



ImmunoScience Academy

Partnering for Education & Optimizing Treatment in ImmunoScience

www.immunoscienceacademy.be

Workshop A3

Patient Education

Convention room 3, Floor 1

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Stefan Rauh, *Centre Hospitalier Emile Mayrisch, Luxembourg*

Moderated by **Johan Vansteenkiste, *UZ Leuven***



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Toxicity management – the wrong way

Stefan Rauh
Centre Hospitalier Emile Mayrisch
Esch LU



Disclaimer

- ▶ The cases within are the healthcare professionals' own and Bristol-Myers Squibb has not made any contribution into them



Case : shortness of breath

- ▶ 64 y/o patient w squamous cell cancer of the left upper lobe: surgery : lobectomy w/ lymphadenectomy : pT2N1 G2 R0 non oncogene addicted, PD-L1 score 20%; adj Cisplatine/Vinorelbine 4 cycles
- ▶ 3 mo after end of adj therapy: 1 new lung lesion + pos. bone scan (> 3 lesions)
- ▶ Anti-PD1 started



Presentation at start of Anti-PD1

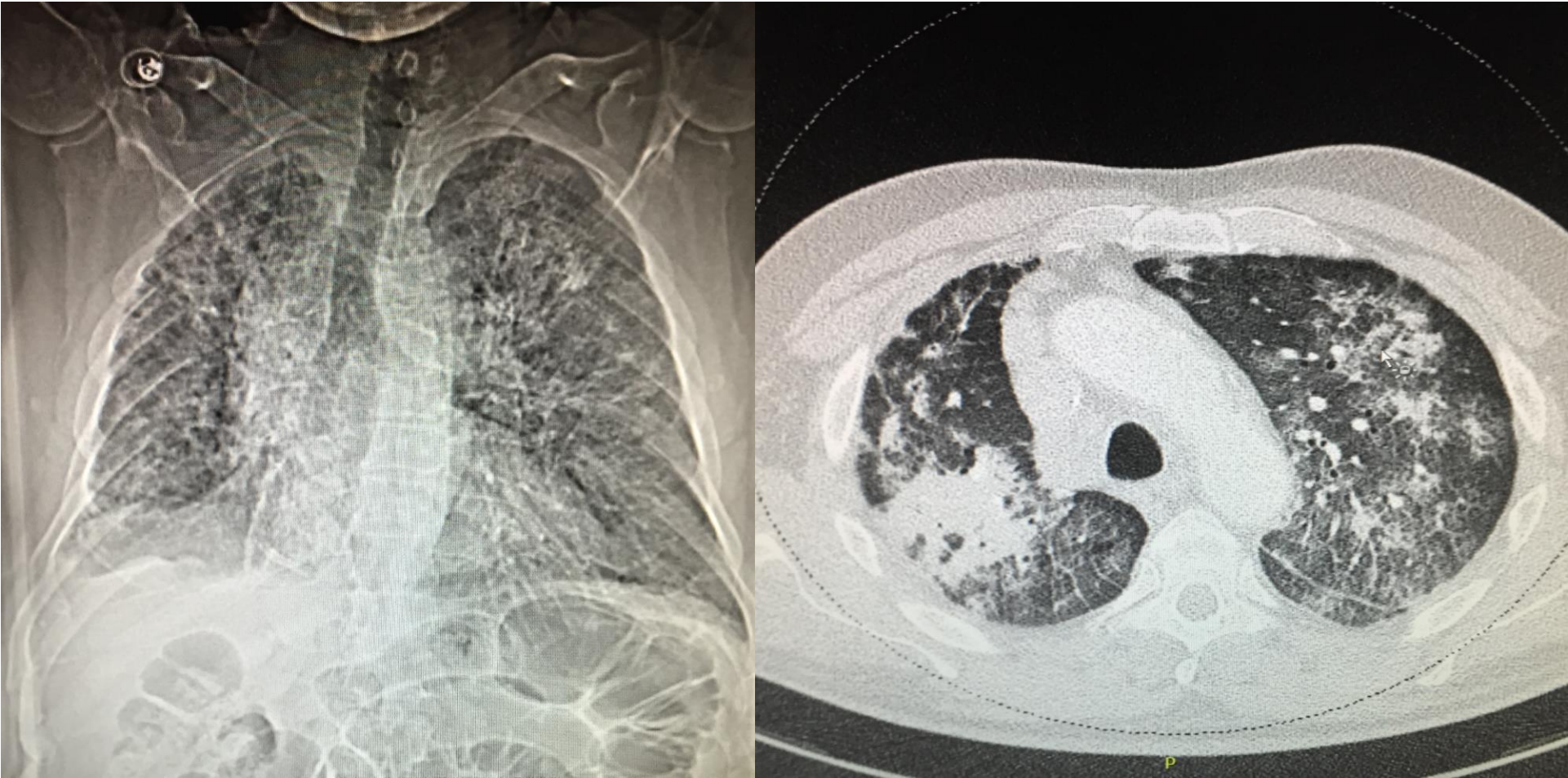


- ▶ After 2 cycles: complains of slight exertion dyspnea
 - Exam: unremarkable, O2sat 92% , blood nl, Chest Xray nl -> treatment continued

- ▶ After 3 cycles: nurses note O2 sat 85% but consider it an artefact

- ▶ At cycle 4: complains of significant exertion dyspnea, was seen by GP who had no clue to diagnosis and convened a consultation with a pneumologist (scheduled 3 d later)
 - Exam: lip cyanosis , O2SAt 80%, auscultation unremarkable, Chest CT scan: see next slide





..this shouldn't have happened with a well educated patient / staff





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Immuno-T: informing patients and their caregivers on immunotherapy

