

Patient Perspective

Pancreatic Cancer Action Network Japan
Yoshiyuki Majima



PANCREATIC CANCER ACTION NETWORK
ADVANCE RESEARCH. SUPPORT PATIENTS. CREATE HOPE.

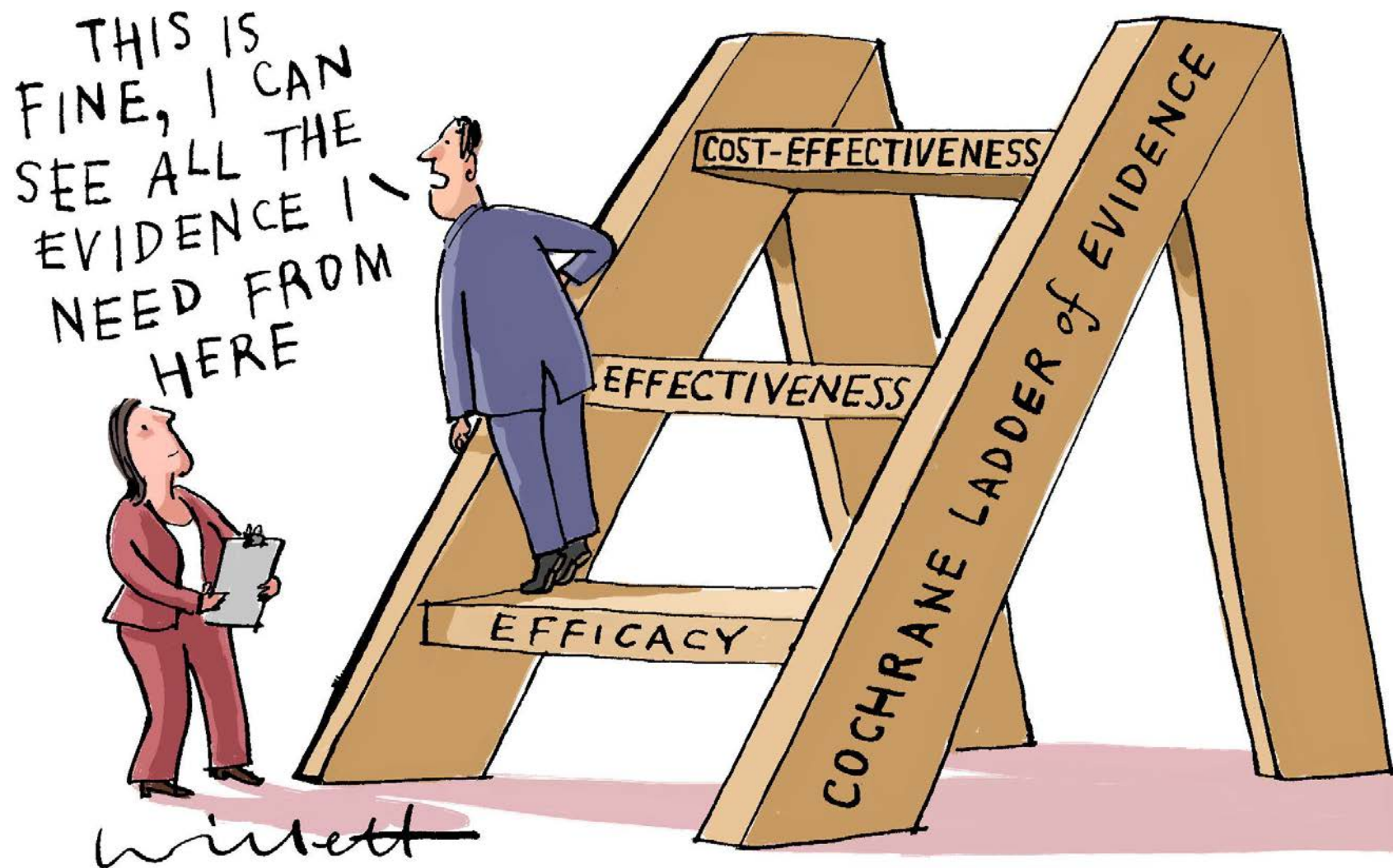




Background

- Cancer Care:
 - ✓ Shift in the health policy climate
 - ✓ Need to improve values in cancer care
 - ✓ Advocates are active in drug development
- My Experience:
 - ✓ Experienced 3 types of tumors







The Stakeholders

Many stakeholders with different interests.

- Patient advocates: Have the most vested interest in securing timely access to effective treatments in order to improve outcomes/QOL.
- Physicians: Treatment options for best outcome.
- Regulators: Fairness and diligence in assessing the risk/benefit ratio according to their methods of appraisal.
- Government agencies: Policy and direction on best spending practices to ensure overall good health of population, while managing sustainable health care system.



