# 20-year experience of a pioneering expert French AYA specific program in Gustave Roussy : Decompartmentalisation is key

GUSTAVE ROUSSY
CANCER CAMPUS GRAND PARIS
PROGRAMME SPÉCIFIQUE ADOLESCENTS & JEUNES ADULTES

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## BACKGROUND

Adolescent and young adults (AYA) are at a crucial stage of their personal, educational, emotional and sexual development. Cancer turns everyone's life upside-down, but at such a crucial life-stage, AYA patients need the personalised support of a multidisciplinary team. The cancers that affect this age group are a mixture of paediatric and adult types, as well as AYA-specific forms, and therefore require interactive medical management. AYA cancer care has long been a priority in Gustave Roussy; from opening the first French AYA specialist unit in 2002 to the development of the Specific Multi/Interdisciplinary AYA team (SPIAJA) following publication of the French National Cancer Institute (INCa) plan in 2012.

## OBJECTIVE

To describe the evolution of AYA care in Gustave Roussy over 10 years 2012 – 2022. Evaluate the holistic care of AYA patients during their treatment. Secondary objectives included an analysis of the levers and obstacles to the diffusion of holistic care within the institution.

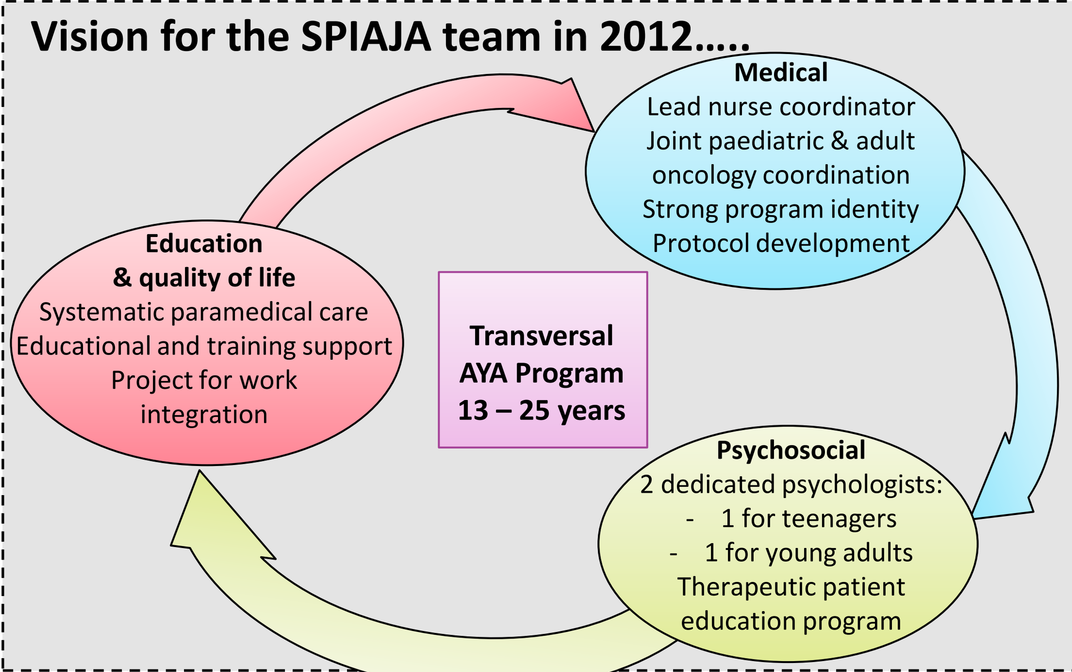
## METHODS

A descriptive analysis of the evolution of the SPIAJA team (Interdisciplinary team to support AYA) since 2012, and a qualitative sociological study using semi-structured interviews recorded from November 2021 to September 2022. Twenty-four individual semi-directed interviews using three interview grids, one each for AYA patients (n=12), SPIAJA team professionals (n=6) and oncologists (n=6). Interviews were recorded, transcribed and analysed.