Prof. Dr. Tessa Kerre

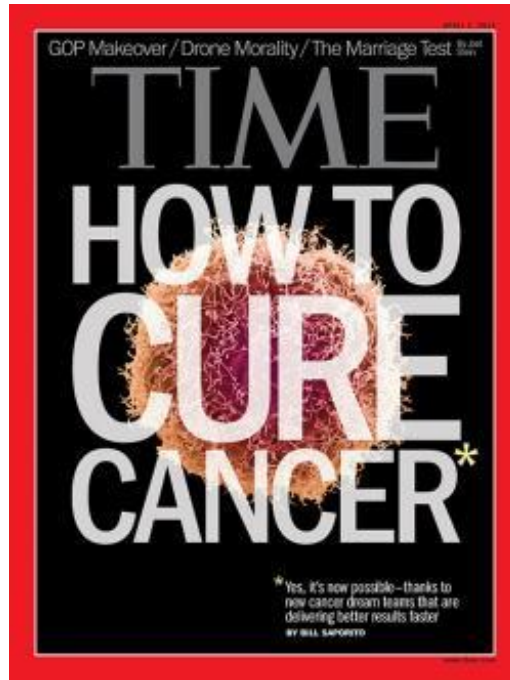


Bristol-Myers Squibb

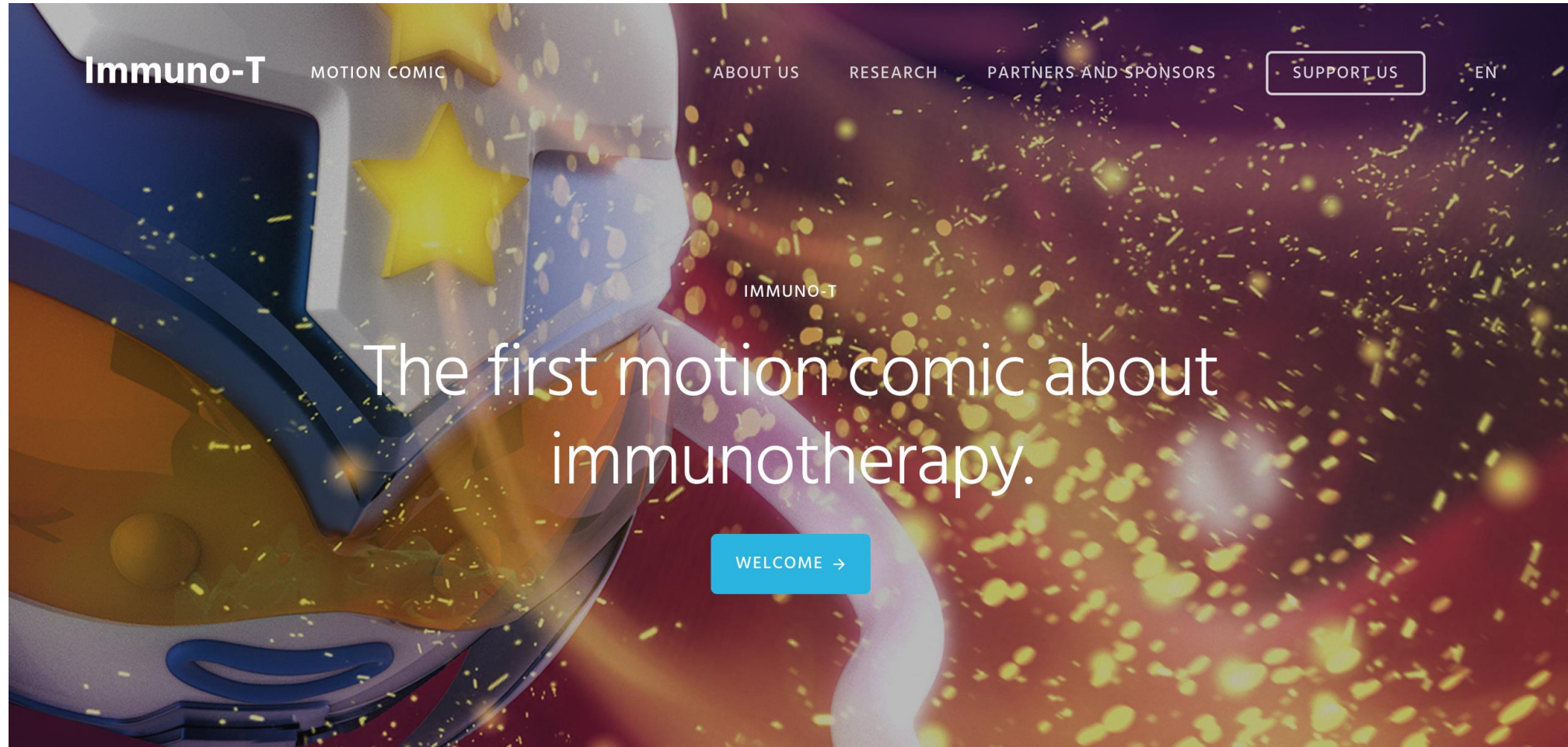


Shared decision making: immunotherapy, a special case

- ▶ High complexity - low basic knowledge on immunotherapy
- ▶ General knowledge biased: immunotherapy is the best!



