



# “Cancer survivorship- approaches and challenges”

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**46<sup>TH</sup> ICRO PG Teaching Program**

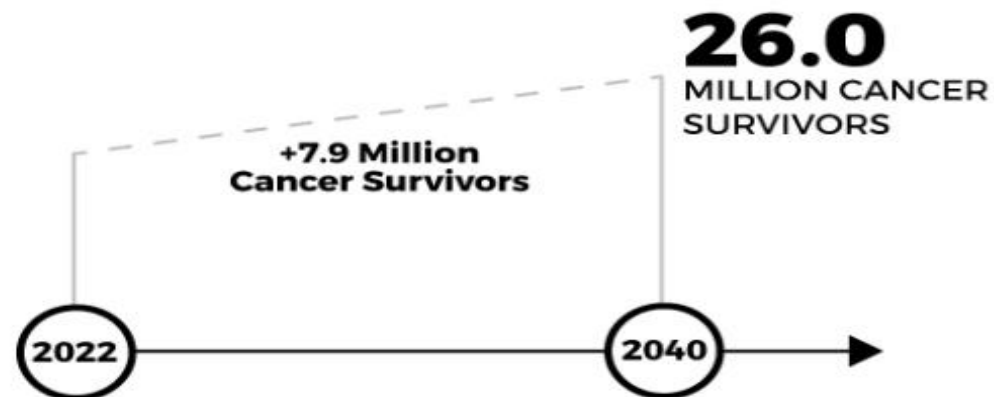
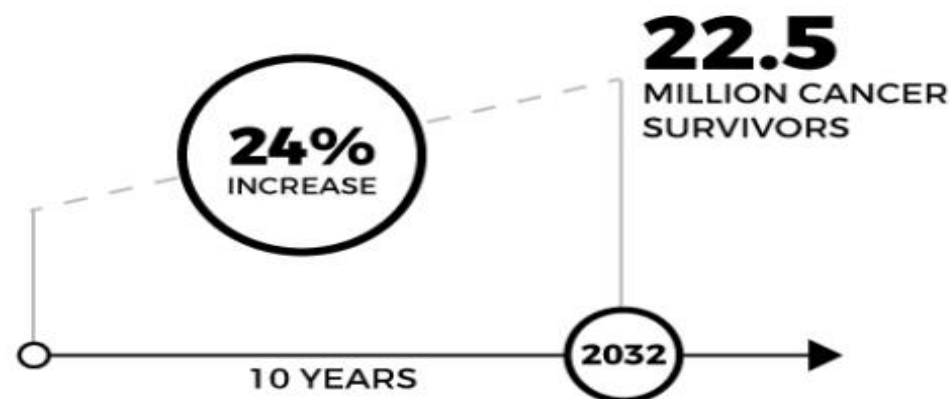
**20<sup>th</sup> & 21<sup>st</sup> April 2024**

**On**

**Management of Radiation Toxicities**



- ▶ As of January 2022, 18.1 million cancer survivors in the United States, which is 5.4% of the population.\*



- ▶ \*American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2022-2024*. Atlanta: American Cancer Society; 2022.

- ▶ <https://cancercontrol.cancer.gov/ocs/statistics#statistics-footnote1->

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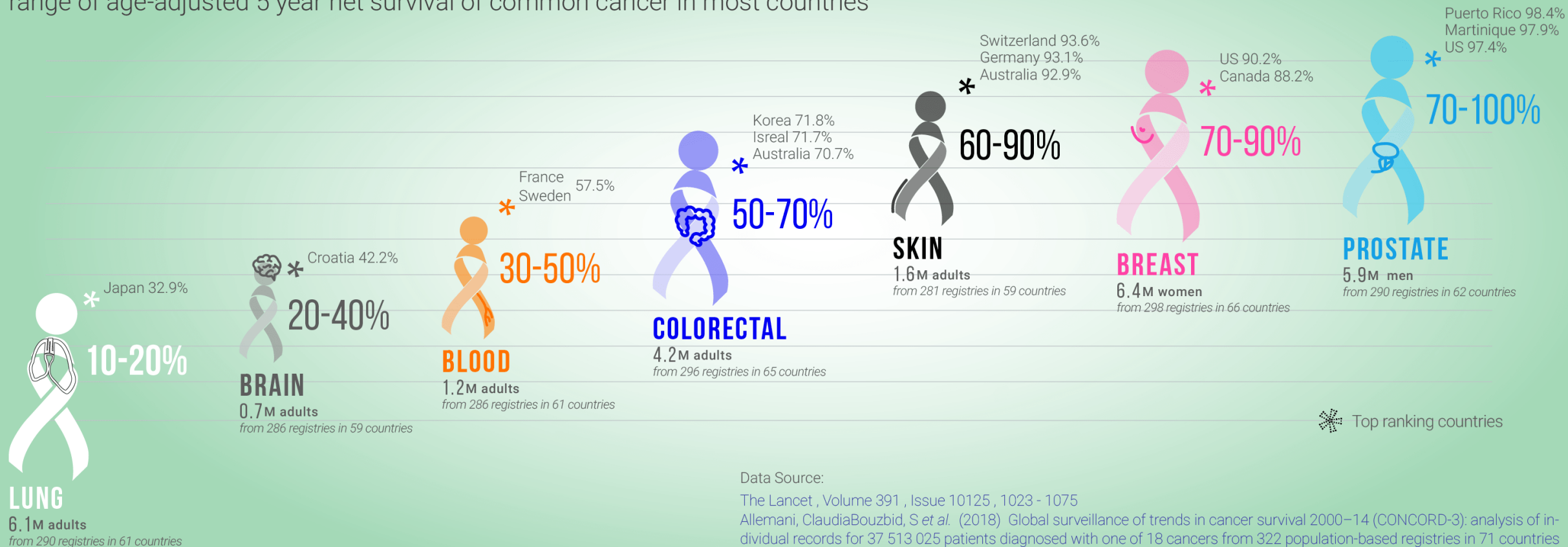