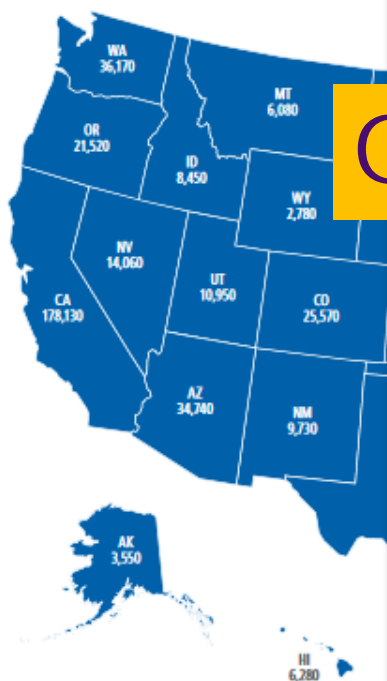
Changing Landscape of Oncology



Cancer Facts and Figures USA

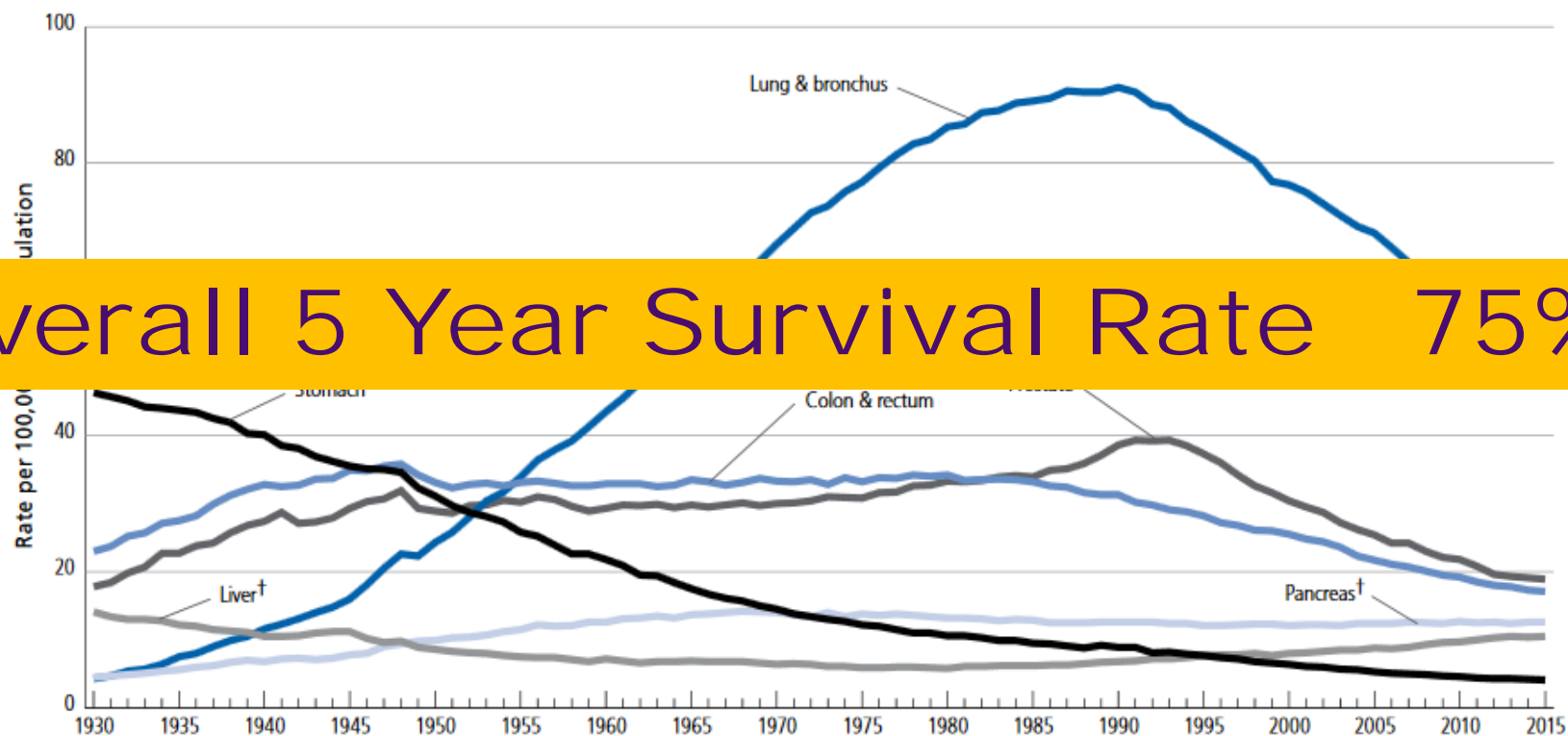


Cancer Facts & 2018



Estimated numbers of new cancer cases for 2018, excluding b...
Estimates are not available for Puerto Rico.
Note: State estimates are offered as a rough guide and should

Figure 1. Trends in Age-adjusted Cancer Death Rates* by Site, Males, US, 1930-2015



*Age adjusted to the 2000 US standard population. †Mortality rates for pancreatic and liver cancers are increasing.