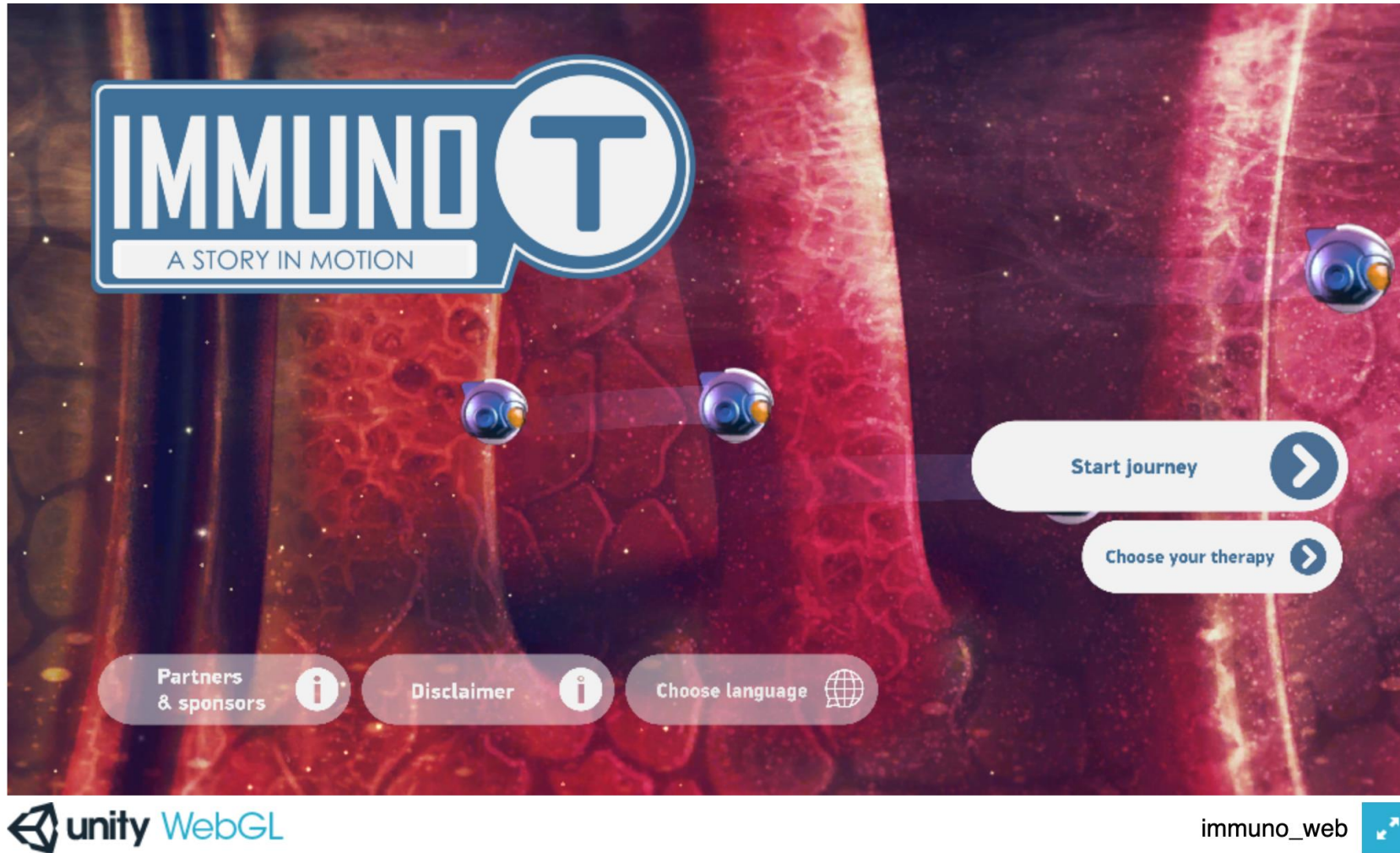
Immuno-T



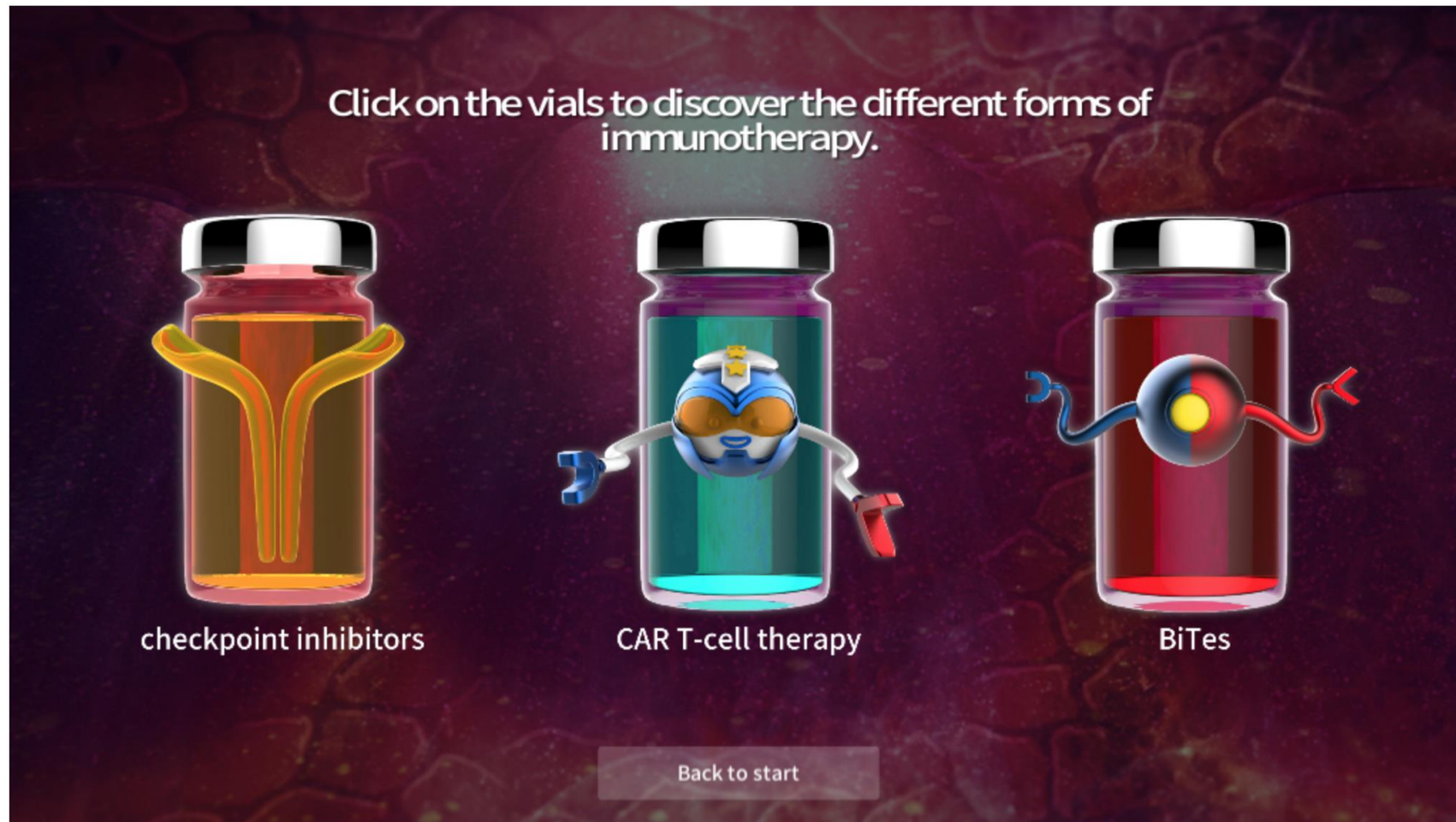
► Immuno-T.inmotion.care



Immuno-T



Immuno-T



Immuno-T

▶ A **communication** tool

- to create awareness
- to visualize the invisible
- to increase literacy on immunotherapy
- to improve knowledge, and create a visual language for doctors and health workers to use and improve communication

▶ Currently **underused** and **suboptimally** used

- used locally (UZGent), and in some other hospitals: how to improve?
- lacks some information needed for shared decision making

▶ More information on **side effects**

- within the tool
- outside the tool





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Patient Education During Immunotherapy

Marie Vandeveldde, RN MSc

Annemarie Coolbrandt, RN PhD



How can effective patient education about immunotherapy (mechanism of action, prospects, possible side effects) be provided before the start of treatment?

