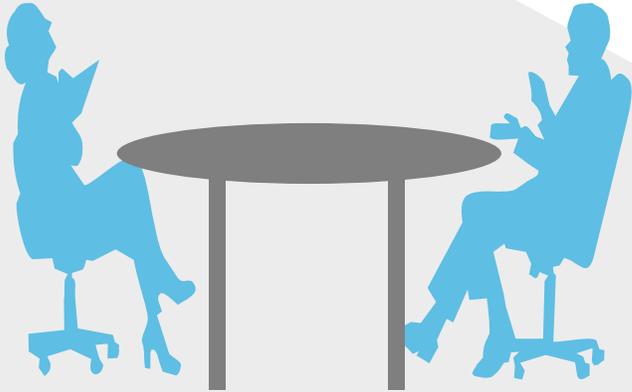
- Update EKPF documentation
- Disseminate Action Plan among all partners and seek alliances
- Define tasks and distribute among leaders
- Define deadlines and form of membership fees

- Fulfill the EKHA membership fee
- Showing the Action Plan to EKHA Board
- Presenting the Action Plan to EKHA Forum
- Contacts and meetings with possible sponsors and funders

- Renew and update website www.ekpf.eu
- Creating and energizing EKPF social networks (facebook, twitter and instagram)
- Disseminating and energizing the online Action Plan (web and social networks)

- Presentation of the Action Plan to EU Policymakers
- Preparing Requests for European programs
- Starting Design for common campaigns (World Kidney Day, European Organ Donor Day, etc.)

04.Schedule

June 2019

Building a New Way

- Reconstruction EKPF and New Board
- Definition Action Plan, Participants and Tasks

October 2019

Starting the Job

- Update EKPF documentation
- Disseminate Action Plan among all partners and seek alliances
- Define tasks and distribute among leaders
- Define deadlines and form of membership fees

December 2019

- Presentation of the Action Plan to EU Policymakers
- Preparing Requests for European programs
- Starting Design for common campaigns (World Kidney Day, European Organ Donor Day, etc.)

2018

Beginning of Contacts

- First meetings (Bussum-Brussels-Madrid)
- First proposals and Draft Action Plan

June-September 2019

Update Alliances

- Fulfill the EKHA membership fee
- Showing the Action Plan to EKHA Board
- Presenting the Action Plan to EKHA Forum
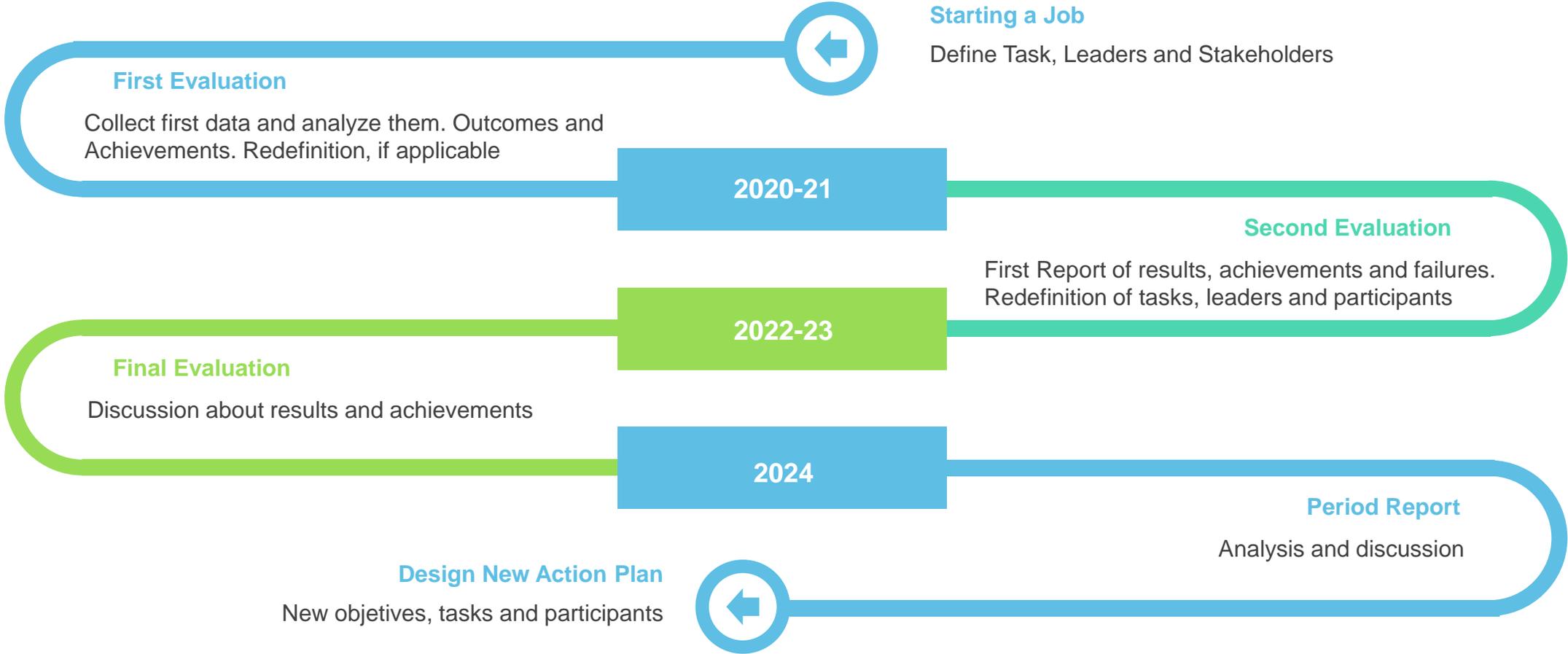- Contacts and meetings with possible sponsors and funders

November 2019

Communication and Dissemination

- Renew and update website www.ekpf.eu
- Creating and energizing EKPF social networks (facebook, twitter and instagram)
- Disseminating and energizing the online Action Plan (web and social networks)

05. Evaluation

Starting a Job

Define Task, Leaders and Stakeholders

First Evaluation

Collect first data and analyze them. Outcomes and Achievements. Redefinition, if applicable

2020-21

Second Evaluation

First Report of results, achievements and failures. Redefinition of tasks, leaders and participants

2022-23

Final Evaluation

Discussion about results and achievements

2024

Period Report

Analysis and discussion

Design New Action Plan

New objetives, tasks and participants

05. Evaluation (2019)

Starting the Job
- Completed tasks
- Contacts Achieved
- Countries Involved

Add Communication and Dissemination
- Number of Visitors to the Web
- Friends on Facebook
- Followers on Twitter

Update Alliance
- Number of alliances to the Action Plan.
- Funders and Sponsors

Lobby Actions
 Response of the EU Policymakers
 Number of Campaign Impacts

Starting the Job

Communication

Updating Alliances

Add Contents

2019

Action Plan