GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

Cancer in Adolescents and Young Adults (AYA) Working Group

SIOP Europe
the European Society for Paediatric Oncology

MAPPING THE SURVIVORSHIP AND SECONDARY PREVENTION SERVICES AVAILABLE TO EUROPEAN PROFESSIONALS IN AYA CANCER CARE

D. Stark[1], E. Saloustros[2], K. Michailidou[3], S. Bielack[4], L. Brugieres[5], F.A. Peccatori[6], S. Jezdic[7], S. Essiaf[8], J.-Y. Douillard[7], G. Mountzios[9]

[1]Institute of Molecular Medicine, Leeds, UK; [2]Oncology Unit, General Hospital of Heraklion 'Venizelio',Heraklion, Crete, Greece; [3]Cyprus Institute of Neurology and Genetics, Nicosia, Cyprus; [4]Klinikum Stuttgart – Olgahospital, Stuttgart, Germany; [5]Gustave Roussy Cancer Campus, Villejuif, France; [6]Fertility & Procreation Unit, Gynecologic Oncology Department, European Institute of Oncology, Milan, Italy; [7]European Society for Medical Oncology, Viganello-Lugano, Switzerland; [8]European Society for Paediatric Oncology (SIOPE), Brussels, Belgium; [9]Department of Medical Oncology, 251 General Airforce Hospital, Athens, Greece

INTRODUCTION

- Adolescents and young adults (AYA) are a distinct group at the interface between children's and adult's cancer patients.
- Increasing numbers of AYA are long-term cancer survivors, based on high cancer survival rate and low mortality from other diseases[1].
- These factors result in several issues of specific or particular relevance to AYA, including[2,3]
  - the early effects of cancer and its treatment on fertility social wellbeing and mental health
  - the risks of late-occurring adverse events (i.e. cardiotoxicity, nephrotoxicity and second primary tumours)
- Recognizing the circumstances and needs of AYA living with and after cancer specifically, several reviews[4,5] of evidence, scientific data and priorities for AYA patients reflect increasing clinical community co-operation and research publication.

ESMO/SIOPE SURVEY

- In 2016, the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) created a Joint Working Group on Cancer in AYA.
- Among its first projects, this group co-operated in an online professional survey to record the current status of AYA cancer care, aiming at identifying inequalities and focusing upon:
  - provision of educational content meeting professionals' interests and needs when managing AYA with cancer
  - widening and deepening of professional awareness of AYA with cancer in Europe
  - enactment of sensitive co-operative professional relations between medical and paediatric oncologists and other healthcare professionals involved in AYA cancer

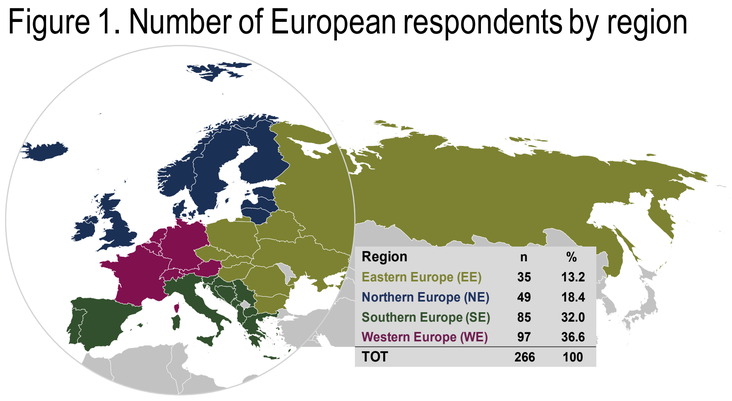
[1]Desandes E & Stark DP. Prog Tumor Res 2016;43:1–15; [2]Skinner R, et al. Lancet Oncol 2017;18:e75–90; [3]Keegan THM, et al. JAMA Oncol 2017;20; [4]Smith AW, et al. Cancer 2016;122:988–99. [5]Stark D et al. Eur J Cancer Care (Engl) 2016; 25(3):419-27.