→ a 30 minute intake-session



Purpose of intake session

ONCOCOACH

PATIENT

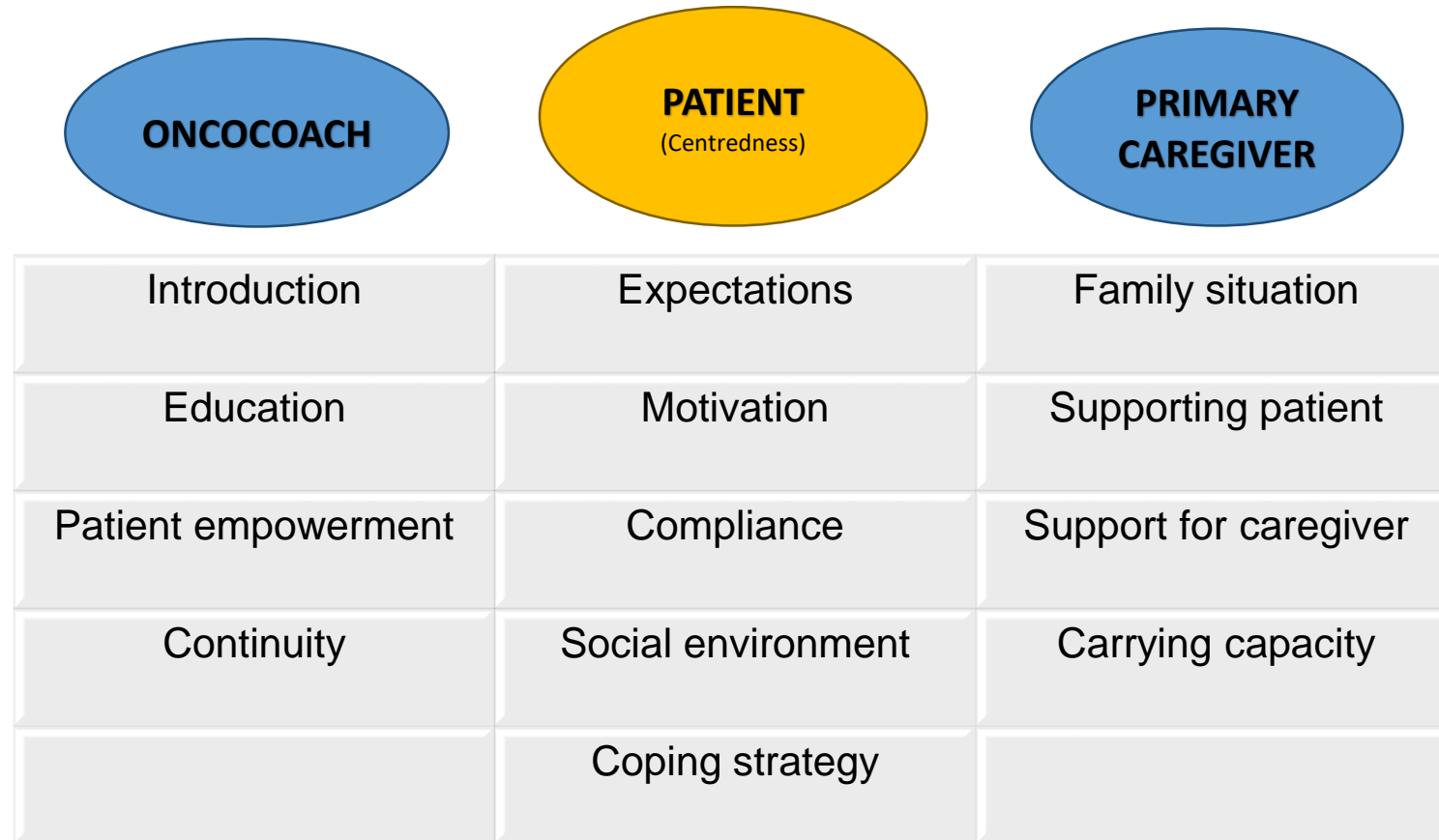
PRIMARY CAREGIVER

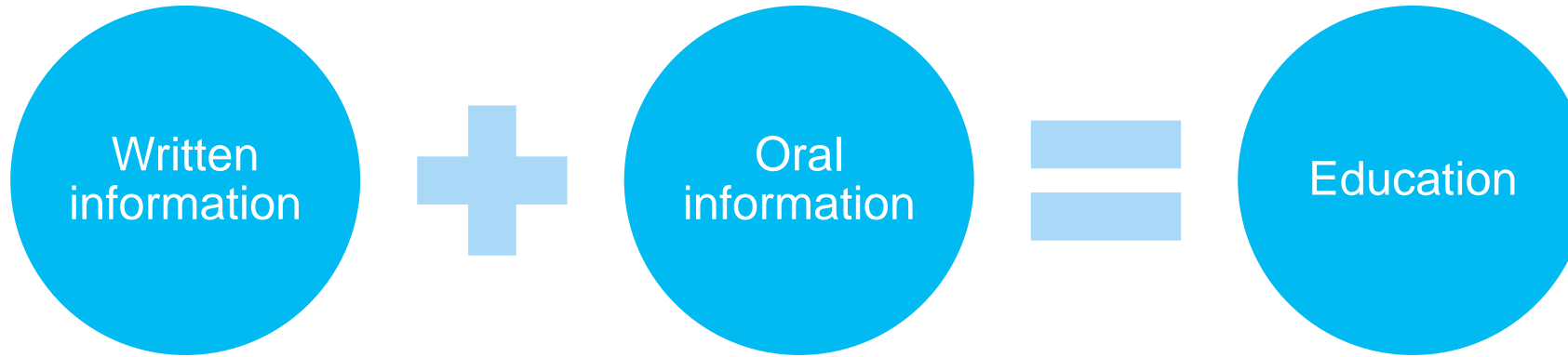
Identifying problems	Prevention of side effects
Predicting potential problems	Early recognizing side-effects
Interacting in advance	Responding to side-effects