# Global surveillance of trends in cancer survival 2000–14 (CONCORD-3): analysis of individual records for 37 513 025 patients diagnosed with one of 18 cancers from 322 population-based registries in 71 countries

Claudia Allemani, PhD • Tomohiro Matsuda, PhD • Veronica Di Carlo, MSc • Rhea Harewood, MSc • Melissa Matz, PhD • Maja Nikšić, PhD • et al. [Show all authors](#) • [Show footnotes](#)

## Global Trends of Cancer Survival (2000 - 2014)

range of age-adjusted 5 year net survival of common cancer in most countries



Research | [Open access](#) | Published: 22 October 2022

# Health status and associated factors of middle-aged and older adult cancer survivors in India: results from the Longitudinal Ageing Study in India

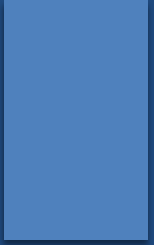
[Aravinda Meera Guntupalli](#) , [Y. Selvamani](#), [Sara J. Maclennan](#) & [T. R. Dilip](#)

*BMC Cancer* **22**, Article number: 1087 (2022) | [Cite this article](#)

- ▶ 2.1 million cancer survivors in India in 2017–18
- ▶ Cancer survivors have significantly higher odds of poor health status

**Results:** According to LASI estimates, there were 2.1 million cancer survivors in India (95% CI 1.8 million to 2.6 million) in 2017–18. Overall, 440 cancer survivors have been identified in this study, with considerable state variations. The number of cancer survivors per 1,00,000 population was relatively more in non-indigenous groups, people with a history of cancer in their families, those who worked earlier but currently not working and those in the richest quintile categories. As compared to those who never had cancer, the cancer survivors are at higher risk of hospitalisation (adjusted odds ratio (aOR)=2.61 CI 1.86, 3.67), poor self-rated health (aOR=3.77, CI 2.55, 5.54), depressive symptoms (aOR=1.53, CI 1.41, 2.05) and sleep problems (aOR=2.29, CI 1.50, 3.47). They also reported higher ADL (aOR=1.61, CI 1.11, 2.34) and IADL (aOR=1.49, CI 1.07, 2.07) limitations. Cancer survivors who had their cancer diagnosis in the past 2 years or a cancer-related treatment in the past 2 years have significantly higher odds of poor health status than middle-aged and older adults without a cancer history.

**Conclusion:** Middle-aged and older cancer survivors, particularly those who underwent cancer diagnosis or treatment in the past 2 years, are at a significantly higher risk of experiencing poor self-reported health and other health challenges, suggesting the need for an integrated healthcare approach.



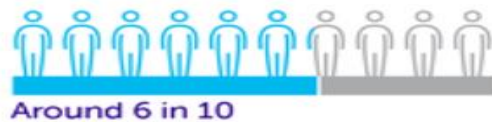
# **Reasons for increased number of cancer survivors**

# Advances in early detection

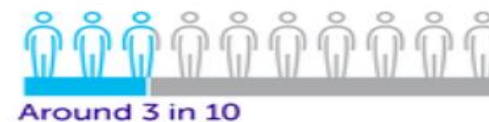
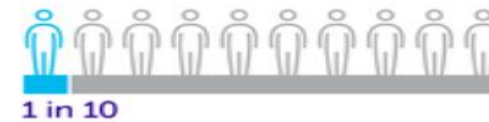
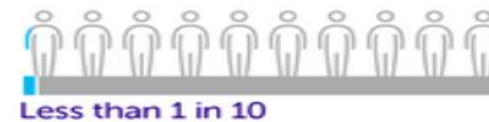
## Cancer survival by stage at diagnosis

