



3rd Victorian
CANCER SURVIVORSHIP CONFERENCE

A 2020 VISION
Building on learnings ... partnering for success

12-13 MARCH 2020
Crown Convention Centre, Melbourne



Defining and Delivering Quality Survivorship Care

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Disclosures

- I am a stockholder and advisor to Carevive Systems
- I will not discuss any drugs during this presentation



Objectives:

- Analyze cancer survivorship trends
- Define cancer survivorship
- Describe quality survivorship care
- Discuss components of quality survivorship care



Outline

- **Cancer trends**
- Defining survivorship
- Quality Survivorship Care
- Strategies for Care



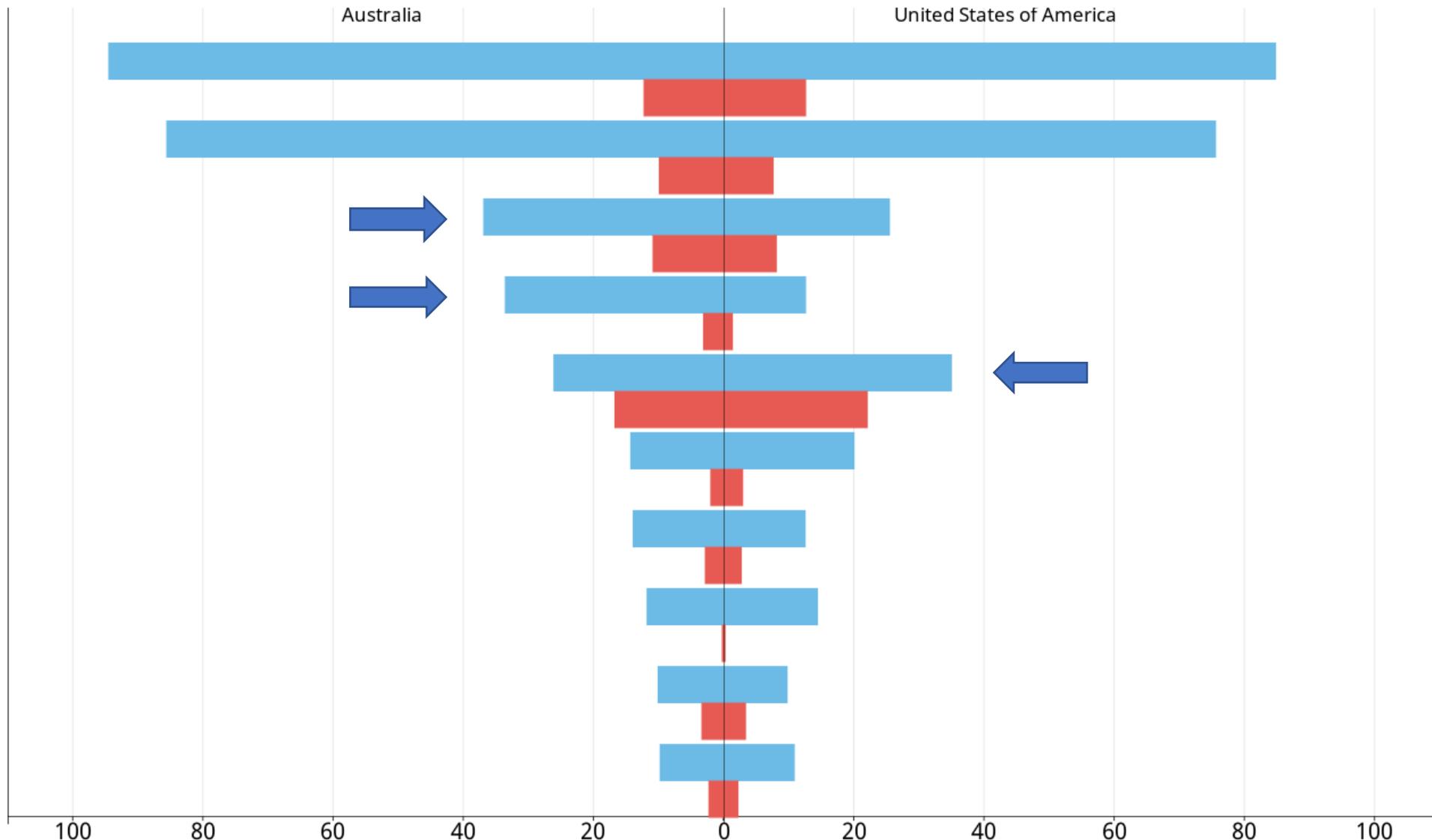
Estimated age-standardized incidence and mortality rates (World) in 2018, both sexes, all ages