Note: Due to changes in ICD coding, numerator information has changed over time. Rates for cancers of the liver, lung and bronchus, colon and rectum, and uterus are affected by these coding changes.

Source: US Mortality Volumes 1930 to 1959, US Mortality Data 1960 to 2015, National Center for Health Statistics, Centers for Disease Control and Prevention.

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Overall 5 Year Survival Rate 75%

ASCO: Financial Toxicity of Cancer Care



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An American Society of Clinical Oncology Journal

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PATIENT AND SURVIVOR CARE

Financial toxicity of cancer care: Defining pathways of decline vs resilience.

[Grace L. Smith](#), [Lisa M Lowenstein](#), [Susan K. Peterson](#), [Alyssa G. Rieber](#), [Nathan Goodwin](#), [Pragati G Advani](#).

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Abstract

e22150

Background: "Financial toxicity", the patient experience of financial declines due to costs of treatment, occurs in about half of cancer patients. It is unknown why some cancer survivors persist in severe decline while others find financial resilience. We identified pathways differentiating trajectories of decline vs

resilience in cancer survivors. **Methods:** We conducted semi-structured interviews in 62 cancer survivors from a comprehensive care center (n = 30), county safety-net

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COMPANION ARTICLES

No companion articles

ARTICLE CITATION

DOI: 10.1200/JCO.2018.36.15_suppl.e22150
Journal of Clinical Oncology 36, no. 15_suppl
- published online before print.

WE RECOMMEND

JAMA: Financial Toxicity of Cancer Care in America



JAMA Network

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Journals



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May 2018

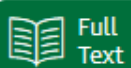
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My Unfortunate Introduction Into the Financial Toxicity of Cancer Care in America—March Forth

Fumiko Chino, MD¹

» Author Affiliations

JAMA Oncol. 2018;4(5):628-629. doi:10.1001/jamaoncol.2017.4436



Full
Text

March fourth. It wasn't just a date, but a command. Maybe it's cliché, but in my own defense, "march forth" chose me.

My husband was diagnosed at age 27 as having aggressive neuroendocrine cancer. Fourteen months, 27 kg, and 3 hospitalizations later, Andrew died. On March 4, 2007, the life we had planned together—my art career, his work as an innovative computer scientist, the children we hoped to raise—was over before it had really even begun.

Andrew had graduate student health insurance when he learned 2 fateful diagnoses: (1) his months of vomiting and weight loss were due to a fast-spreading tumor and (2) he was grossly underinsured. Our subsequent

struggle through the health care system, as many Americans are, is a

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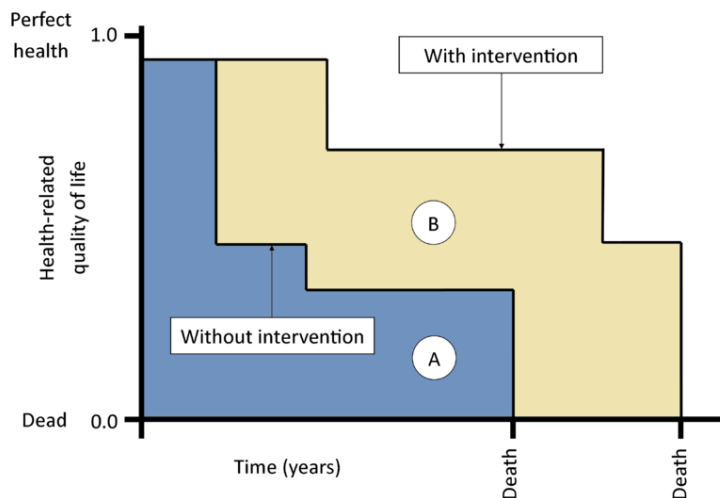
Price is what you pay.
Value is what you get.