Proportion of people surviving their cancer for five years or more

Diagnosed at earliest stage



Diagnosed at latest stage

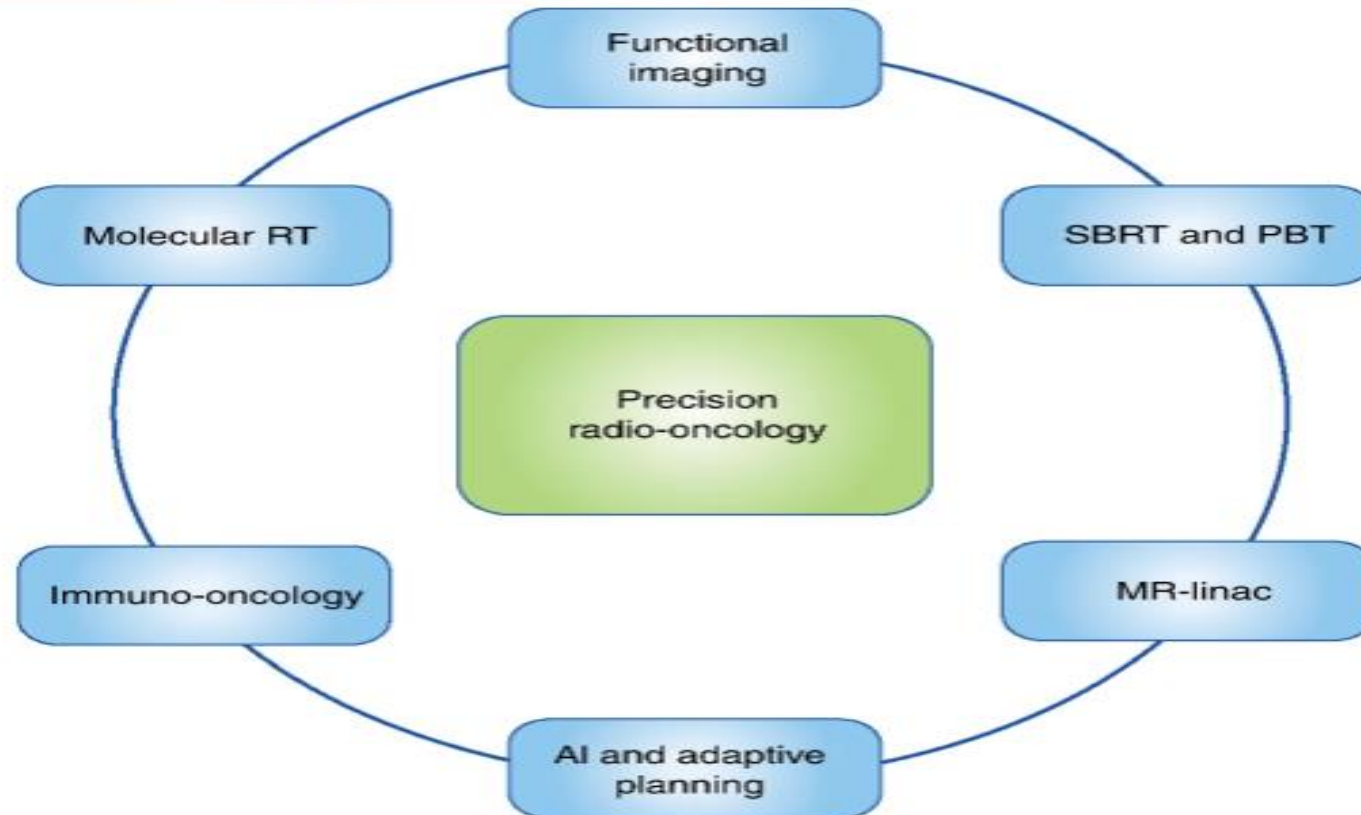


Earliest stage = stage 1; latest stage = stage 4.  
Data is age-standardised net survival for adults (aged 15 to 99 years) in England in 2015-2019 followed up to 2020. Breast cancer data is for females only.

# Advances in therapeutic strategies

**Fig. 4**

From: [How rapid advances in imaging are defining the future of precision radiation oncology](#)





- ▶ **Advances in early detection**
- ▶ **Advances in therapeutic strategies**
- ▶ **Widespread use of combined modality therapy**

- ▶ **Socio-cultural factors-**
  - ❖ **psychological and behavioural interventions,**
  - ❖ **(counsellors and social workers)**
  - ❖ **active screening behaviours**
  - ❖ **healthier lifestyles**

- ❖ **Cancers like testicular cancers, hodkins lymphoma- considered amenable to cure**
- ❖ **Certain common cancers- breast cancer, colorectal cancers- vastly improved DFS and OS**

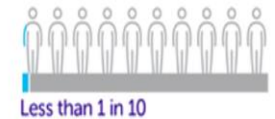
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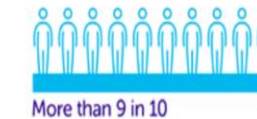
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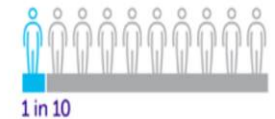
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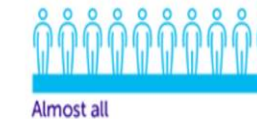
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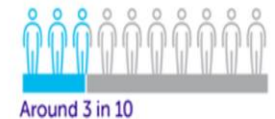
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Earliest stage = stage 1; latest stage = stage 4.  
Data is age-standardised net survival for adults (aged 15 to 99 years) in England in 2015-2019 followed up to 2020. Breast cancer data is for females only.