Incidence
Mortality

Australia

United States of America

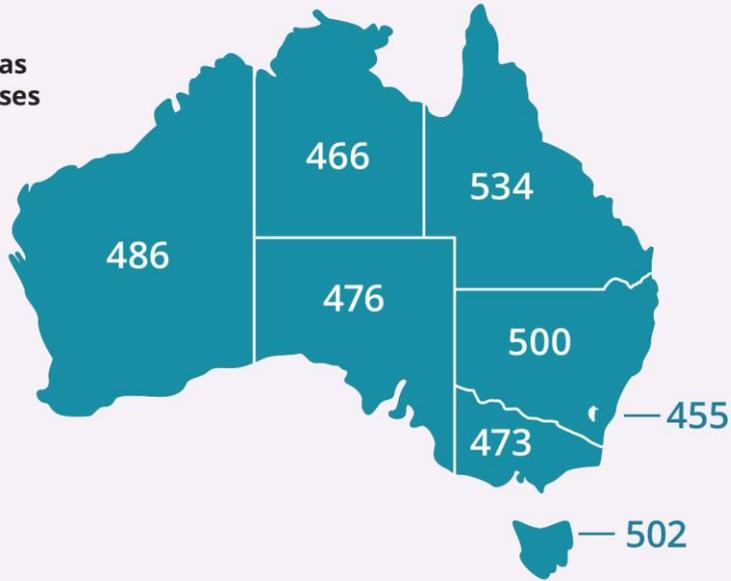
Breast
Prostate
Colorectum
Melanoma of skin
Lung
Corpus uteri
Non-Hodgkin lymphoma
Thyroid
Leukaemia
Kidney



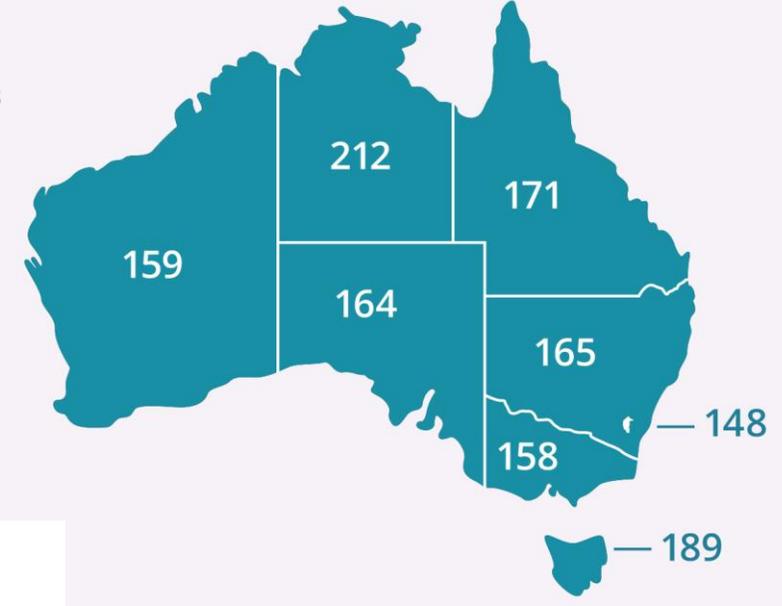
Data source: Globocan 2018
Graph production: Global Cancer Observatory (<http://gco.iarc.fr>)

Incidence and Mortality Rates by State (all cancers combined)

Rates shown as number of cases per 100,000



Rates shown as number of cases per 100,000



By age 85...



1 in 2 will develop cancer.



1 in 5 will die from cancer.



Source: AIHW Australian Cancer Database 2015.



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Cancer in Australia

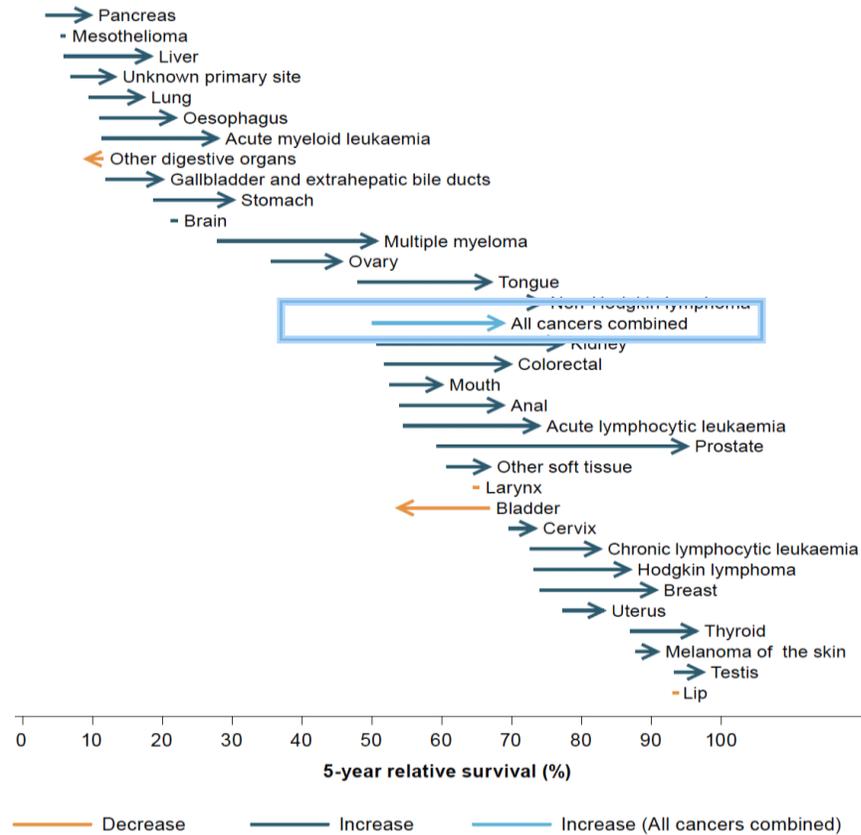


Time since Diagnosis	Number	% Population
5 years	431,704	1.8%
10- years	701,247	3%
33 years*	1,082,511	4.6%