Preparing patient for start of therapy	Early warning of healthcare workers



A 30 Minute Intake Session

- planned after diagnosis
- shortly before start therapy





<https://www.uzleuven.be/nl/chemotherapie/over-cyztra>



Attention !

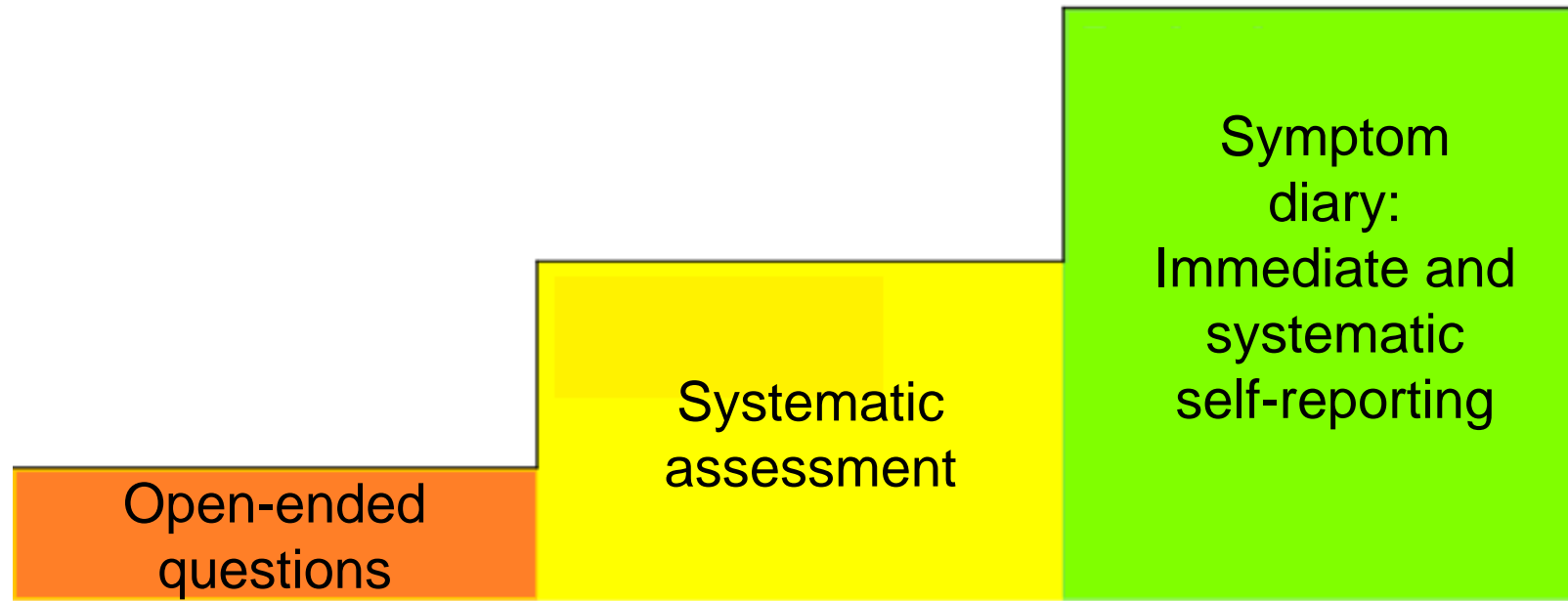
- ▶ Timing:
 - After diagnoses
 - Short before the start of immunotherapy
- ▶ Privacy
- ▶ Other: translator, ...