Adolescent/ young adult centred care

## RESULTS

### Vision for the SPIAJA team in 2012…..




### …..and the current team

The SPIAJA team aims to improve the holistic care of AYA patients via a medico-psycho-socio-educative program. A mobile team, who identify AYA patients and go to them, whether care is delivered in AYA or adult departments. Complementary "AYA friendly" professionals are also identified within the Institute.

Paediatric Oncologists: Dr Nathalie Gaspar (Onco-pédiatre), Dr Lucie Metayer (Oncologue médicale)
Coordinating nurse: Charlotte Mortier (Infirmière de coordination)
Psychologists: Anna Bruguera (Psychologue), Séverine Chiesa (Psychologue)
Dietician: Laurence Dupuis (Diététicienne)
Social worker: Joy Vaudron (Assistante sociale)
Physical therapist: Helaïjah Abati
Adult Oncologists (sarcoma, urology, haematology): Dr Benjamin Verret (Oncologue médical), Dr Natacha Naoun (Oncologue médicale), Dr Anna Patrikidou (Oncologue médicale)
SPIAJA
Specialist educator: Fanny Morin (Éducatrice spécialisée)
Psychomotor therapist: Carine Da Fonseca (Psychomotricienne)
Associated: Long term FU: Dr Brice Fresneau

**AYA friendly**
- **National Education**: Teachers, exams (BAC, Brevet)
- **Supportive Care Department:** Pain & palliative care team; Physio; Addiction team
- **Tumour specific Committee**: Lead AYA nurse & Dr per dept
- **Child Ado Cancer Dept**: Neuropsychology; Creative arts

### Activity of SPIAJA team since 2013

Number of new AYA patients and AYA nurse evaluations per year
(2013–2023; legend: N° AYA Nurse Eval, <18, >=18, Total)

N° of patient education workshops run/year
(2013–2023; Covid-19: No group sessions allowed from mid-2020 - 2021; legend: Basics about cancer, Body image, Stopping pain, Nutrition, Sexuality & fertility, Exercise & activity, Addictions, End of treatment)

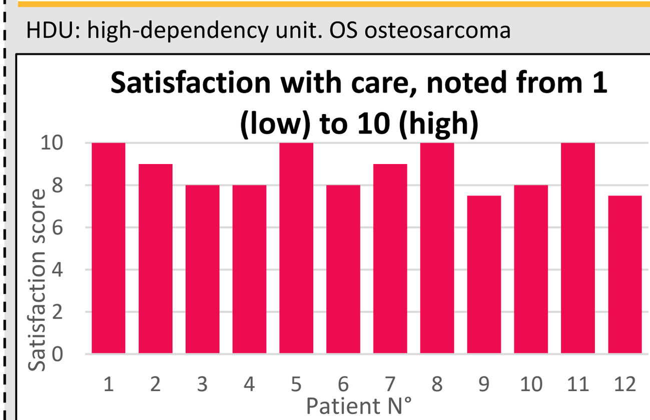
Total of 1390 AYA patients seen over this time, with 809 detailed coordinating nurse evaluations for educational needs. Recently, the proportion of patients identified and having detailed assessments has increased although COVID-19 impacted team stability affecting patient identification educational workshops.

Therapeutic patient education workshops are offered after a consultation with the coordinating nurse, during which needs are identified and prioritised conjointly. Interactive, group sessions that run regularly but require presence in the hospital (admission, clinic or imaging). See detailed complementary poster.