Warren Buffet





- QALY
- EQ-5D



健康関連QOLの評価尺度

包括的(汎用的)尺度

➤どのような疾患にも適用可能なように一般的な状態を評価するもの

○ QALY (Quality-adjusted Life Year : 質調整生存年) 算出に用いるもの

例) EQ-5D, HUI, SF-6Dなど

EQ-5D (EuroQol 5 Dimension), HUI (Health Utilities Index), SF-6D (Short Form 6 Dimension)

○ QALY算出に用いないもの

例) SF-36, WHOQOL, など

SF-36 (Short Form 36)

疾病特異的尺度

➤疾病に特異的な症状などについて評価するもの

例) がん(EORTC, FACT-Tax等)、呼吸器疾患 (SGRQ等) など

EORTC: European Organisation for Research and Treatment of Cancer, FACT-Tax (Functional Assessment of Cancer Therapy-taxane), SGRQ (St. George's Respiratory Questionnaire)



ASCO defined framework to determine the value of different cancer treatments. “Value” is defined by:

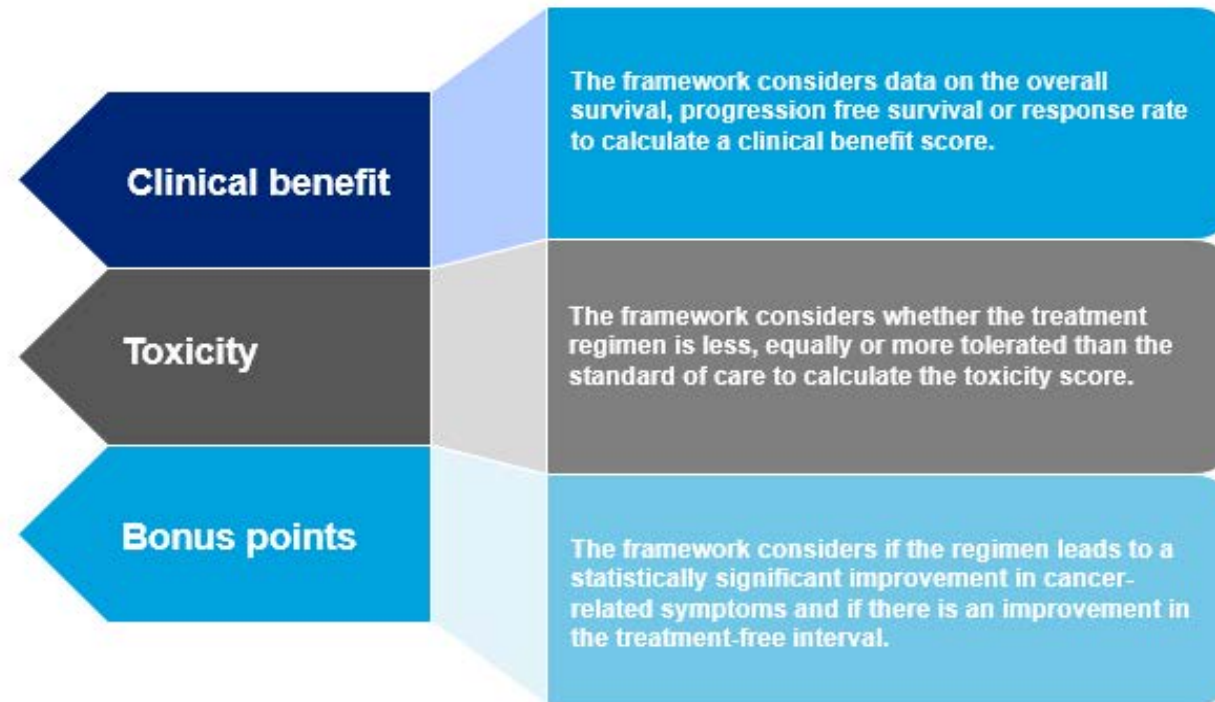
- **Clinical Benefit:** an improvement in survival
- **Toxicity:** adverse events, those that affect QoL or daily living.
- **Cost:** Expenses incurred by patients, society, and insurers.



