



European Kidney Health Alliance

Survey of National Organisations

Results

Bringing value from EKHA's EU work to national level



Survey to understand needs of national societies

- Online Survey of EKHA national associations
- Focus on national priorities
- Open September - December
- **37 Responses**



Goal: Build a strategy for national advocacy

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Questions



- Is your association **involved** in national health policy-making ?
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- Do you feel **your association's voice** is heard by those in charge of your national health policy?
- Has your association ever engaged in **advocacy activities or campaigning** targeting health policy-makers at national level?
- What is the most **desired outcome** an advocacy programme could deliver in your country to address the current challenges encountered by the renal community?
- What do you perceive as being **the top 3 major issues** -- whether they are obstacles or opportunities -- for the renal community **in your country**, including patients and health care providers, in the coming two to three years?
- What are **the 3 major issues that your association** -- whether they are obstacles or opportunities -- intends to focus on in the coming two to three years?
- Are you aware of **EKHA's advocacy activities at EU level**?
- Do you feel **EKHA's work could be helpful to your association** in terms of prioritising the needs of the renal community on your country's national health policy agenda?
- Do you have **any suggestions** on how you think EKHA could build or strengthen collaboration with your association ?

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Involvement in National Health Policy-Making

✓ **27 out of 37 (73%) are involved in policy-making**



Examples of involvement with national policy

- Opinion-leaders sit on advisory boards or committees on the national level
- Contribute to NICE guidelines relating to anaemia of chronic kidney disease.
- Sit on Advisory boards for pharmaceutical companies and research
- Provide position statements, recommendations, consultancy in a case of drug indication regulations, good clinical practice definitions, pricing constructions
- Participation in working groups (national policies on kidney transplantation, dialysis, treatment of MBD, renal anemia, etc.)
- Presentation of data from national registry to Ministry of Health
- Input to national programme on prevention of CKD

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Desired Outcomes from Advocacy Activities

Increased Stakeholder Collaboration

- Increased cooperation with the patient organisations – to speak to the policy-makers with a united voice
- Closer collaboration with Primary Care
- Collaboration with other stakeholders on anti-smoking, restriction of salt and diabetes control campaigns
- Collaboration on organ donation campaigns to increase participation in donation schemes

Improved Patient & Public Awareness

- Routine screening in high-risk patients, secondary prevention programmes
- Increased the public awareness about importance of kidney health
- Education programme for pre-dialysis/pre-transplantation patients

Funding & Better Access to Care

- Increased funding for research
- Increased reimbursement of costly treatments
- Funding for educational programs in CKD prevention
- Recognition and funding for advance competence in Nursing care



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Key Issues for the Renal Community in 2014

Direct Influence on National Health Policy

- Help health policy-makers understand the severe consequences of CKD and RRT (quality of life + productivity, socio-economic aspects)
- Implement a national programme for prevention of CKD/ Funding for research in CKD prevention
- Increase funding available to renal replacement therapy / reimbursement

Improve Standards of Care

- Continuing to provide a high standard of care within a financially challenging environment
- Implementation (and reimbursement) of a structured national screening programme
- Peritoneal dialysis vs. Haemodialysis – best choice of treatment
- Empowering patients with CKD to self care

Increase Organ Donation & Transplantation

- Increase organ availability, implement national donor policy
- Improve access to waiting list
- Increase of pre-emptive transplantation



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Awareness of EKHA activities & desire to collaborate



- ✓ **58% are aware of EKHA's activities**
- ✓ **80% feel that EKHA's activities can support their national objectives**

'Wish list'

- Sharing information of common needs in renal care across EU countries
- Help preparing recommendations for our national health system - particularly in the issue of cost-effectiveness
- Contact at national level / national coordinator who acts as liaison with EKHA board
- Dissemination of experience of other countries / Sharing of best practices
- Representation in national educational programmes, at national meetings
- Templates of recommendations and letters to national health authorities
- Regular news about EKHA activities

Bringing value from EKHA's work to national level



Areas of shared interest: Ideas for Action

1. Increased Stakeholder Collaboration

- **Idea:** Facilitate EKHA-model of collaboration at national level (nurses, nephrologists, and patient groups advocating together)

2. Increase National Participation

- **Idea:** Increase Associate Membership and establish national EKHA liaison in each country to increase communication and understanding of the issues at national level

3. Sharing of Best Practices

- **Idea:** Create catalogue of best-practice in Europe: prevention programmes, organ donation & transplantation access, national guidelines implementation, cost-effectiveness studies, screening and secondary prevention programmes, etc

4. Research Group Coordination

- **Idea:** EKHA can act as coordinator to put together research consortia based on shared goals





Thank you!