### Participating AYA demographic characteristics

| | |
|---|---|
| **Gender** | 6 Male 6 Female |
| **Age, median (range)** | 19 yrs (14 – 25) |
| **Living situation** | 6 parental home<br>6 alone |
| **Diagnoses** | |
| Mature B lymphoma | 3 |
| Hodgkin | 1 |
| Bone tumour (OS, Ewing) | 4 new, 1 meta relapse |
| Testicular tumour | 1 |
| Ovarian tumour | 1 |
| Pinealoblastoma | 1 |
| **Site of hospital treatment (may have multiple)** | |
| AYA Unit | 9 |
| Paediatric HDU | 4 |
| Children's ward | 3 |
| Adult day unit | 2 |
| Adut ward | 4 |

HDU: high-dependency unit. OS osteosarcoma




### Evaluation of the AYA experience of care during treatment

**Verbatim patient phrases to illustrate AYA's experience of *Care***

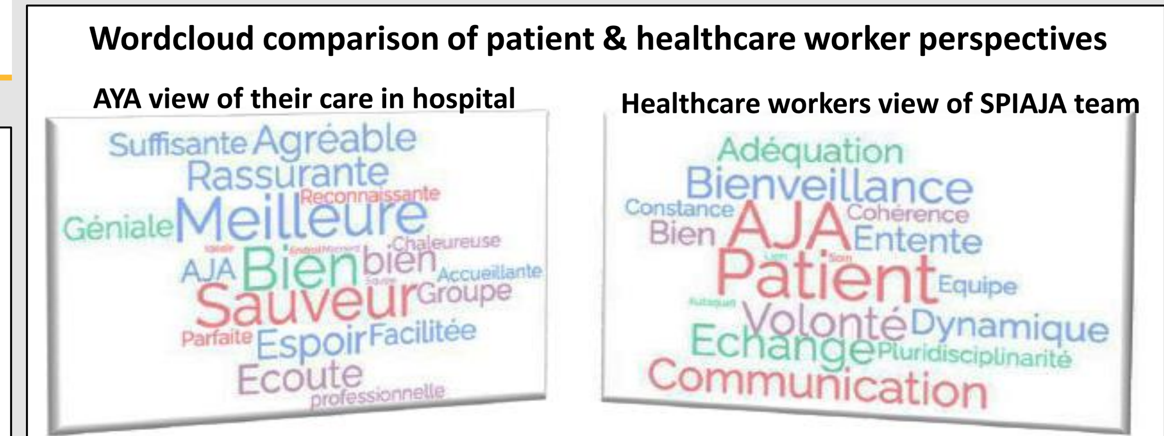
J, 22 yrs, for whom no member of her entourage was able to visit during admissions, describing her relation with the Coordinating nurse:

*She was there. She followed me throughout… And she was really kind. She was there. She listened. She was there even when I didn't have chemo, I mean after I returned home, she was there. Even now I call her.*

F, 25 yrs:

*…I got on really well with the team….Sometimes, they obviously tried to boost me a bit when I was feeling a bit low. When I started to maybe stop believing…They really really supported me. So yeah, they really helped me to overcome that. And to give me back courage and morale which I didn't really have.*

**Wordcloud comparison of patient & healthcare worker perspectives**




### So good quality holistic care is delivered. How and why?

### 1) Institutional culture: Proactive support of holistic cancer care

Supportive care to offer "a better quality of cure to each patient" is a central part of the institutional strategy 2020–2030. It is accepted that decompartmentalising institutional structures and interdisciplinary collaboration is essential to achieve this, complex in a hospital as large as Gustave Roussy where >46 000 patients/year are seen in outpatients, including 2500 in Dept of childhood & adolescent oncology (DCAO). Several other complex institutional projects requiring this approach are also ongoing eg. Interception (cancer prevention). Some examples of decompartmentalising include:

- **Timescale:** Considering the post-treatment from diagnosis, actively managing the "after" phase.
- **Spatial:** mobile teams covering all patients wherever they are hospitalised, separate buildings for survivors' clinics, appropriate meeting rooms for joint multidisciplinary meetings
- **Socio-cultural:** accepting non-healthcare workers in teams, eg. specialist educators. Creating a place for complementary therapy to support psychosocial well-being

