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A European Network for Teenagers and Young Adults with Cancer.

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1. Etc
2. Etc
3. etc

The huge challenges of having cancer at a young age are well described. The challenges of providing cancer care services for this patient group are also increasingly described, although new challenges of increasing disease and new patterns of disease are also emerging (1). Questions clearly remain about what we do to provide optimal care for this challenge, medical and psychosocial. Effective teamwork is critical (2, 3). Providing specialised teams with a focus upon this group, which bring together experts on cancer in younger children and older adults, is one approach, and brings measurable clinical benefits to patients treated in that setting (4). However such models of care inevitably also have weaknesses, potentially including disjointed care and inequity of access (5).

As care coordination challenges for patients with cancer continue to grow, as cancer treatment and care become more and more complex, the need to work both within a team and to coordinate across disciplines, organizations, and geographic boundaries increases (6). Wider networks and even inter-team working may be useful next steps to improve clinical outcomes, including cancer control and quality of life, reduce treatment-related medical errors and manage care costs (7). Some believe cancer care is moving inevitably beyond improving the teamwork processes within the teams directly involved, towards a network of inter-dependent teams, across specialities and geographies (8).

Adolescent and young age (AYA)-specific specialist care systems are especially complex and multi-team. They often require engagement with paediatric and adult care models, covering oncological and haematological malignancies. They benefit from a particular set of engagements between patients, their families and service providers (9, 10). The specific challenges in co-ordinating professional stakeholder groups range from the clinical and biological (such as diagnosis and appropriate protocol selection (11, 12)) to the psychological and social domain where an even wider range of healthcare professional expertise is required (13-15). Many cancers seen are rare, and therefore wide-enough information exchange is challenging. A lack of such wide inter-team working may be contributing to disappointing timescales between symptoms and cancer diagnosis and treatment, with associated poorer

outcomes for many young patients (16-18). These challenges to networks are only going to become wider, according to current epidemiological trends, including interventions for healthy lifestyle in cancer survivors (19, 20).

The provision of services to AYA remains very variable. A survey conducted in 2017 described the training and different practices of European healthcare providers in regard to AYA and the availability of specialised AYA services. This revealed important under-provision and inequity of specialised AYA cancer care across Europe, particularly evident in Eastern and South-Eastern Europe. Over two-thirds of respondents did not have access to specialised centres for AYA (67%), were not aware of research initiatives focusing on AYA with cancer (69%) and had no access to specialist services for managing the late effects of treatment (67%). More than half of respondents reported that they had no access to an AYA-specialised nurse in the oncology team or elsewhere, and 38% reported that their AYA patients did not have access to fertility specialists (21). This built upon earlier surveys and suggested the need to expand awareness of the particular needs of AYA patients with cancer among a wider range of health professionals and to encourage provision of specialist services for AYA cancer (22).

Adolescent and young adults (AYAs) with cancer often experience a sense of isolation from friends and family who may not fully comprehend what they're experiencing and for many AYAs it's helpful to connect with other patients of their age, who are living with a cancer diagnosis. Patient, their advocates and carer's voices are also essential to construct services, focussed on the needs of the young people, and to deliver research that is a priority to them and relevant to those, receiving them. (23, 24) Models for structured Public and Patient Involvement (PPI) are available (<https://www.invo.org.uk/resource-centre/>) and gaining wider acceptance across Europe in the patient advocacy community, and thus should be put in place in cancer research as a means to include young patients' expertise, to improve research and care, and also to collaborate with patient experts as equal partners on shaping the future of oncology. These, when delivered well, can to empower patients to get the best possible quality of cancer treatment,

Narrowing the differences between the entire range of stakeholders in AYA cancer, identifying interventions that engage all those with a stake, and devising professional educational approaches that can inform multiple professional groups at the same time all require development and testing as ways to improve patient outcomes. Boundary-spanning models of AYA clinical care are in place in some locations (13). If the community with a stake in AYA care in Europe are to place the right services within the right settings by influencing healthcare services and policies, these initiatives will need to fit into many local contexts and structures across Europe and will require very wide co-operation. Mutual trust and novel ways of working will need to extend beyond the team or speciality that AYA healthcare professionals are an immediate part of, more and more widely (25).

In Europe in 2011 a group of 10 clinicians with an interest in AYA cancer were funded by the European Union FP7 programme to develop a programme for AYAs with cancer, and bring professionals together (26). This began strongly, but did not accelerate after research funding ended. It contributed in 2015 to the European Society for Paediatric Oncology (SIOPE) policy

on TYA with cancer¹. Moreover in 2014 the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) began working together on these issues and in 2016 formally created a joint working group on Cancer in Adolescents and Young Adults². This provides education to members and aims to cultivate a sensitive collaborative relationship between medical and paediatric oncologists for the benefit of AYA.

However, in response to the diversity and increasing complexity of cancer care for AYA and the landscape across Europe, now there is a need to widen this engagement. To achieve this, ENTYAC – European Network for Teenagers and Young Adults with Cancer was founded in 2020. This aims to build:

- Collaboration with a complete range of health care professional societies in Europe, including ESMO (<https://www.esmo.org/>), SIOPE (<https://siope.eu/>), EONS (<https://cancernurse.eu/>), and seek to develop wider linkages such as with the EHA (<https://ehaweb.org/>), ESTRO (<https://www.estro.org/>) and others.
- Integration with Non-Governmental Organisations (<https://www.ccieurope.eu/>), that enable high quality engagement with patients, advocates and their families.
- Work as a federation where existing national professional organisations, clinical, non-clinical, NGO and patient-based that have a stake in AYA cancer can co-operate and grow.
- Provide support and advice to all who have a stake in AYA cancer care but are not part of a formal national or international professional society, such as for patient advocates and health care professionals to stay connected and develop and gain state of the art education and information about AYA cancer and care.
- Maps of progress, from different clinical, geographical and cultural perspectives, in age-specific cancer care across the diverse European landscape and share that data with policy-makers to seek improvements.
- A higher European profile of AYA cancer-related issues.
- International priorities for research from multiple perspectives.
- A wider awareness, availability and visibility of clinical trials and participation in those.

ENTYAC exists to improve and enhance inter-professional teamwork processes, to promote team-based specialist care, to prioritize among the key scientific, medical, nursing and psychosocial barriers facing AYA cancer patients and to develop strategies to improve their outcomes. If we are successful, services, teams, inter-team working, research and education for and about young people will move forward more quickly, and improve outcomes.

¹ <https://worldspanmedia.s3-eu-west-1.amazonaws.com/media/siope/PDF/the-siope-strategic-plan.pdf>

² <https://www.esmo.org/about-esmo/organisational-structure/educational-committee/adolescents-and-young-adults-working-group>

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