How does the patient monitor symptoms during treatment and for which ones is contact with the hospital team needed, in order to allow early detection of potentially serious adverse events?



Assessing treatment-related symptoms



Digital symptom diary in oncology

► Has shown to improve...

- Communication
- Symptom management
- Quality of life
- Survival

[JAMA](#), 2017 Jul 11;318(2):197-198. doi: 10.1001/jama.2017.7156.

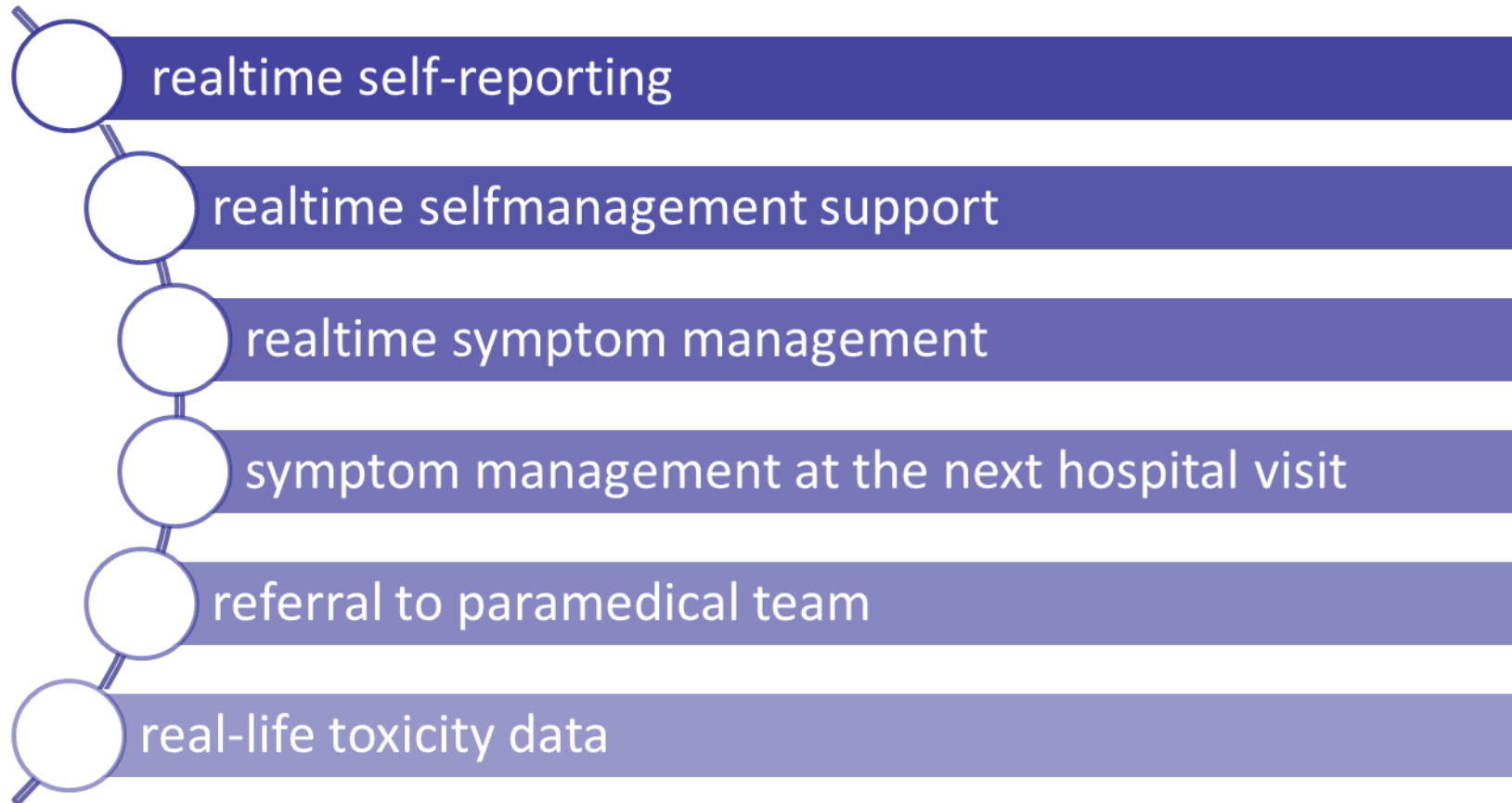
Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment.

[Basch E](#)¹, [Deal AM](#)², [Dueck AC](#)³, [Scher HI](#)⁴, [Kris MG](#)⁴, [Hudis C](#)⁵, [Schrag D](#)⁶.

- Hypotheses:
- More timely detection and management of severe symptoms
- Improved symptom management > improved QoL > longer treatment tolerance



Digital diary via mynexuzhealth



Self reporting (PROMs)

14:38

Symptoomlast

Noteer dagelijks welke nevenwerkingen u ondervindt bij uw therapie. Zo kunnen uw zorgverleners de ondersteunende zorg afstemmen.

Misselijkheid

Niet

Ik ben misselijk, maar kan wel normaal eten en drinken.

Door de misselijkheid eet of drink ik minder, maar ik verlies geen gewicht.

Door de misselijkheid kan ik niet meer voldoende eten of drinken.