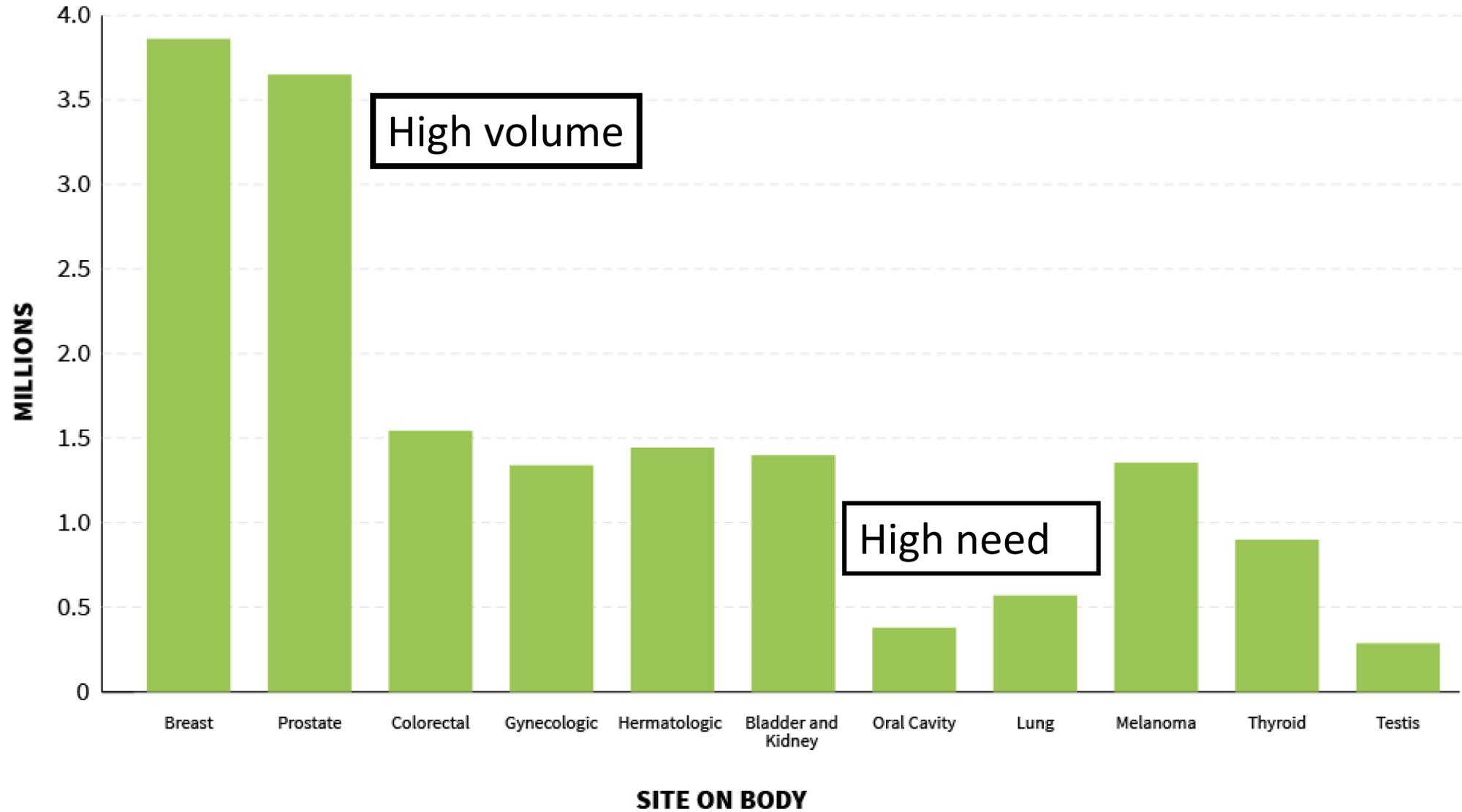
Source: AIHW Australian Cancer Database 2015. *Maximum that could be calculated

From 1990→2015 5-year relative survival for all cancers increased from 50% to 69%

Figure 7.6: Survival trends for selected cancers, between 1986–1990 and 2011–2015



Estimated Number of Cancer Survivors in the U.S., by Site



REFERENCE: American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta: American Cancer Society; 2016.

Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016), Cancer treatment and survivorship statistics, 2016. CA: A Cancer Journal for Clinicians.

Outline

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The Face of Cancer



Cancer Survivorship Defined

- A person is a cancer survivor from diagnosis for the remainder of their life.
- People living with and beyond cancer.



Figure 3. Integration of care for cancer survivors



Updated NCI Survivor and Survivorship Definitions

- **Cancer Survivor:** An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.
- There are **many types of survivors**, including those living with cancer and those free of cancer.
- This term is meant to **capture a population** of those with a history of cancer **rather than to provide a label** that may or may not resonate with individuals.