METHODS OF THE RESEARCH

- A link to a questionnaire was sent by e-mail in 2016 to all members of the ESMO and SIOPE and other AYA networks about:
  - availability of the services specialized in AYA patients
  - educational activities available to healthcare providers
  - maintaining the health of AYAs after cancer
  - means of raising awareness and improving care and outcome
- Data were analysed using $\chi 2$ and Fisher's exact test.
- In this report we focus the display of results and the analysis upon:
  - late effects of cancer and its treatment
  - prevention of secondary malignant neoplasms
  - lifestyle to improve health

RESULTS

Figure 1. Number of European respondents by region



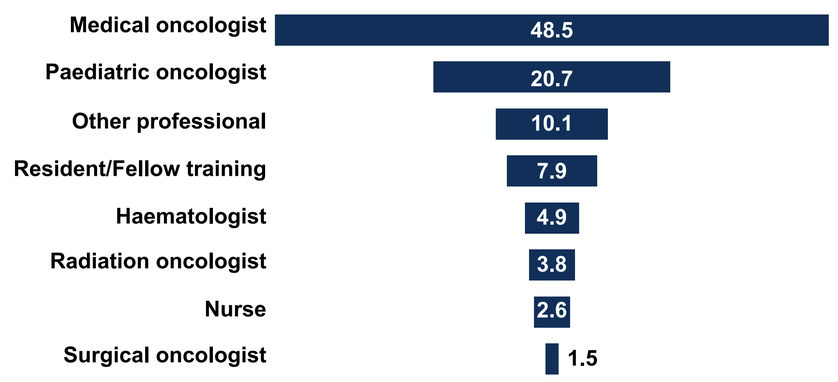
EE: Belarus (n=2), Bulgaria (n=2), Czech Republic (n=3), Georgia (n=1), Hungary (n=3), Poland (n=5), Romania (n=8), Russia (n=5), Slovakia (n=3), Ukraine (n=3)

NE: Denmark (n=5), Estonia (n=2), Finland (n=1), Iceland (n=1), Ireland (n=5), Latvia (n=2), Lithuania (n=4), Norway (n=1), Sweden (n=4), United Kingdom (n=24)

SE: Albania (n=2), Andorra (n=1), Bosnia and Herzegovina (n=1), Croatia (n=6), Cyprus (n=3), Greece (n=27), Italy (n=15), Malta (n=2), Montenegro (n=1), Portugal (n=11), Serbia (n=3), Slovenia (n=2), Spain (n=9), (TFYR of) Macedonia (n=2)

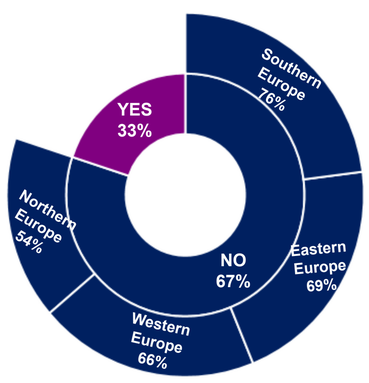
WE: Austria (n=2), Belgium (n=13), France (n=26), Germany (n=37), Luxembourg (n=1), Netherlands (n=9), Switzerland (n=9)

Figure 2. Characteristics of the respondents



- Respondents were largely medical or paediatric oncologists, followed by other specialized physicians (Figure 2).
- 52% worked in general academic centres, 19% in specialised cancer hospitals and 11% in paediatric hospitals.
- 60% were trained to treat adult cancer patients, 25% paediatric patients and 15% both.

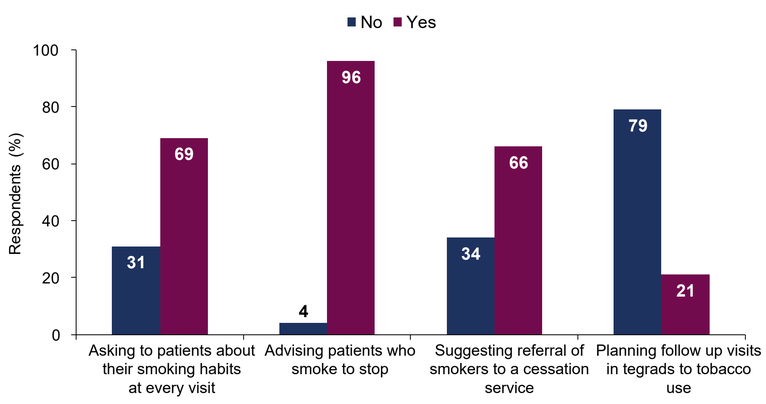
Figure 3. Access to specialist services for late effects



- The majority of professionals reported that 67% of their AYA patients had no access to specialist services to manage late effects.
- This trend was higher in SE and lower in NE (Figure 3).