# Who is a cancer survivor?

- ▶ **Philosophically , anyone who has been diagnosed with cancer is a survivor, from the time of diagnosis to the end of life**

(National coalition of cancer survivors)

- ▶ **Includes, caregivers and family members-secondary survivors**

# What is cancer survivorship?

- ▶ The health and life of a person with cancer until the end of life.
- ▶ Process with predictable stages

**Acute survival** - extending from diagnosis to completion of initial treatment; issues dominated by treatment and its side-effects

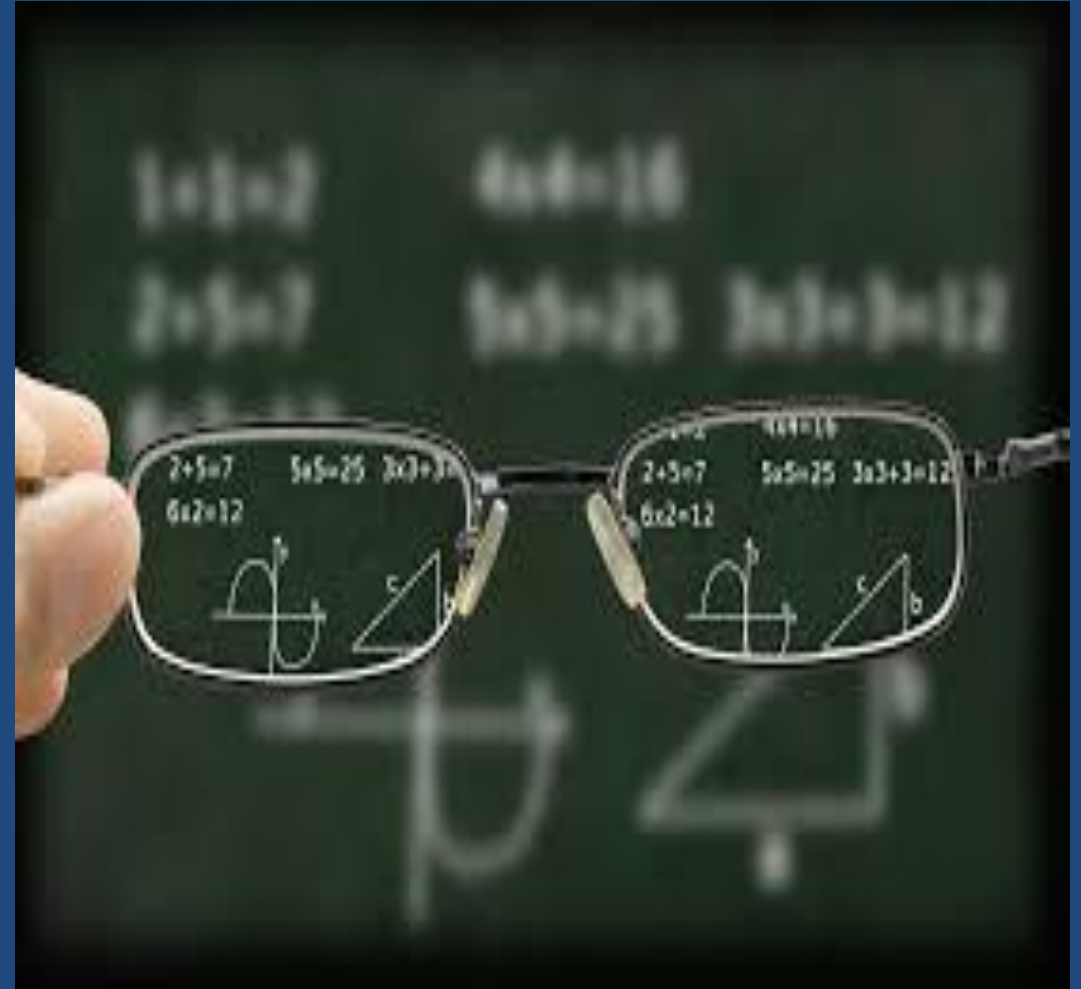
**Extended survival**— begins with completion of treatment for primary disease, remission of disease or both; dominated by watchful waiting , regular follow-up examinations, and perhaps intermittent therapy

**Permanent survival**- extended disease free survival when the likelihood of recurrence is sufficiently low

► **In the absence of a structured survivorship plan,**

**the current follow-up care plan-**

- ❑ **Myopic perspective**
- ❑ **Largely deals with anticipation and surveillance for recurrence**