Adapted from the National Coalition for Cancer Survivorship

<https://cancercontrol.cancer.gov/ocs/statistics/index.html#definitions>



Survivorship Defined

- **Living cancer free**

- For remainder of life
- Experiences ≥ 1 treatment complication
- But dying after a late recurrence
- But develops another cancer

- **Living with cancer**

- Intermittent periods of active disease on/off treatment
- Continuously without disease free period



Survivorship Definition and Attributes

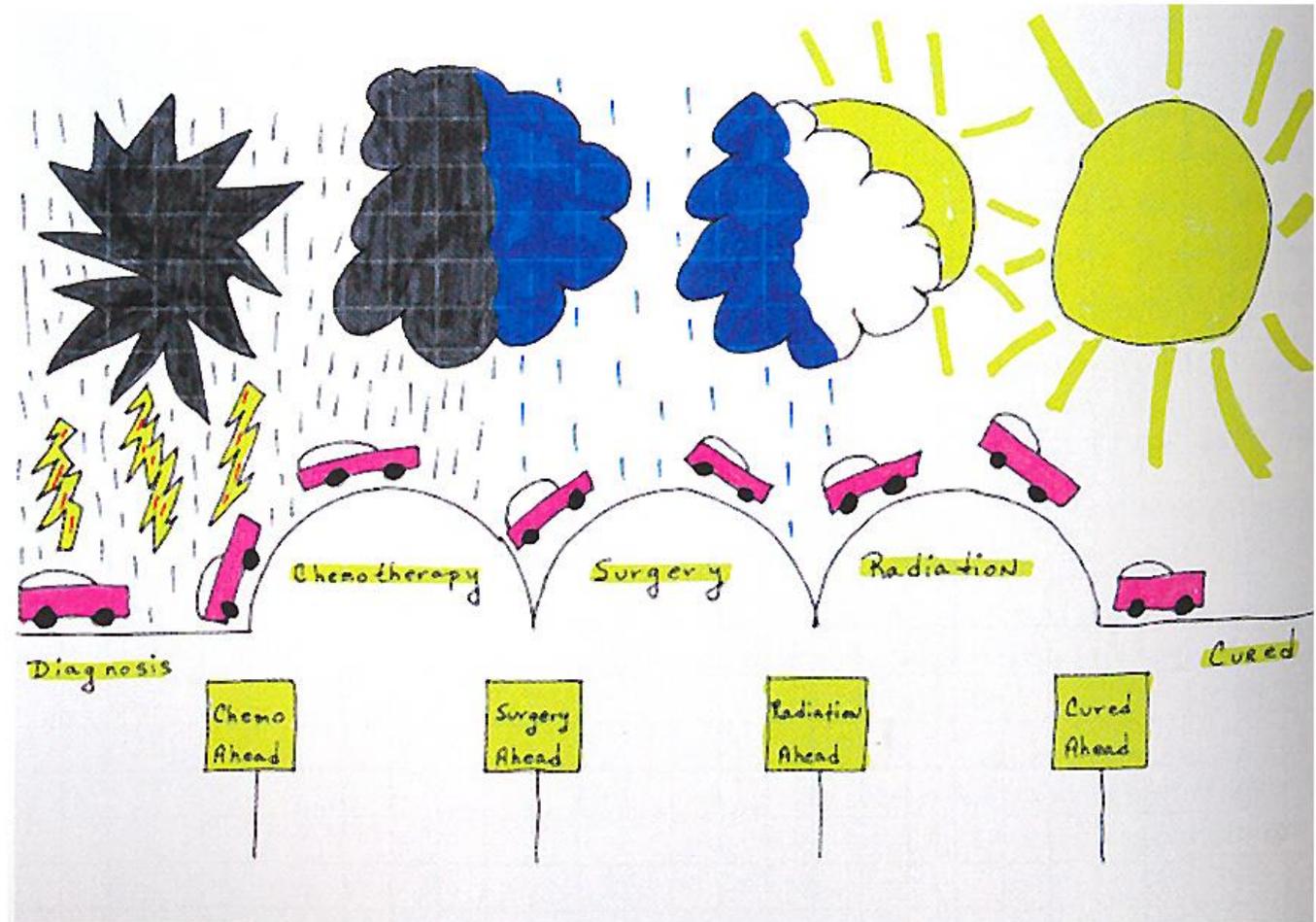
- Defined as those who have lived through a potentially deadly or life altering event.
- It is a dynamic process
- It involves uncertainty
- It is a life changing experience
- It has duality of positive and negative aspects
- It is an individual experience with universality

- Berry, LL., Davis, S., Flynn AG, et al. (2019). Is it time to reconsider the term 'cancer survivor'. *J Psychosocial Oncology*, 37(4):413-426.
- Doyle, N. (2008) Cancer survivorship: evolutionary concept analysis. *J Adv Nursing*, 62(4): 499-509.
- Hebdon, M. (2015). Survivor in the cancer context: a concept analysis. *J Adv Nursing*, 71(8): 1774-1786.
- Marzorati, C., Riva, S., Pravettoni, G. (2017). Who is a cancer survivor? *J Cancer Education*; 32:228-237.
- Peck (2008) Survivorship: A concept analysis. *Nsg. Forum*, 43(2), 91-102.