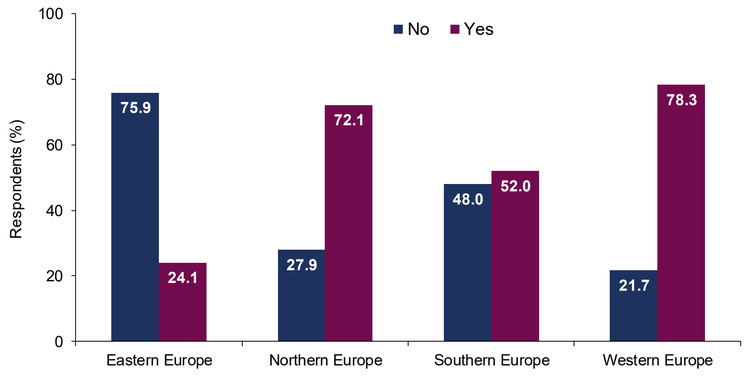
- Nonetheless over 85% of professionals reported:
  - monitoring of cardiovascular disease risk factors (e.g. high-blood pressure, high cholesterol, obesity) after cardio-toxic treatments
  - advice on healthy body weight, alcohol consumption, diet, physical activity and safe sun exposure

Figure 4. Attitude of respondents towards tobacco use



- Smoking enquiry was reported as active by many respondents but simple action to modify behaviour about tobacco use is limited in AYA patients (Figure 4).

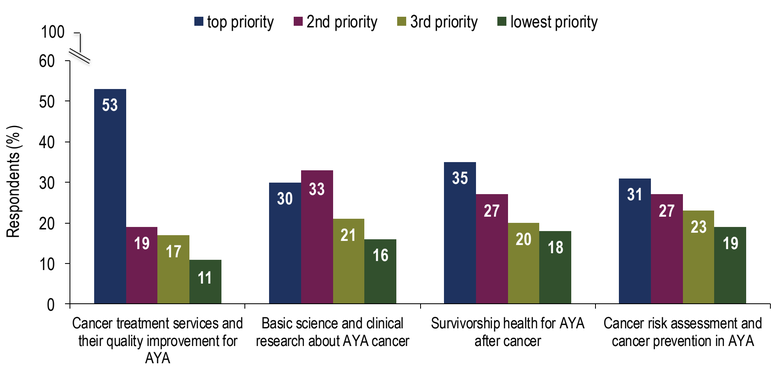
Figure 5. Evaluation of fertility



- Despite being a longstanding issue[6], clinicians reported a very varied access of AYA patients to a fertility specialist across the four European regions (Figure 5; $p<0.001$).

[6]Chapman RM et al. Lancet. 1979;1(8111):285-9.

Figure 6. Specialised AYA care



- Respondents wanted education that ESMO and SIOPE should offer together, prioritizing cancer treatment services, basic science and clinical research (Figure 6).

- Awareness of research initiatives, clinical trials or studies focused upon the specific clinical, epidemiological or psycho-social features of AYA with cancer was only 11.8% and 10% for respondents in SE and EE, respectively, but 44% in EE and 54% NE.
- Access to an age-specialized nurse (10% and 32%), availability of specialised AYA education (7% and 14%) or support by young patient groups (34% and 48%) are alarmingly low in SE and EE, respectively.

CONCLUSIONS

- **This first survey of ESMO and SIOPE is a baseline to identify inequalities for AYA with cancer across Europe.**
  - The lack of access to specialized AYA care is more profound in Southern and Eastern Europe
- **There are significant limitations and inequalities in specialist services for AYA patient living after cancer.**
  - Fertility services before and after cancer treatment are significantly unequal across Europe
  - Late effects services, prevention of second cancers and advice on lifestyle are very variable and widely need improvement
- **ESMO and SIOPE are ideally placed to raise the profile of AYA cancer-related issues**
  - increasing professional awareness of AYA cancer issues
  - providing further excellent educational material such as e-learning, specific guidelines, practical guides for clinicians, congress activities, educational lectures, interactive sessions
  - encouraging research
- **Education for AYA professionals should be developed by ESMO and SIOPE in co-operation to reduce inequalities in AYA cancer outcomes.**