14:40

Symptoomlast

kunnen (ik pieker constant, huil de hele tijd, ben erg prikkelbaar, erg angstig, ...) en kom hierdoor niet meer toe aan mijn dagelijkse taken, sociale contacten, ontspanning of slaap.

Temperatuur
Bv. 37,5. Bij meer dan 38 neemt u best contact op met de (huis)arts. ✓

38.5

Onsteking van het mondslijmvlies

Ik heb geen last in de mond.

Ik heb milde pijn of milde letsels in de mond (bv aften).

14:39

Symptoomlast

Vermoeidheid, futloosheid

Niet meer dan normaal.

Ik voel me licht vermoeid of futloos, maar ik kan mijn dagelijkse activiteiten wel doen.

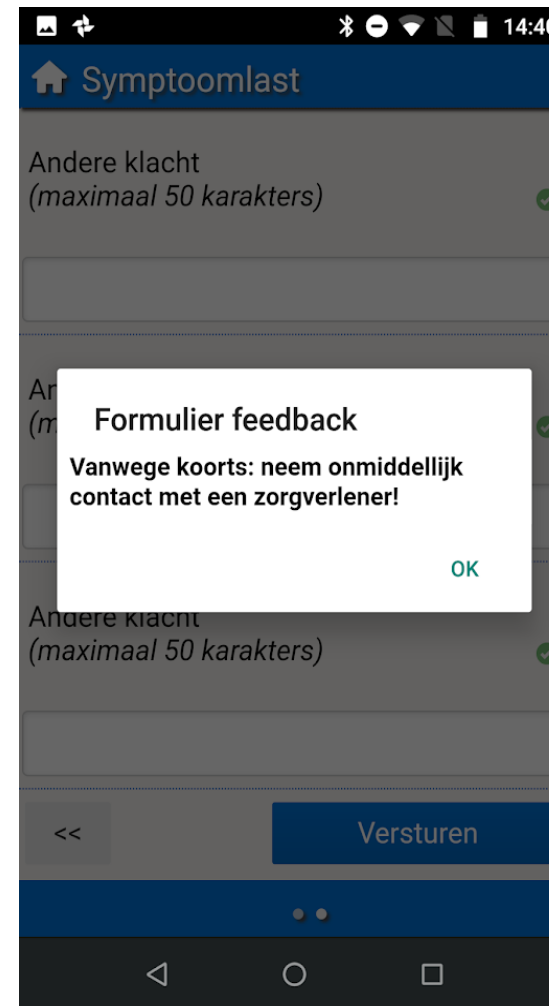
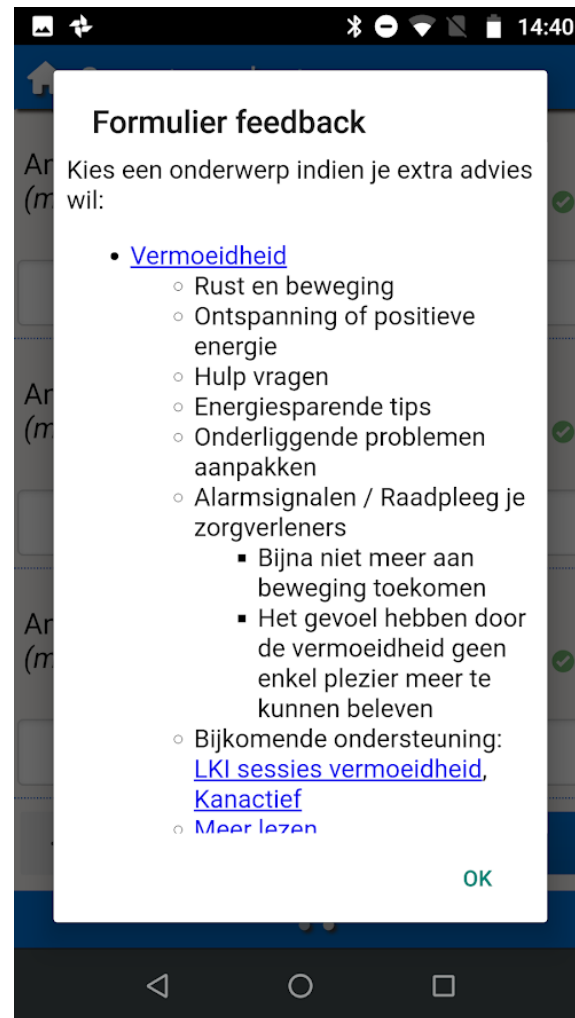
Ik voel me matig vermoeid of futloos en sommige dagelijkse activiteiten lukken moeilijker.

Ik voel me zo vermoeid dat ik nauwelijks of niet aan mijn dagelijkse activiteiten toekom.

Spier- en gewrichtspijn



Self management support



Symptom management at next visit

Wo 21-03-2018	Do 22-03-2018
A	N O A N

Thuis:
Graad 3: Vermoeidheid / futloosheid
Graad 2: Psychische belasting
Graad 1: Misselijkheid, Verminderde eetlust of smaakverandering, Ontsteking mondslijmvlies, Ontsteking mondslijmvlies,

Symptoomlast thuis (Onco alg.) Verslag van thuis ervaren symptoomlast na chemotherapie

Type melding: A.h.v. dagboek | Mondeling | Na behandelin

15-06-2018 - O

Toon mynexuz insuling

Symptoomlast thuis - Algemene nevenwerkingen

Bevraagd maar geen nevenwerkingen

Op te nemen symptomen

- Misselijkheid
- Braken
- Verminderde eetlust of smaakverandering
- Ontsteking mondslijmvlies
- Buikloop
- Verstopping
- Vermoeidheid / futloosheid
- Pijn
- Huiduitslag
- Psychische belasting