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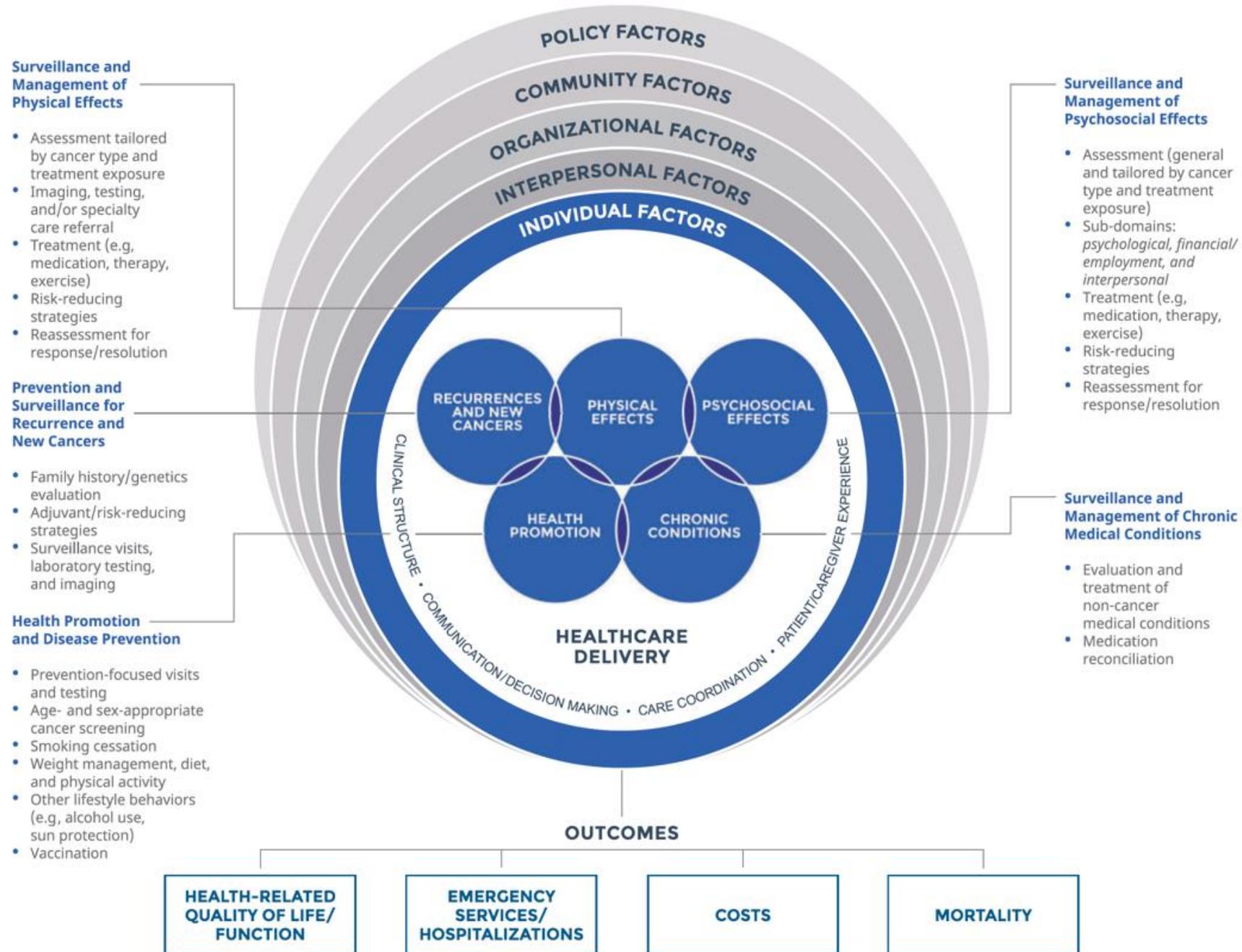