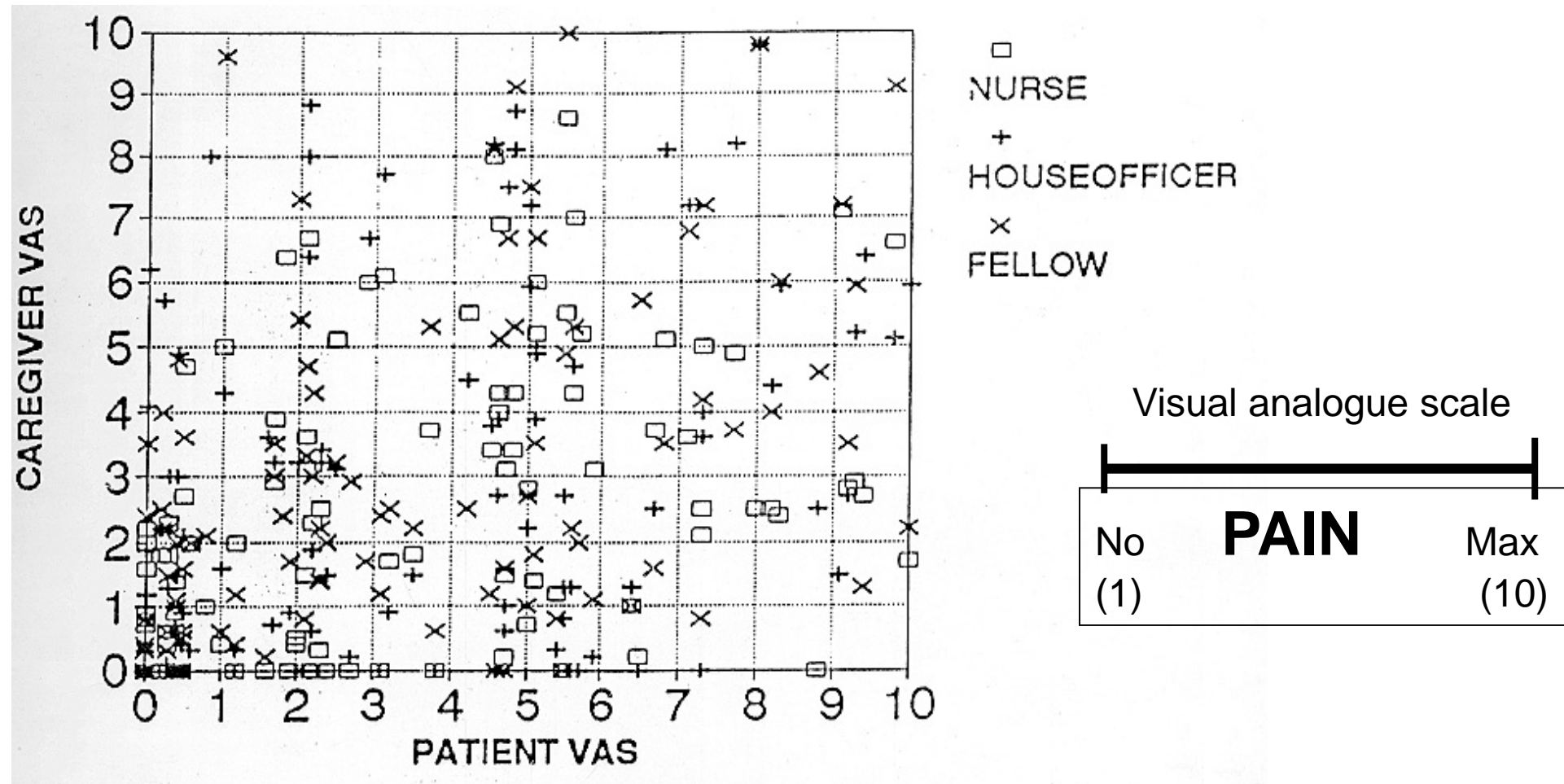
ASCO: Focus On Value



Physicians & patients add the three scores (clinical benefit, toxicity and bonus points) together to calculate the net health benefit (Value) of the t



Evaluation of Cancer Pain by Various Persons



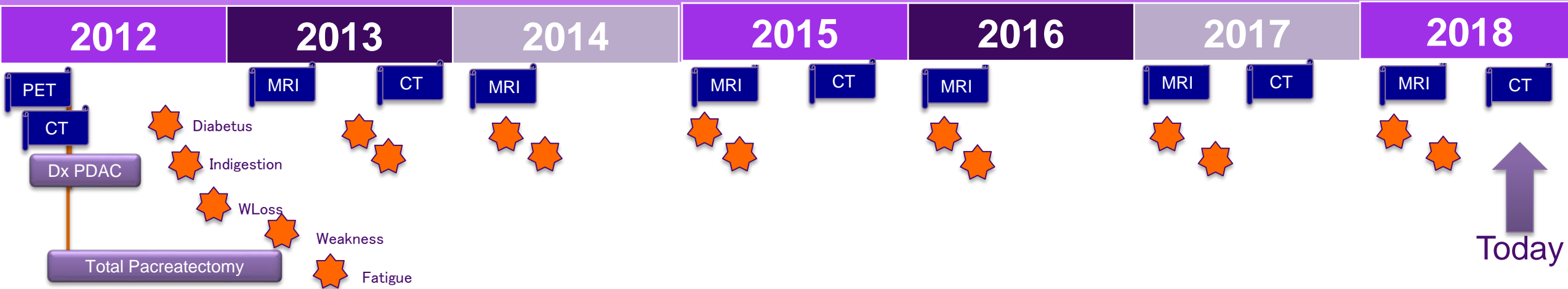
Grossman et al, J Pain Symp Manag, 6:53-57, 1991



