



We would like to hear from you! – EPIC: Enhancing palliative care in intensive care units. European patient and family advisory group (PAG)

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Background

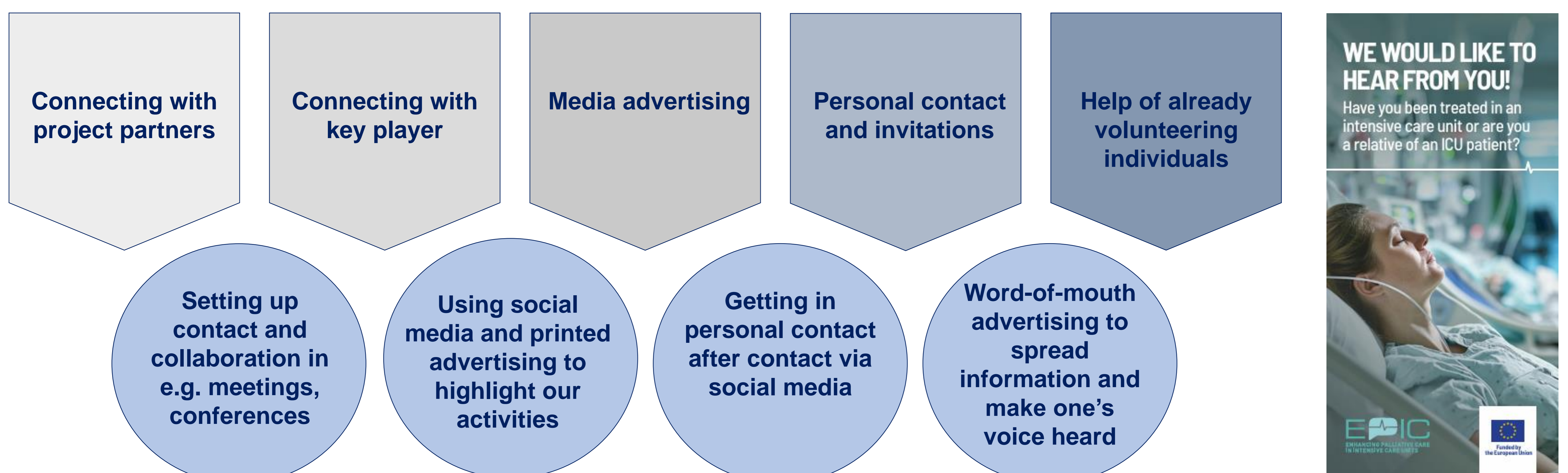
EPIC seeks to enhance palliative care in the intensive care unit (ICU) through an interdisciplinary consortium, utilizing telemedicine to harmonize palliative care practice in Europe. One of the project initiatives is to establish a European Patient and Family Advisory Group (PAG) to ensure patient and family voices are heard. This abstract outlines the group's objectives, participant inclusion criteria, and the challenges and facilitators in the process of establishing this group.

Method

A dual-purpose strategy was defined for the PAG: firstly, to incorporate patient and family perspectives on ICU care into the project, and secondly, to empower participants by sharing experiences and developing peer support activities. Membership requires personal ICU experience as a patient or relative, a willingness to share experiences within a peer group, and a commitment to participate consistently in ongoing international meetings over an extended period.

Results

Setting up the group, which started in November 2023, involved disseminating information via project partners in meetings, flyers, and social media. Successful strategies included direct invitations from health professionals, word-of-mouth by volunteers in patient organizations, clear commitment outlines handed to health professionals as guides for inviting members, and collaborating with international professional organizations to benefit from their established information distribution channels. In March 2024 2 patients and 6 relatives committed to participate in the group starting in April, 2024. Challenges arose from language barriers, using digital technologies, emotional concerns, and time constraints of individuals interested in participating. These led to strategies such as planning bi-monthly meetings, translation services during meetings, and personalized outreach using video messages of the group's moderators to enhance engagement. We plan a long-term strategy of including new members throughout the project as we expect drop-outs.



Conclusion

Initial efforts to establish the PAG highlight the challenges of engaging a diverse, international group and underscore the need for tailored strategies to overcome language and accessibility barriers.

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Conflict of interest

No conflicts of interest are declared.

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