Bumps on the Road of Life



Quality of Cancer Survivorship Framework

Nekhlyudox et al. (2019). *JNCI J Natl Cancer Inst*; 111(11): djz089





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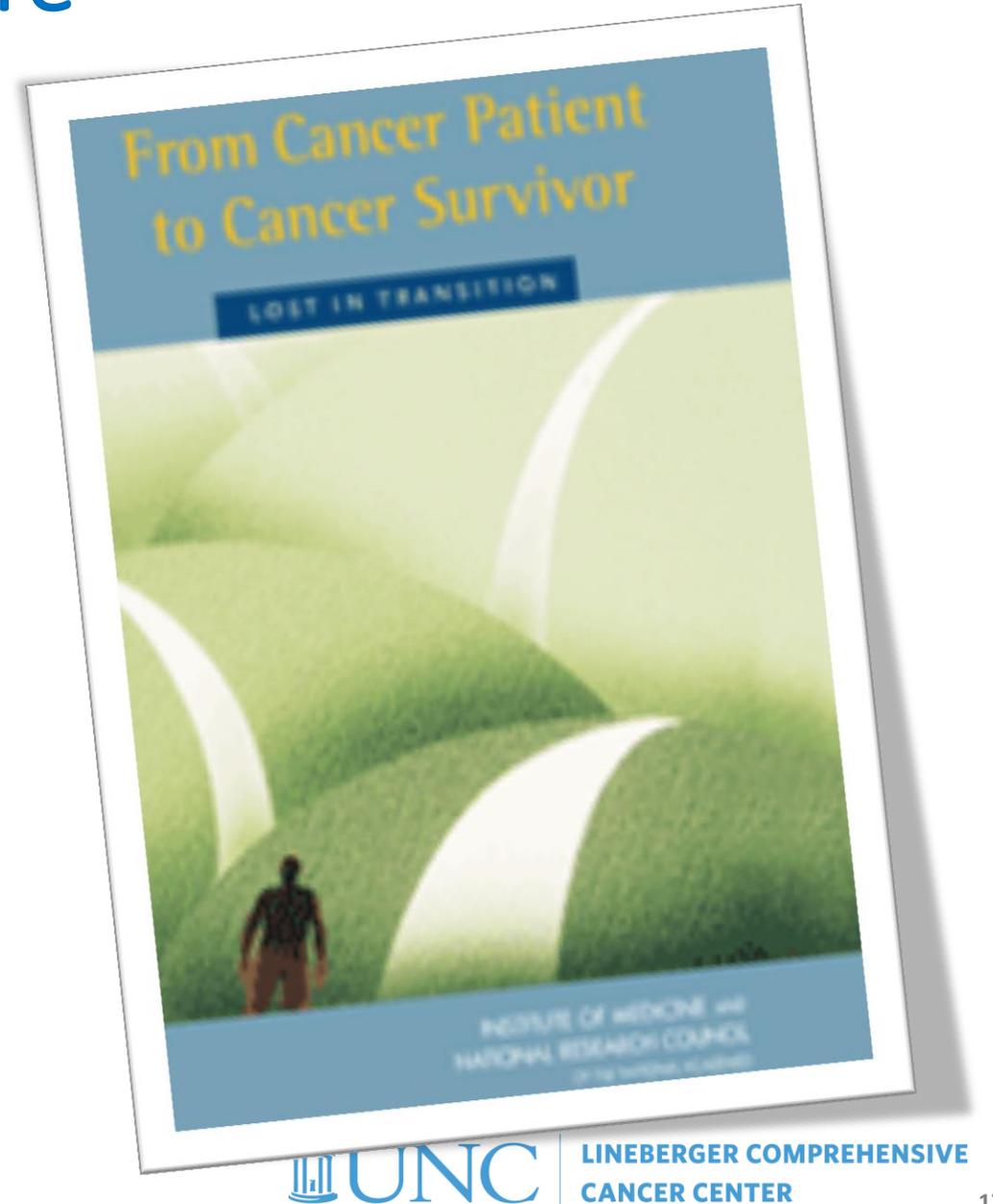
Revelations



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Components of Survivorship Care

- **Prevention and Surveillance for Recurrences and New Cancers**
- **Management of Long-Term and Late Effects: Physical**
- **Management of Long-Term and Late Effects: Psychosocial**
- **Health Promotion**
- **Care Coordination**



Prevention and Surveillance for Recurrences and New Cancers



The Path



Prevention and Surveillance for Recurrences and New Cancers

Gaps include:

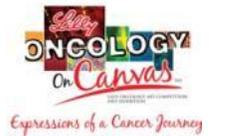
- Understanding of **cancer, cancer recurrence and survivorship** in different populations:
 - Different ages, ethnicities, immigrant status, SES, LGBTQI, and rural populations
 - Improving recruitment of diverse participants into clinical trials
- Better epidemiologic surveillance:
 - Registry capture of subsequent cancers, recurrences, detailed treatment history, risk factors, screening behaviors, and patient-reported outcomes
 - Better identification of at-risk populations, particularly with emerging treatments and immunotherapies
- **Surveillance schedules:**
 - What are the optimal evidence-based schedules for screening and follow-up?
 - Optimal frequencies by risk
 - Harms associated with too much screening



Management of Long-Term and Late Physical Effects



Healing Mandala



Management of Long-Term and Late Effects: Physical

Gaps include:

- Profiles of **natural history** and **relevant biomarkers** of late and long-term effects in prevalent adult onset cancers
- Identify and collect **consistent core measures** to capture comorbid conditions and functional impairment
- Shared process for information exchange, goal/priority setting, activation for **self-management** of risks for and ongoing management of long-term and late effects to achieve personal health goals



Management of Long-Term and Late Psychosocial Effects



Shiny
ONCOLOGY
On Canvas
Expressions of a Cancer Journey



FEELINGS OF DISFIGURATION



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Management of Long-Term and Late Effects: Psychosocial

Gaps include:

- Implementation of psychosocial interventions in **real-world settings** (e.g., community oncology, primary care)
- Psychosocial focus on those living with **advanced cancers**, recurrences, or additional cancers
- Addressing **vulnerable populations** (e.g., low SES, rural, rare cancers, and LGTBQI)
- Addressing the **unmet needs of caregivers**
- **Identifying strategies to prevent and mitigate using a stratified approach to identify optimal intervention time frame and self-management approaches**



Health Promotion



Hurdles of Hope



Health Promotion

Gaps include:

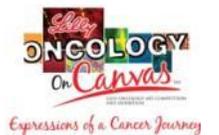
- Main focus: health behaviors including **diet, physical activity, weight management**, smoking, sun protection, and alcohol use (there is less work on alcohol than other behaviors)
- Tailoring and triaging people to the **right programs at the right time** with interventions addressing understudied populations [one size does not fit all]
- **Implementation science** for health behaviors in cancer survivors— especially focusing on multiple health behaviors
- Identify **mechanisms/biomarkers** that would be affected by interventions and are linked to recurrence and poorer outcomes, including late effects
- Identify **exercise prescriptions**, which may be more specific for cancer survivors than general physical activity guidelines for Americans