### SPIAJA Team: Approach, expertise, multidisciplinarity, teamwork, management

Caring, but not infantilising, approach. Rooted in paediatric culture and adapted for this age-group, Dr A, paediatric oncologist: *It is by definition to care for the person… The whole person, with the disease and all that is not the disease…all their life, accumulated experiences & the impact the disease can have in all that.*

Expertise not only in the management of cancer, but for AYA patients. Dr A about treatment refusal, describes that it often arises from suffering, and a difficulty for young people to recognise that, or ask for help, when they don't yet know themselves and should be becoming more autonomous. *So instead, they say "I'm stopping treatment". …But if you search, "that hurts!". And there are things that you can do to help, allowing them to continue treatment.*

Multidisciplinarity. In particular the socio-, non-medical role of specialist educator: *My role is to "build towards", to support AYAs. To get them out of their status of patient which is imposed by cancer & the institution. To remind him of "who he is" before becoming ill, before being here. To look at him with a supportive, non healthcare, gaze.*

Teamwork & management style: Weekly patient-focused and project meetings with whole-team participation and open discussion allowing support of team members, flexibility of approach and nurtures a culture of reciprocal confidence. Participative approach allows innovative solutions and development.

### What challenges remain?

Persistent lack of clarity about the precise nature of the role of non-traditional healthcare workers – when nurses/healthcare assistants can and should call them. More true in the wider hospital than within the DCAO but still the case after 2 years of daily DCAO presence, impacting confidence of team-members and patient reach.

Use of SPIAJA for socially and/or psychologically complex situations at a 'last resort'. Resistance by some teams / individuals to cooperate in the management of AYA patients generally because of a lack of perceived need for medical expertise – failing to understand the psychosocial-educative needs or accept a joint approach.

Cultural barriers between adult & paediatric oncologists, affecting AYA patients at this interface. Explained by different training routes, differing patient numbers with "weight of expertise in numbers" for adults, and clinical experience impacted by patient cohorts including treatment toxicity and different treatment goals.

Not universal, but nevertheless slowing the real-world roll-out & usefulness of mixed adult-paediatric multidisciplinary team (MDT) meetings for AYA patients, a statutory requirement. Some individuals show a lack of flexible thinking and openness to why different approaches could be considered. Different "languages" used.

### Recommendations

**Specific: Mixed AYA MDTs**

Key role of higher management to improve the functioning of mixed AYA MDT with a combined political-participative management approach:

- Imposed political management to provide the framework of obligation confirming the importance of these MDTs, clarify the resources available and the expected results by the direction
- A participative management approach could then be used by interested parties to identify together the key role of these meetings and develop a new model

**General: Use Lean management approach to improve care quality**

The successful management of the SPIAJA team with regular meetings, open communication and supportive environment, enabling a strong team identity and support network, as well as innovative projects, resembles the Healthcare-adapted lean management style. Institutional management should take note of this "bottom-up" approach as a way to continue to advance their quality-of-care focused program as it may help resolve some of the cultural issues currently provoking difficulty as wells as valorising healthcare professionals improving their wellbeing and patient care.

## CONCLUSIONS

The evolution of the AYA team to the current SPIAJA mobile model has improved patient reach. Currently, AYA cancer patients feel well supported in their holistic psychosocial-educative, not just medical, needs. Understanding the success of this program is complex but institutional support is fundamental. Breaking down barriers between health and social care, as well as between departments and teams is also key. Finally, the SPIAJA team itself in its multidisciplinarity, team dynamic, expertise and management style play a role.

Barriers remain, but will improve as the SPIAJA team increases its reach and confidence in a joint approach is learned through experience. Ongoing institutional investment is necessary to overcome particularly difficult problems. A lean management style, inspired by the SPIAJA team, could be extended to other projects within the institution as a means to improving patient care.

All translation of verbatim quotes by Lucy Métayer, aiming to capture the essence of what was said as faithfully as possible.