

ESW | **Patient
Advisory
Group**

**A Strategy for 2019
and Beyond**

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ESR Patient Advisory Group
A Strategy for 2019 and Beyond



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ESR Patient Advisory Group - A Strategy for 2019 and Beyond

The ESR Patient Advisory Group (ESR-PAG) was established in 2013 to bring together patients, the public and imaging professionals in order to collectively address and leverage developments in the field of radiology. The ESR-PAG advocates for a patient-centred approach in the activities of the ESR with the aim of benefiting patients across Europe. The ESR is the first medical specialty to successfully launch a professional-patient body that gathers patient representatives from various disease-specific fields.

Key action points:

- The ESR-PAG seeks to enhance its membership to advocate for a patient-centred approach within radiology across Europe and to maintain a close alignment between professionals and the patient community.
- The ESR-PAG strives for enhanced visibility at the annual European Congress of Radiology (ECR) to emphasise the crucial role of patients in the ESR's activities.
- The ECR serves as an excellent forum for patients to address topics that are key to the patient-professional relationship and which pay reference to new developments in patient care.
- The concept of value-based healthcare should urge the ESR-PAG to actively bring forward the patient perspective in discussions on the value of imaging to the patient within the ESR and affiliated publications.
- The ESR-PAG will launch concrete initiatives to raise awareness for radiology within the wider patient community to achieve more targeted patient representation and to precise the role of radiologists to the public.
- In the short term, the ESR-PAG seeks a more active role in ESR activities to better reflect the patient perspective in ESR publications and scientific statements to the benefit of patients' understanding of radiology.
- To conclude, the ESR-PAG should become a group of committed patient advocates aimed at strongly embedding the patient perspective within radiology in full collaboration with the ESR.

Achievements to date:

- The ESR-PAG has continued to play a prominent role in shaping ESR activities since its establishment in 2013.
- The ESR-PAG has contributed to the ESR flagship radiation protection initiative "EuroSafe Imaging" by offering input on topics in relation to patient safety and quality of care. A patient representative is included in the EuroSafe Imaging Steering Committee.
- Dedicated patient sessions at the European Congress of Radiology (ECR) provide a platform for patient representatives to highlight the value of a patient-centred approach in medical imaging.
- The ESR-PAG together with the ESR Audit & Standards Subcommittee developed a driver diagram on patient-centred care in clinical radiology in order to better embed a patient-centred human approach in both the activities of the ESR and radiology departments.
- An "ESR-PAG leaflet" was developed and released to increase visibility in the health community and to encourage stakeholders to engage with the ESR-PAG in the field of medical imaging.
- The ESR-PAG was counted on for providing the patient's perspective in official ESR publications and statements and position papers developed in close collaboration with partner organisations.
- Members of the ESR-PAG have shared insights and knowledge at various ESR events in light of the ESR's strong commitment to patient engagement.
- The ESR-PAG has participated in the ESR Annual Leadership Meetings to actively highlight the role of patients in the activities of the ESR.
- In collaboration with the ESR Audit & Standards Subcommittee, the ESR-PAG successfully developed a "Patient Satisfaction Questionnaire", which was introduced at the ECR 2017, in view of improving performance in radiology departments.
- The ESR-PAG has contributed to ESR activities in the area of value-based radiology to provide the patient's perspective on value in radiology.

Brief SWOT Analysis

Strengths

- Significant commitment to the patient's perspective, and the patient's voice through the ESR-PAG from the ESR leadership
- Strong ESR secretariat support and empathy
- Close and trusted group of patient leaders with knowledge and experience
- Track record of quality delivery at the ESR Congresses (ECR)
- Campaign and policy potential is there but could be enhanced

Weaknesses

- Too few patient representatives in the ESR -PAG
- Follow up by ESR and patients of key projects not always consistent
- Too little awareness of the ESR-PAG amongst the rank and file and national radiology societies to ensure a cascade effect in the work we do

Opportunities

- Several themes are emerging that are central to ESR's future work, that require strong patient input (value based health, the digital agenda, patients' safety, integrated care)
- Collaboration between patient organisations and the radiology community at national level is feasible- there is the opportunity to replicate good practice

Threats

- Over-reliance of the handful of active ESR-PAG members, no succession strategy
- Risk that the ESR- PAG is not considered integral to the body politic of ESR and its vision

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**GOAL 1:
Membership Growth**

In response to growing patients' and professionals' expectations and to remain operational and sustainable, the ESR-PAG seeks to enhance its membership to advocate for a patient-centred approach and strong patient-professional relationship within radiology across Europe. In addition to raising interest for the ESR-PAG among EU patient organisations, the ESR-PAG should be promoted through personal contacts. The ESR-PAG should also consider inviting external patient advocates to contribute to projects that require a high level of expertise. The ad-hoc approach has the potential to culminate in permanent membership for patient advocates who develop a strong interest in promoting the patient's voice in radiology.

- KPI – Engage external patient advocates to work on specific ESR-PAG projects based on their expertise in view of permanent membership
- KPI – Increase in the ESR-PAG membership by 2-4 patient representatives by ECR 2020

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**GOAL 2:
Leveraging the ECR**

The Annual European Congress of Radiology (ECR) is an excellent forum to promote the ESR-PAG, emphasising the patients' voice in the ESR's activities. The ESR-PAG sessions at the ECR should address burning topics that are at the centre of the patient-professional relationship, and which reflect actual developments in patients' care. While ensuring that the topics continue to be relevant for the patient-professional relationship, the ESR-PAG sessions should offer a platform that reflects the broad spectrum of patient topics in order to sustain patients' interest. Over the years, the ESR-PAG led sessions have seen increased attendance, and patient representatives have spoken at other 'mainstream' sessions. In future years we should build on this.