Care Coordination



Color of Courage



Care Coordination

Gaps include:

- Research to meaningfully **engage all stakeholders** and coordinate post-treatment care for patients beyond the creation of a survivorship care plan
- Factors important for **stratifying risk-based care**
- Key outcomes to assess **quality care coordination**
- Policies that could effectively **incentivize the provision of coordinated cancer care**



COSA 2019 Survivorship Care Recommendations

1. Healthcare teams should implement a systematic approach to enhance coordinated and integrated **survivor-centered care**.
2. **Stratified pathways** of care are required.
3. Survivorship Care should **support wellness**, healthy lifestyle and 1^o and 2^o prevention while preventing and managing treatment related symptoms, late-term effects and comorbidities, in addition to cancer surveillance.
4. At transition to follow-up care, healthcare teams should develop a treatment summary and **survivorship care plan**.
5. Survivors require **equitable access** to services in a timely manner, while minimizing unnecessary use of healthcare services and resources.



Model of Survivorship Care: Appendix 1

Cancer Survivorship: Living well with and beyond a cancer diagnosis

PRINCIPLES OF CARE

- Survivor centred (enabling, engaging, empowering)
- Integrated care across all service levels at every time point
- Coordinated care
- Promote, prevent, manage
- Accessible and equitable

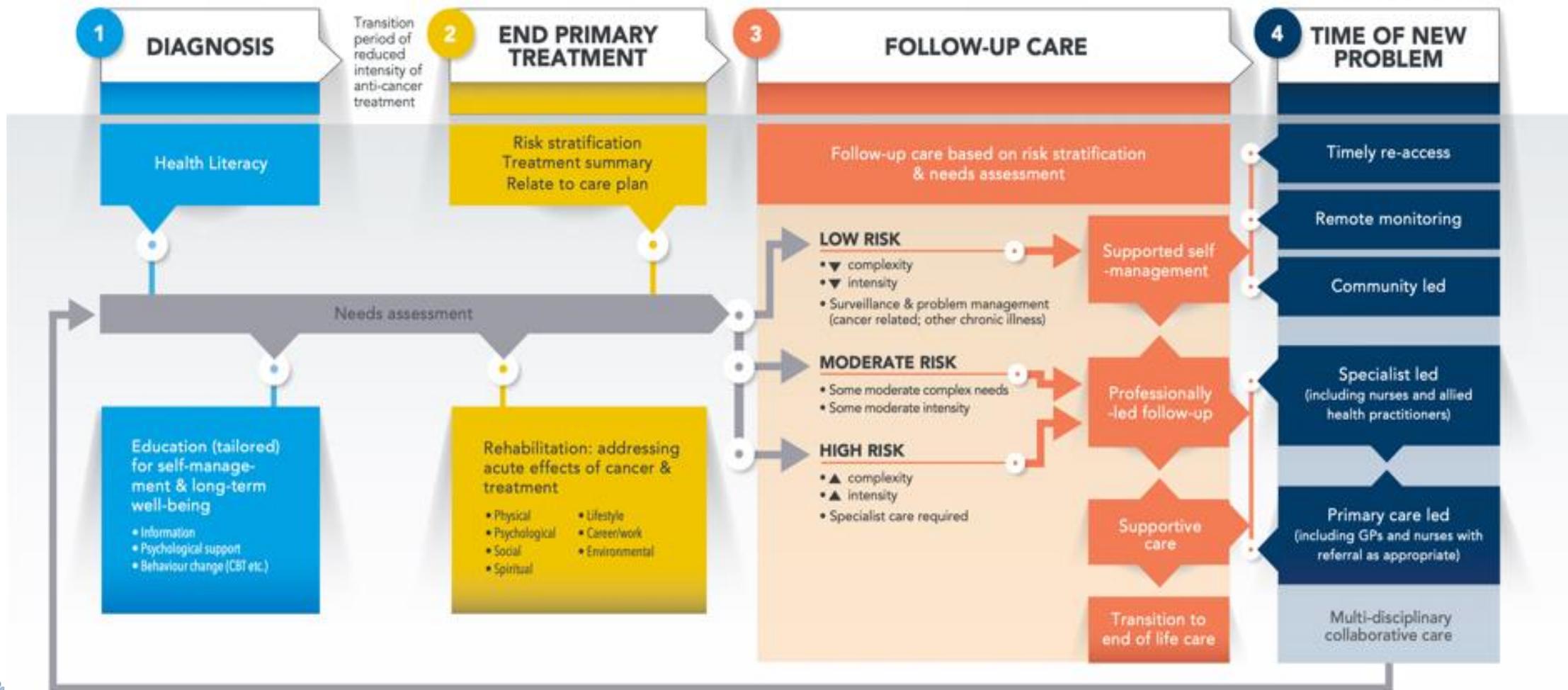


Figure 1. Model for wellness in cancer survivorship



Essential Components Of Survivorship Care

- Risk Stratification
- Care Plan
- Care Coordination
- Time Factors
- Tools

RISK STRATIFICATION

- Level of risk associated with cancer type
- Needs assessment
- Short & long term effects of treatment
- Comorbidities
- Patient ability & motivation to self-manage
- Level of professional involvement required

CARE PLAN

- Aims to document main concerns of survivor & health professional & agreed actions for:
 - Surveillance
 - Management
 - Discussion
 - Patient action
 - Rehabilitation
 - Clinical team follow-up, sign posting on referral