# Routine follow-up plan

- ▶ **SURVIVORSHIP is Under-recognized phase of cancer continuum**
- ▶ **Follow-up care following cancer treatment is focused primarily on **surveillance** for disease recurrence**
- ▶ **Other significant health problems may persist or become apparent later in the course of cancer trajectory**
- ▶ **Success of an efficient initial treatment gets undermined by failing to anticipate and address later detrimental health effects.**

# Survivorship care plan

- ▶ 1<sup>st</sup> goal- Prevent disconnect between successful initial cancer therapy and sub-optimal long term follow-up care.
- ▶ Prepared by- primary oncologist
- ▶ Tailored to each survivor

## **Survivorship care plan**

### **Should include**

- ▶ **detailed cancer specific information**
- ▶ **detailed information of treatment history**
- ▶ **define surveillance schedules- and what ought to be done during both short and long term follow-ups**
- ▶ **identify health problems related to cancer therapy**
- ▶ **identify general health problems**
- ▶ **also, likely course of recovery, expected short-term toxicities related to treatment**



## Survivorship care plan

- ▶ Follow-up care is **complex**,
- ▶ involves a **number of disciplines**/departments and thus care might be poorly co-ordinated and fragmented
- ▶ Surveillance frequency and type varies.
- ▶ Because of lack of well defined, evidence based guidelines.
- ▶ And thus lack of consensus among providers of health care.
- ▶ 2<sup>nd</sup> goal- optimize the continuity and co-ordination of care

**The current recommendations- ASCO, NCCN are **consensus** based and not evidence based**

**As no evidence based guidelines, patients tend to receive more intense surveillance than needed**

**MORE CARE DOES NOT EQUATE TO BETTER CARE**

**Develop **evidence base surveillance guidelines and post treatment assessment guidelines** – to form a basis of survivorship**

**Lesser variability in clinical practice; more coordinated**

# Models for delivering survivorship care

1. **SHARED CARE MODEL**
2. **RISK BASED FOLLOW-UP CARE**
3. **CANCER SPECIFIC SURVIVORSHIP CLINICS**
4. **INSTITUTION BASED SURVIVORSHIP PROGRAMMES**

# 1. Shared care model

- ▶ Care is **shared and coordinated** between multiple health care providers
- ▶ Regular, personal communication and periodic knowledge transfer between specialists and primary care physicians
- ▶ \* study reported CRC survivors managed by oncologist and primary care physician more likely to receive recommended care compare to either alone
- ▶ Easily implemented- because it utilises the existing resources

\*Earle CC, Neville BA. Under use of necessary care among cancer survivors. Cancer 2004;101:1712–1719. [PubMed: 15386307]

## 2. Risk-based follow-up care

- ▶ Useful for survivors at **high risk** of health detriment, who require more **intense surveillance** and care
- ▶ differential surveillance requirements based on severity of disease, treatment characteristics
- ▶ Eg- Childhood cancers, Breast cancers
- ▶ Adaptable and can be tailored to specific needs of survivor

# 3. Cancer specific survivorship clinics

- ▶ Dedicated clinics dealing with specific cancer survivors
- ▶ Surgical, medical and radiation oncologists
- ▶ With social worker and psychiatry services
- ▶ Risk based assessment, care-coordination
- ▶ Eg- dedicated breast cancer survivorship clinic- lymphedema, body image changes, depression, weight control, cardiac **disease**

# 4. Institution-based survivorship programs


- ▶ Provide coordinated and tailored care to survivors of all cancers in a single clinical setting
- ▶ Potentially complex
- ▶ More efficient because uses shared clinical and research resources



**Enhancing cancer survivorship through  
research and innovation**



## Challenges and solutions to embed cancer survivorship research and innovation within the EU Cancer Mission

Mark Lawler<sup>1,2</sup> , Francesco De Lorenzo<sup>3,4</sup>, Pernilla Lagergren<sup>5,6</sup>, Francesco S. Mennini<sup>7,8</sup>, Saronas Narbutas<sup>9</sup>, Grazia Scocca<sup>3</sup>, Françoise Meunier<sup>10</sup> and the European Academy of Cancer Sciences

1 Patrick G Johnston Centre for Cancer Research, Queen's University Belfast, UK

2 European Cancer Organisation, Brussels, Belgium

3 European Cancer Patient Coalition, Brussels, Belgium

4 Italian Federation of Cancer Patients Organisations, Rome, Italy

5 Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institutet, Karolinska University Hospital, Stockholm, Sweden