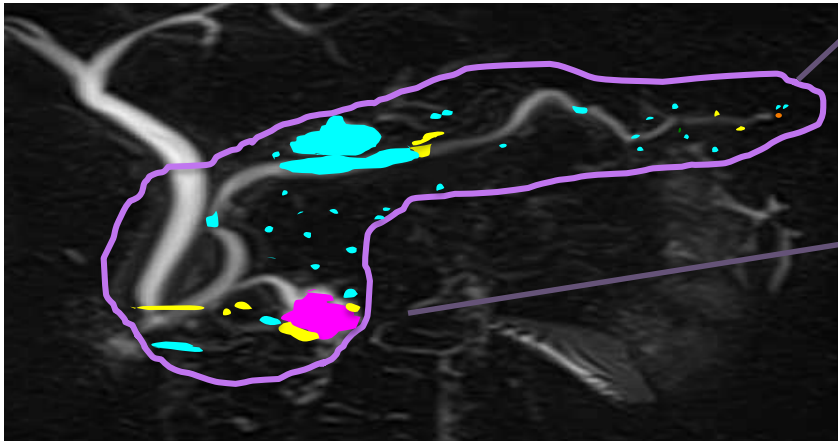
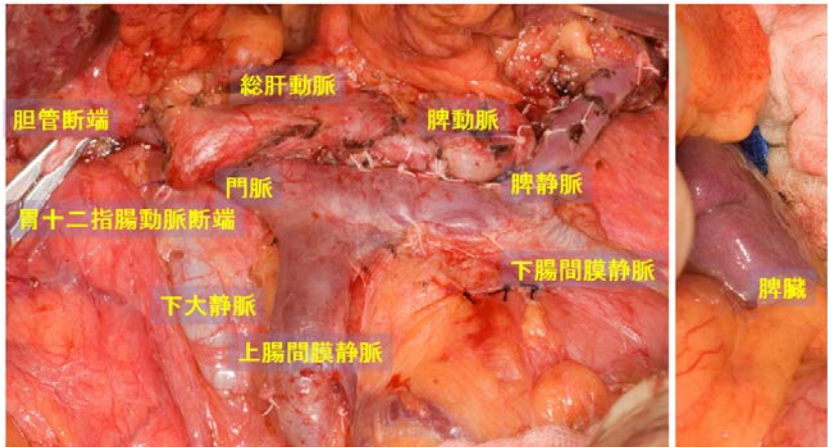
HOW CAN I MAKE
HIM UNDERSTAND
WHAT THIS ILLNESS
MEANS?



First Experience¹ – Pancreatic Cancer



Pylorus ring / spleen-preserving Total Pancreatectomy



Neuroendocrine Tumor

Pancreatic Cancer

Without Pancreas



インスリンポンプと24時間血糖値モニター



膵消化酵素

- Impact on Quality of Life:
 - Type I Diabetes
 - Indigestion
 - Long term monitoring is essential
 - Filling data gap for better control of diabetes
- Mid-Long term side effects?