- KPI – Increase the number of attendees at the ESR-PAG led session at the ECR 2019 and 2020
- KPI – Concentrate patient sessions and activities on a single day to foster engagement on patient relevant topics
- KPI – Making patient engagement a central theme at the ECR 2021

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GOAL 3: Patient-Centred Care and Patient - Professional Dialogue

The ESR-PAG will continue to prioritize existing policy areas and embed new topics in its activities. Patient and professional communication and patient centred care will remain at the top of the ESR-PAG agenda.

- KPI – A regular session will take place at the ECR on this specific topic with good attendance (see above)
- KPI – The Driver Diagram on Patient Centred Care will continue to be promoted widely and a review of its impact will be undertaken by ESR and presented at the ECR 2020

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GOAL 4: Value-Based Healthcare

The current discussion on value-based healthcare incentivised the ESR to take part in shaping the debate and to develop the concept of value-based radiology. The patient is the recipient of value gains in the clinical process, of which diagnosis is an essential element and first outcome, and an improved patient-professional dialogue is to be strived for. The ESR-PAG will thus further explore value-based radiology so to bring the patient perspective and a multidisciplinary approach to the centre of the debate. In this sense, the ESR and the ESR-PAG should actively look for collaboration with stakeholders to express this view in scientific publications and at congresses.

- KPI – In collaboration with the Value-Based Radiology Subcommittee, the ESR-PAG should be actively involved in developing upcoming ESR publications on value-based radiology in order to emphasise the value to patients and the patient-professional dialogue
- KPI – VBHC and the link to patients should feature in future ESR events, starting with an event in 2019 in Brussels (see below)

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**GOAL 5:
Digital Health**

Radiology is at the forefront of technological innovation and digital solutions, including Artificial Intelligence, in healthcare, which triggers new opportunities in patient care and increases responsibilities for patients in clinical decision-making, laying the foundations for enhanced patient empowerment. The ESR-PAG should bring forward the patient perspective in discussions on digitalisation of healthcare, cybersecurity and data protection. In its activities, the ESR-PAG will emphasise the need for informing and educating patients concerning digital health applications in radiology aimed at further empowering patients, and put on the agenda of the ESR initiatives to this end.

Considering the impact of digital innovation on the patient-professional relationship and clinical practice, the ESR-PAG should explore concerns of patients regarding digitalisation of radiology, stringent data protection rules and sufficient room for personal contact in the radiology department and work with ESR on appropriate communication strategies. Taking into consideration patients' concerns, the ESR-PAG will reflect on how digital solutions integrated in radiology and throughout the care pathway could be optimally adapted towards patient-centeredness and measure patient expectations towards the use of digital health tools in radiology, including teleradiology. Furthermore, ethical aspects are to be central themes with regards to patient empowerment in an era of digital innovation and Artificial Intelligence in healthcare. In this context, the ESR-PAG will launch initiatives to bring forward a patient perspective in the activities of the society.

- KPI – The patient perspective on Artificial Intelligence and digital should be strongly embedded in ESR activities, starting with patient session at the ECR 2020 and an ESR event in 2019 in Brussels.
- KPI – The ESR-PAG should deliver input to ESR activities and the ESR leadership with the aim of raising awareness for patient concerns linked to digital health and adapting practices to patient-centeredness.

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**GOAL 6:
Value-Based Healthcare**

It is crucially important to communicate to the patient community what is the precise role of the radiologist/radiographer within a multidisciplinary framework. Initiatives should be launched to redefine this message and to target a broad patient and wider health stakeholder population, using targeted communication. This requires adequate quality & safety measures are applied in clinical practice, upholding trust in the radiology profession and better addressing patient expectations.

The ESR-PAG is aware that radiology is not considered a priority in respect of the overall EU patient agenda. In view of raising awareness for radiology, the ESR-PAG will explore the possibility to raise its voice in Brussels (e.g. through an event) in 2019 and beyond to trigger additional interest in patient representation within radiology. Such a meeting would connect the radiology profession with patients, offering a platform to inform the patient community on issues with a lasting impact for quality of care and patient safety. Value-based radiology and other emerging topics are to be presented in concrete terms, and simultaneously the patient community should be encouraged to participate in this debate in order to achieve patient-centred outcomes.

- KPI – Embedding this topic in an ESR event in Brussels in 2019, taking on board the EP election period, with good attendance from ESR leadership, patient leaders and policy makers and a tangible outcome

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GOAL 7: The ESR-PAG as Driver to Inject a Strong Patient Perspective in the ESR's Work

The ESR-PAG should ideally receive ESR publications and official statements during drafting stage and be given the opportunity to provide input and advice to the authors, ensuring that the patient perspective is adequately addressed. In this respect, the ESR-PAG should strive for adequate representation within ESR committees, subcommittees and working groups to guarantee that patients' input feeds into initiatives that matter to the patient community. KPI - A regular session will take place at the ECR on this specific topic with good attendance (see above)

- KPI - A clear process is established in 2018 to ensure that ESR-PAG is consulted during the drafting stage of all relevant documents and represented within ESR bodies when patient relevant initiatives are developed
- KPI - In 2019, there are at least three tangible examples of this happening in practice, while continuation should be ensured for the years beyond 2019

The ESR-PAG should ultimately be transformed into a group of committed patient ambassadors that gives a unique voice to patients in the area of medical imaging. Together with the expertise and resources of the ESR, the ESR-PAG should aim at putting the patient at the centre of medical imaging.

Notes