6 Department of Surgery and Cancer, Imperial College London, UK

7 EEHTA CEIS, DEF Department, Faculty of Economics, University "Tor Vergata" Rome, Italy

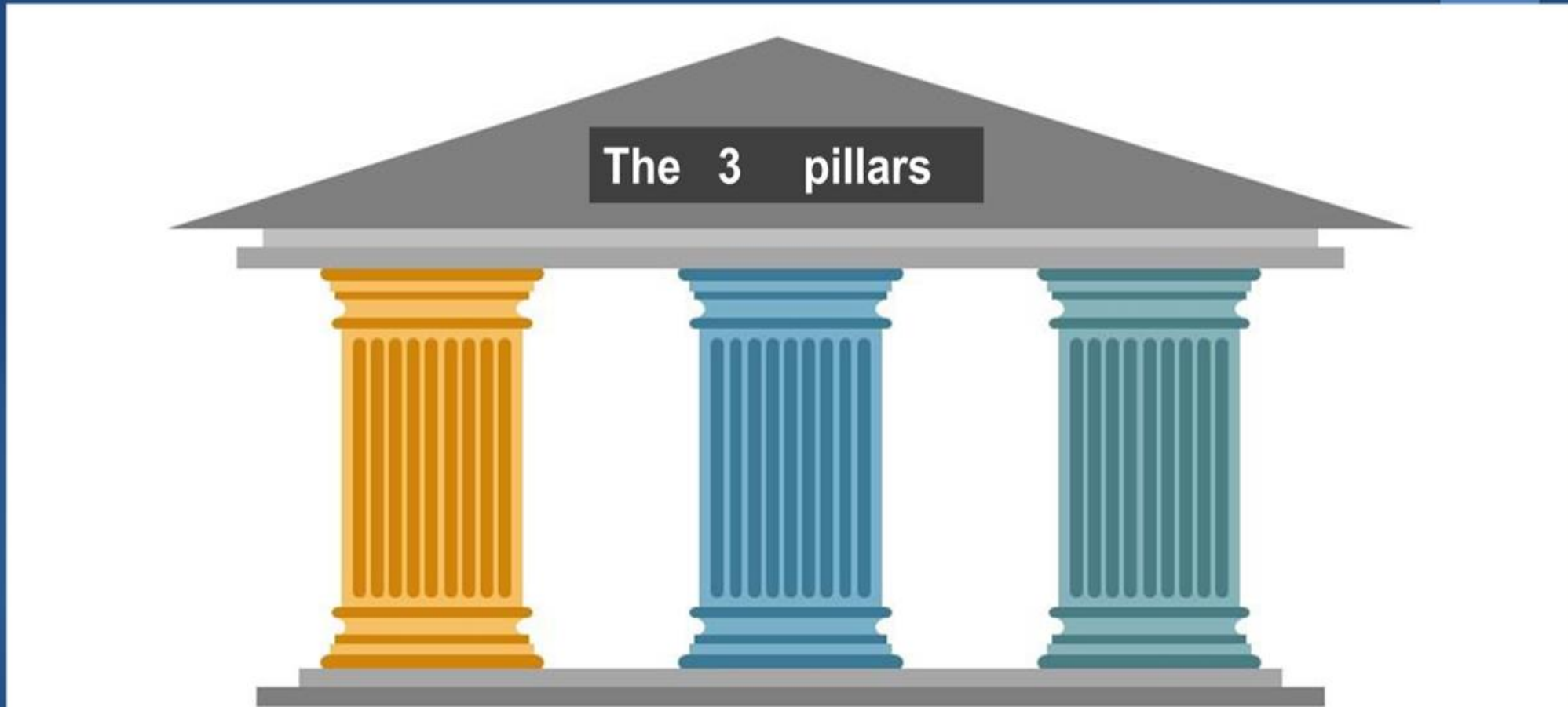
8 Institute of Leadership and Management in Health, Kingston University, London, UK

9 Lithuanian Cancer Patient Coalition, Vilnius, Lithuania

10 Federation of European Academies of Medicine, Brussels, Belgium

2021

## 3 distinct pillars for cancer survivorship research and innovation



▶ **Medical**

**Socio-economic**

**Politico-legal**

## **Challenges within the Medical Cancer Survivorship Research and Innovation Pillar**

*Challenge 1.1:* Cancer survivorship research is not sufficiently integrated into cancer research activity in Europe.

*Challenge 1.2:* Lack of a European Cancer Survivorship Research and Innovation Plan.

*Challenge 1.3:* Lack of robust data intelligence to underpin cancer survivorship research prioritisation.

*Challenge 1.4:* Research activities often do not underpin cancer survivors' needs.

*Challenge 1.5:* Lack of integration of patients into the research and innovation agenda, with limited active involvement in survivorship research.

*Challenge 1.6:* Limited interdisciplinary research activity in the survivorship domain and a paucity of survivorship research tools.

*Challenge 1.7:* Lack of appreciation of the potential value of the international collaborative research dimension.

*Challenge 1.8:* Paucity of specific research programmes for children, adolescents and young adult survivors.

*Challenge 1.9:* Lack of focus on Palliative/End of Life research.

*Challenge 1.10:* Improve cancer survival such that an average of 70% survival is achieved across Europe by 2035 (the 70:35 vision).