営利目的での使用はご遠慮ください



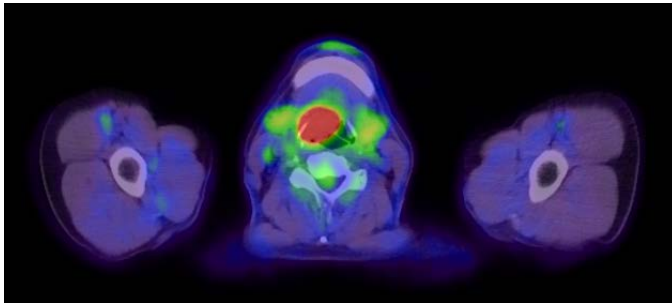
血糖値モニター

<https://www.wicweb.jp>

The Patient Experience2 – Oropharyngeal Tumor

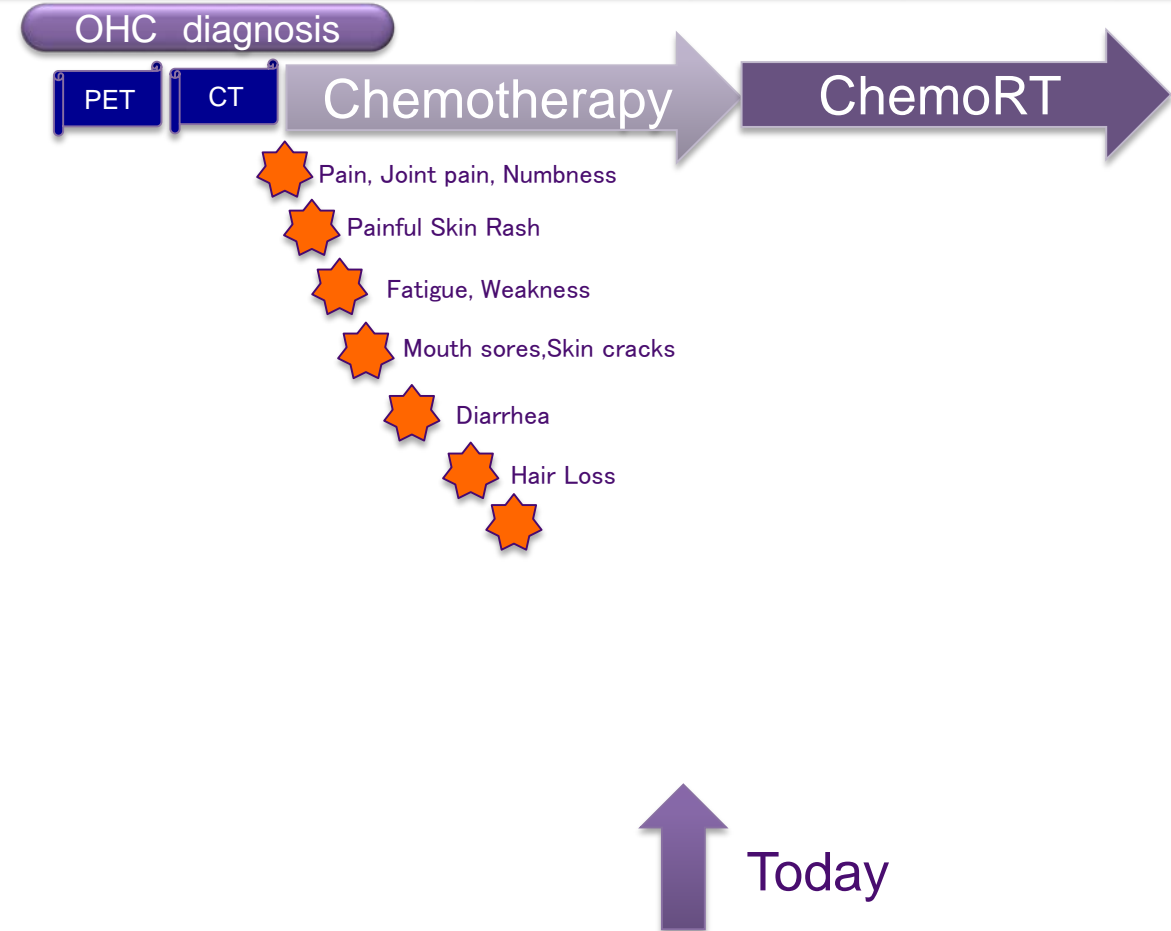


Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec



• Impact on Quality of Life:

- ✓ **Paclitaxel:** mouth sores, joint or muscle pain, diarrhea, constipation, weakness, dizziness, drowsiness, slow heart rate, darkening of your skin or nails, temporary hair loss, numbness or tingling of the hands or feet, increased blood pressure, fever, flushing (skin warmth or redness), nausea, vomiting,
- ✓ **Carboplatin:** nausea, vomiting, numbness and tingling of extremities, pain, weakness, hair loss.
- ✓ **Cetuximab:** rash, itching, dry or cracked skin, headache, diarrhea, nausea, vomiting, upset stomach, weight loss, weakness



NCI- PRO-CTCAE™ ITEMS - JAPANESE

Item Library Version 1.0

がんの治療を受けている方は、しばしば異なる症状や副作用の順序を経験いたします。それぞれの質問事項について、過去7日間にそれぞれの症状を経験されたかどうか、また経験された方は、その症状がどの程度だったか、もっとも自分の症状に当てはまると思われる回答に×印をつけてください。

1. PRO-CTCAE™ Symptom Term: Dry mouth.				
口の中の乾き。				
この7日の間で、口の中の乾きは一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

2. PRO-CTCAE™ Symptom Term: Difficulty swallowing.				
食べ物が飲み込みにくい。				
この7日の間で、食べ物が飲み込みにくいことは一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

3. PRO-CTCAE™ Symptom Term: Mouth/throat sores.				
この7日の間で、口の中や喉の痛みは一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。
この7日の間に、口の中や喉の痛みはどの程度あなたの生活の妨げになりましたか？				
<input type="radio"/> 全然ならなかった。	<input type="radio"/> 少し。	<input type="radio"/> ある程度。	<input type="radio"/> かなり。	<input type="radio"/> ものすごく。

4. PRO-CTCAE™ Symptom Term: Cracking at the corners of the mouth (cheilosis/cheilitis).				
口の端のひび割れ。				
この7日の間で、口の端のひび割れは一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

5. PRO-CTCAE™ Symptom Term: Voice quality changes.				
声の変化。				
この7日の間で、声の変化がありましたか？				
<input type="radio"/> はい。	<input type="radio"/> いいえ。			

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NCI- PRO-CTCAE™ ITEMS - JAPANESE