CARE COORDINATION

- Places survivor & their needs at centre of healthcare & wellness interactions
- Facilitates communication between all health professionals
- Gets survivors to the right services at the right time
- Ensures regular review of survivorship care plan and survivor needs
- Ensures appropriate follow-up for cancer recurrence and late effects of treatment

TIME FACTORS

- Survivors engage with services they need when they need them
- Survivor priorities & needs are addressed from most to least urgent
- Survivor time in healthcare environments is minimised to that required to maintain health & well-being
- Survivors have rapid access to healthcare support when required for cancer & treatment related events
- Resource use is minimised to the level that is effective and meaningful

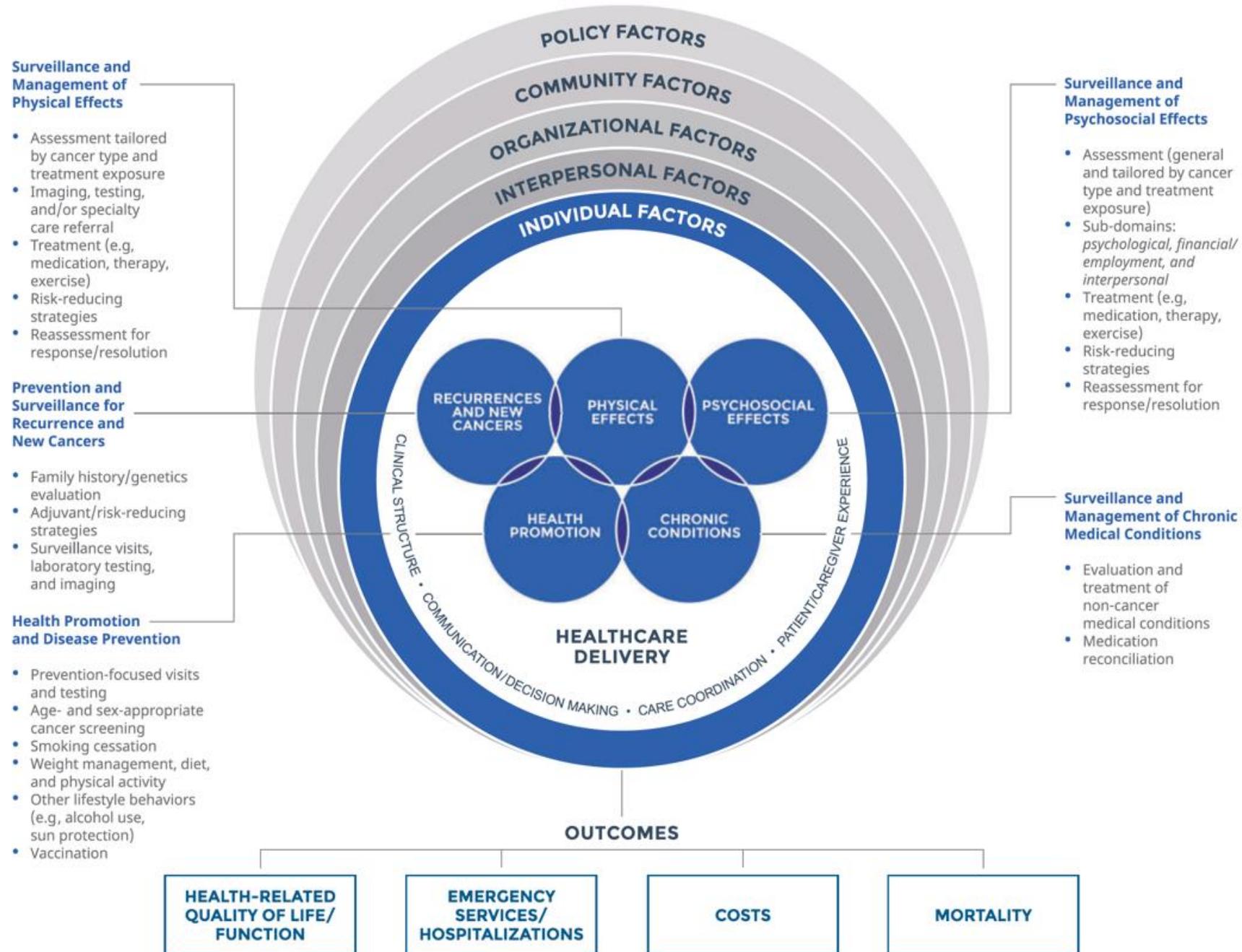
TOOLS

- Needs assessment tools
- Care plan (electronic)
- Directory of services
- Referral pathways
- Motivational interviewing
- Telehealth tools
- Information & support services



Quality of Cancer Survivorship Framework

Nekhlyudox et al. (2019). *JNCI J Natl Cancer Inst*; 111(11): djz089



Conclusions

- Current cancer care cannot be sustained without addressing the needs of survivors.
- Subgroups of survivors have greater unmet needs.
- Non-medical aspects of survivorship care are not as well integrated into cancer care.
- We need to develop *and implement* a range of evidence-based programs in a variety of models based on patient risk.
- More research is needed in all components of survivorship care linking to clearly identified outcomes.





*When Life Is Sewn Back Together,
It Has Changed*



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