# **1. Cancer survivorship research is not sufficiently integrated into cancer research activity**

- ▶ **Ensure that survivorship is an integrated component of cancer research**
- ▶ **Clear protocol should be set at the beginning of each treatment for evaluation of late effects of treatment.**

## **2.Lack of Cancer Survivorship Research and Innovation plan**

- ▶ **Cancer survivorship research and innovation plan to be embedded in a country's cancer programme**

### **3. Lack of robust data intelligence to underpin cancer survivorship research prioritisation**

- ▶ **Clinical registries with quality data combined with long term follow-up information, including HRQOL data across centres and countries**
- ▶ **Define subgroups- age (at treatment, at followup), diagnosis, treatment**

## **4. Research activities often do not underpin cancer survivors' needs**

- ▶ **Cancer survivors should be active participants in defining their long term needs**
- ▶ **Eg- Fertility preservation, mental health, dental health**
- ▶ **And research should then prioritise these areas**

## **5. Limited interdisciplinary research in survivorship domain**

- ▶ **Survivorship research activities should promote interdisciplinary approach**
- ▶ **Multiple disciplines- added insights – best solutions**

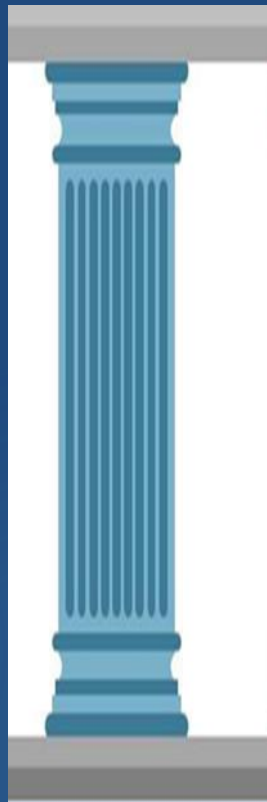


## **6.Lack of international collaboration in survivorship research**

- ▶ **Collabroration between countries to help set research priorities in cancer survivorship**
- ▶ **PRO should be captured, reported and compared with data from international partners.**

## 8. Lack of focus on palliative/end of life research

- ▶ **Promote research for full spectrum of palliative cancer patients**
- ▶ **- chronic cancer diagnosis under prolonged treatment**
- ▶ **- end of life care**
- ▶ **- very poor outcomes where PRO measures are challenging**



**Socio-economic**

## Delineating the challenges within the Socio-Economic Cancer Survivorship Research and Innovation Pillar

### **Challenges within the Socio-Economic Cancer Survivorship Research and Innovation Pillar**

*Challenge 2.1:* Lack of detailed knowledge of the specific social determinants of cancer inequalities that impact on cancer survivorship.

*Challenge 2.2:* Paucity of relevant tools to assess health-related quality of life (HRQoL) in cancer survivors.

*Challenge 2.3:* Lack of accurate robust data on the economic burden of cancer for cancer survivors.

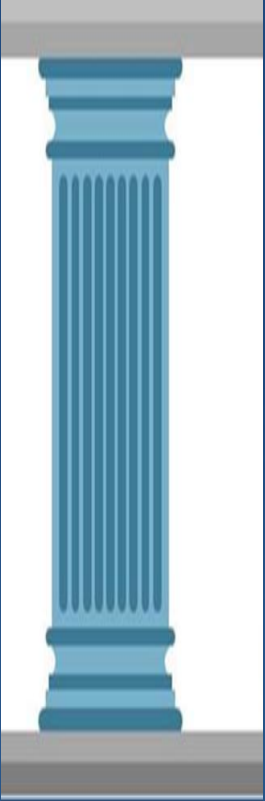
*Challenge 2.4:* Paucity of data on the impact and cost-effectiveness of interventions for cancer survivors.

*Challenge 2.5:* Lack of financial support for cancer survivorship research at European level.

*Challenge 2.6:* Limited integration of social issues into cancer survivorship research activities.

# **1. Lack of detailed knowledge of specific social determinants of cancer inequalities that impact on cancer survivorship**

- ▶ **Promote research to identify determinants of inequalities linked to social rehabilitation**
- ▶ **Research should better assess impact of cancer and the treatment on people's daily lives to understand and be able to target the sources of inequalities**
- ▶ **Promote research on social issues- factors affecting return to work, access to education, loan.**
- ▶ **Research on how to offer skill development to survivors**



**Socio-economic**

## **2. Paucity of relevant tools to assess the HR-QOL in cancer survivors**

- ▶ **Maximise the use of existing tools to compare between different studies**
- ▶ **Create and evaluate new research tools (EORTC)**



**Socio-economic**

### **3. Lack of data on economic burden of cancer for cancer survivors**

- ▶ **Promote research for economic evaluations of indirect costs – loss of productivity of survivors, financial burden on survivors and their families**
- ▶ **Research should better assess impact of cancer and the treatment on people's daily lives to understand and be able to target the sources of inequalities**