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6. PRO-CTCAE™ Symptom Term: Hoarseness.				
かすれ声。				
この7日の間で、かすれ声は一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

7. PRO-CTCAE™ Symptom Term: Taste changes.				
食べ物や飲み物の味がわからない（または、味が変わった）。				
この7日の間で、食べ物や飲み物の味がわからない（または、味が変わった）ということは一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

8. PRO-CTCAE™ Symptom Term: Decreased appetite.				
食欲不振。				
この7日の間で、食欲不振は一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。
この7日間に、食欲不振はどの程度あなたの生活の妨げになりましたか？				
<input type="radio"/> 全然ならなかった。	<input type="radio"/> 少し。	<input type="radio"/> ある程度。	<input type="radio"/> かなり。	<input type="radio"/> ものすごく。

9. PRO-CTCAE™ Symptom Term: Nausea.				
吐き気。				
この7日の間で、吐き気はありましたか？				
<input type="radio"/> なかった。	<input type="radio"/> ほとんどなかった。	<input type="radio"/> とときどき。	<input type="radio"/> 頻繁に。	<input type="radio"/> ほとんどいつも。
この7日の間で、吐き気は一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

10. PRO-CTCAE™ Symptom Term: Vomiting.				
嘔吐。				
この7日の間に、嘔吐はありましたか？				
<input type="radio"/> なかった。	<input type="radio"/> ほとんどなかった。	<input type="radio"/> とときどき。	<input type="radio"/> 頻繁に。	<input type="radio"/> ほとんどいつも。
この7日の間で、嘔吐は一番ひどい時でどの程度でしたか？				
<input type="radio"/> そういうことはなかった。	<input type="radio"/> 軽度。	<input type="radio"/> 中等度。	<input type="radio"/> 高度。	<input type="radio"/> 極めて高度。

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ASCO APP for iPHONE

App Store Preview

This app is only available on the App Store for iOS devices.



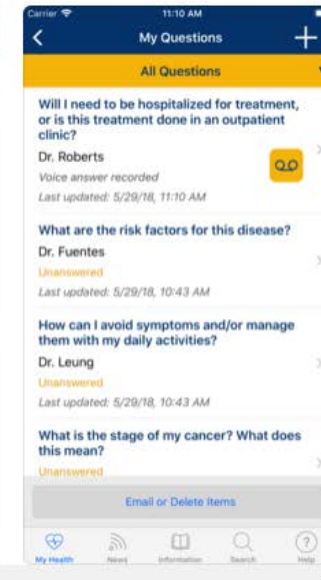
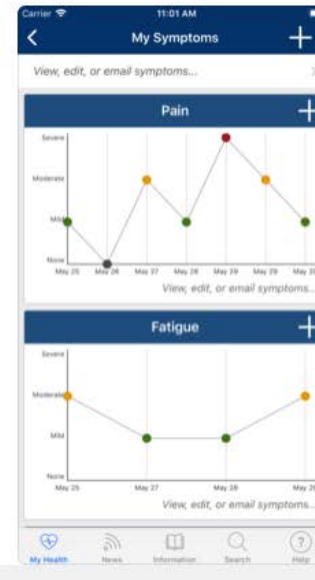
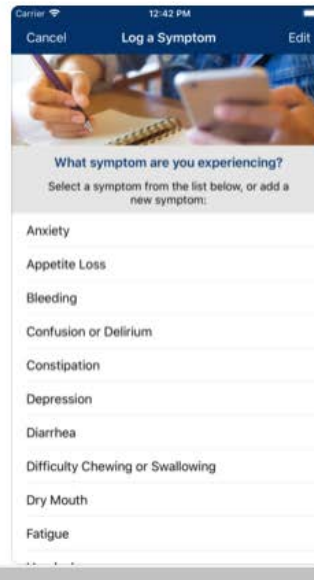
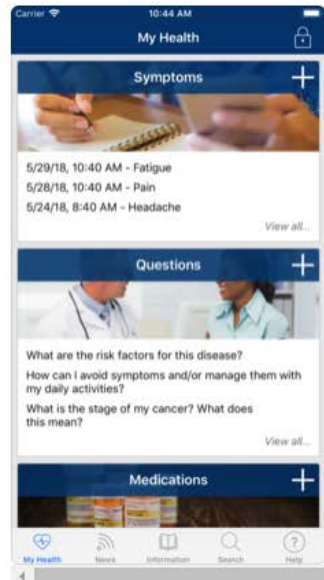
Cancer.Net Mobile 17+

ASCO

Free

Screenshots

iPhone iPad



Summary

- Patients want better clinical outcomes as well as QoL.
- Understanding patient experiences using PRO, especially outside of the clinical settings is important.
- Technology will play a more important role in clinical trials, PRO data gathering.
- “Value” of cancer care is becoming more important globally.

Thank you