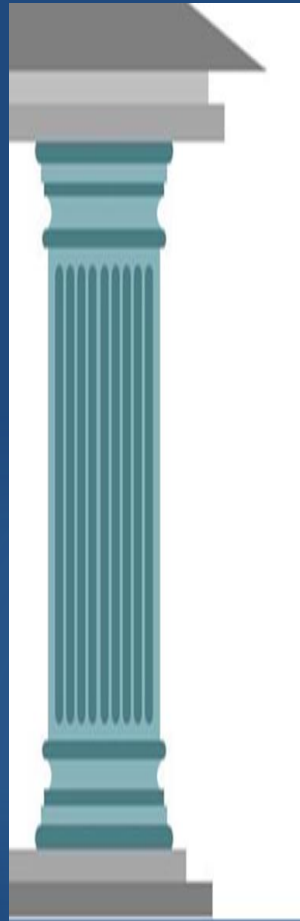
**Socio-economic**

## **4. Paucity of data on cost-effectiveness of interventions for cancer survivors**

- ▶ **Evaluate cost-effectiveness of interventions for survivors- supportive care, rehabilitation, palliative care**



**Socio-economic**



Politico-legal

## Delineating the challenges within the Politico-Legal Cancer Survivorship Research and Innovation Pillar

### **Challenges within the Politico-Legal Cancer Survivorship and Innovation Pillar**

*Challenge 3.1:* Limited detailed intelligence on the legal aspects of discrimination for cancer survivors.

*Challenge 3.2:* Lack of research on the legal aspects of reintegration of cancer survivors back into society.

*Challenge 3.3:* Paucity of research that specifically focusses on the activities and requirements of Cancer Patient Advocacy Groups.

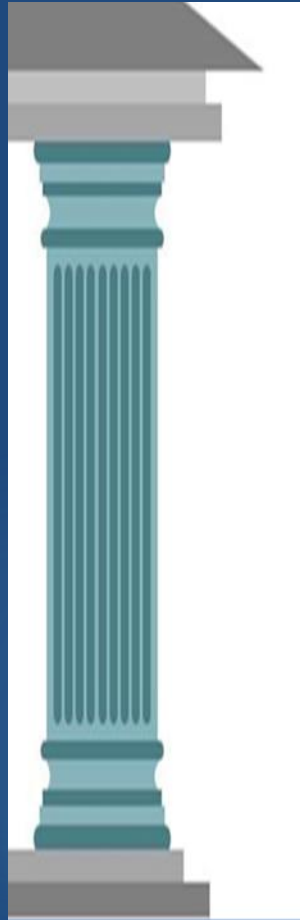
*Challenge 3.4:* Lack of knowledge of the stigma associated with cancer.

*Challenge 3.5:* Lack of specific research on survivorship support for patients and for patient empowerment.



# **1. Limited detailed intelligence on legal aspects of discrimination for cancer survivors**

- ▶ **Promote studies on causes and find out legal aspects of discrimination against cancer patients**
- ▶ **How this discrimination can be mitigated**



Politico-legal

## **2. lack of research on legal aspects of re-integration of cancer survivors back into the society**

- ▶ **Adopt the legal provisions in promoting reintegration**
- ▶ **And evaluate its adoption**

### **3. Lack of knowledge of stigma associated with cancer**

- ▶ **Research to define challenging stigmas associated with cancer**
- ▶ **Promote cultural shift- cancer is not a death sentence;**
- ▶ **and once cure achieved, survivors have the right to return to normal life.**

## 4. Lack of specific research on survivorship support

- ▶ **Promote self management of survivors by developing tools**
- ▶ **Online programmes and e-health tools- potential late effects and their management**

# PHYSICAL ACTIVITY AND EXERCISE

- ▶ **Focus on improving the translation of exercise oncology research into practice using a variety of quantitative and qualitative research designs**
- ▶ • **Investigate referral pathways to evidence-based exercise programs**
- ▶ • **Identify cancer survivors' challenges in incorporating exercise/physical activity into their life**

# HEALTHY LIFESTYLE CHANGES

- ▶ • Consider lifestyle interventions in both common and rarer cancers, as well as throughout the survivorship trajectory
- ▶ • Consider the use of **mobile internet capable technologies** and devices to promote **behavior** change

# Take home message

- ▶ **Survivorship phase is as important as the treatment phase**
- ▶ **A successful treatment will only be truly successful when the survivor is leading a satisfied life after the treatment phase is over**
- ▶ **Survivorship care plan**
- ▶ **Emphasise on research in the domain of cancer survivorship – evidence based survivorship care plans.**

JUNE is *National*  
**CANCER**  
**SURVIVOR**  
MONTH

A purple awareness ribbon is positioned behind the text, starting from the bottom left and looping around the word 'SURVIVOR'.

**Thankyou.**