Ernst symptomen

0 1 2 3

	do 8/3	vr 9/3	za 10/3	zo 11/3	ma 12/3	di 13/3	wo 14/3	do 15/3	vr 16/3	za 17/3	zo 18/3
legende	0	1	2	3							
misselijkheid	1	1	0	0	0	0	0	0	0	0	0
braken	0	0	0	0	0	0	0	0	0	0	0
eetlust	1	1	1	1	1	1	1	1	1	1	1
mond	0	0	0	0	1	1	2	2	3	2	2
buikloop	0	0	0	0	0	0	0	0	0	0	0
verstopping	0	0	0	0	0	0	0	0	0	0	0
vermoeidheid	2	2	0	1	3	3	2	3	3	3	2
pijn	3	2	1	2	2	2	2	2	3	2	3
huid	0	3	3	3	3	3	3	3	3	3	3
emotie	1	1	1	1	1	1	1	1	1	1	1
tintelingen	2	1	1	1	2	2	2	2	2	2	2
tranende_ogen	1	1	0	0	1	1	1	1	1	1	1
gehoor	1	1	1	1	1	1	1	1	1	1	1
temperatuur	0	0	0	0	0	0	0	3	0	0	0



Real time symptom management

Wintermute specialty board Thuisopvolging symptoomlast

Van 30-10-2019 tot 13-11-2019

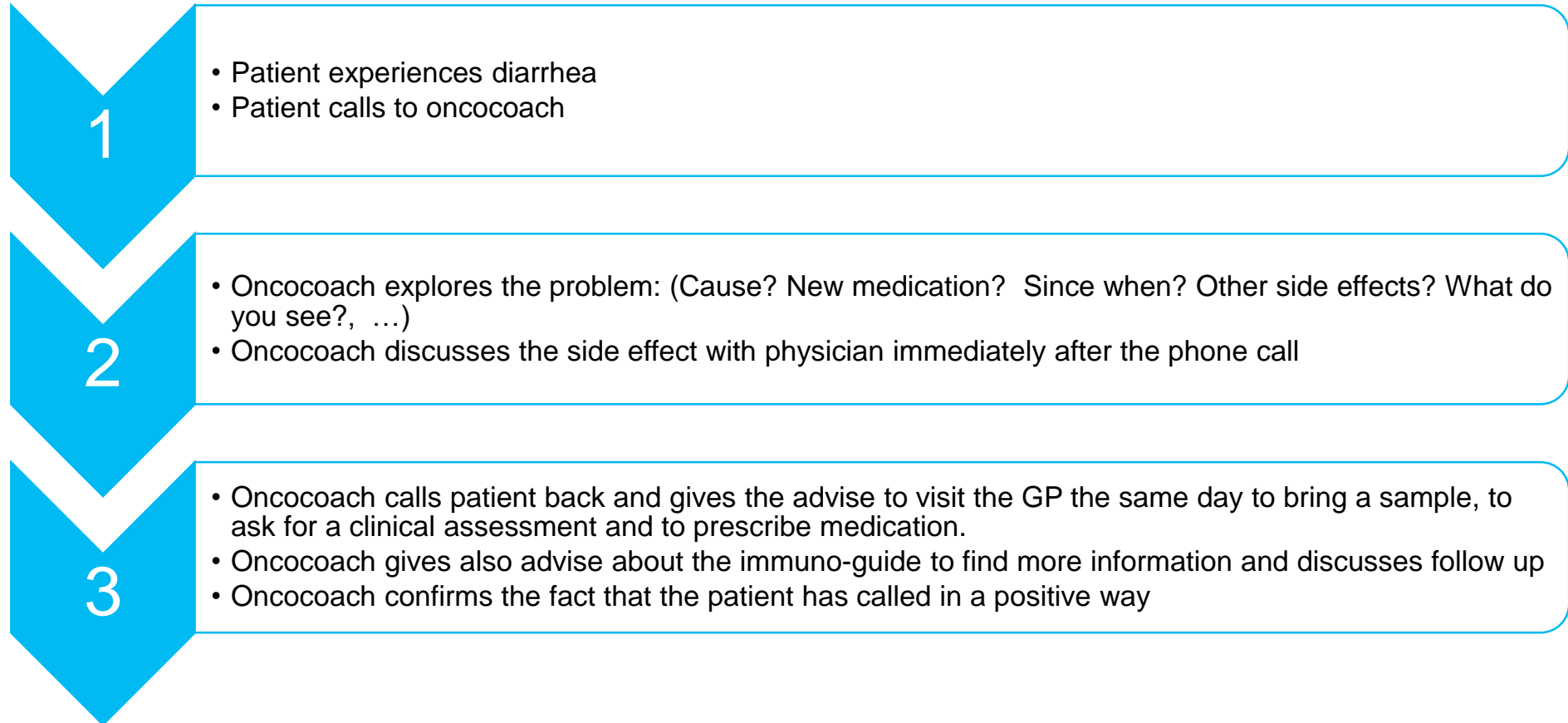
Filter	van	s	sv	data	a
<input type="checkbox"/> nu alarmerend	13-11	●	0	misselijkheid	
<input checked="" type="checkbox"/> verberg overleden patië	13-11	●	0	pijn	
<input checked="" type="checkbox"/> verberg DNR 3 en palli	13-11	●	0	hoest	
<input type="checkbox"/> enkel aanwezige patië	12-11	●	0	kortademigheid	✓
▶ Uitgevoerde acties 1	12-11	●	0	misselijkheid	✓
▶ Uitgevoerde acties 2	12-11	●	0	sys	✓
▼ Status regel	12-11	●	0	misselijkheid	✓
	11-11	●	0	misselijkheid	✓
	09-11	●	0	temperatuur	✓



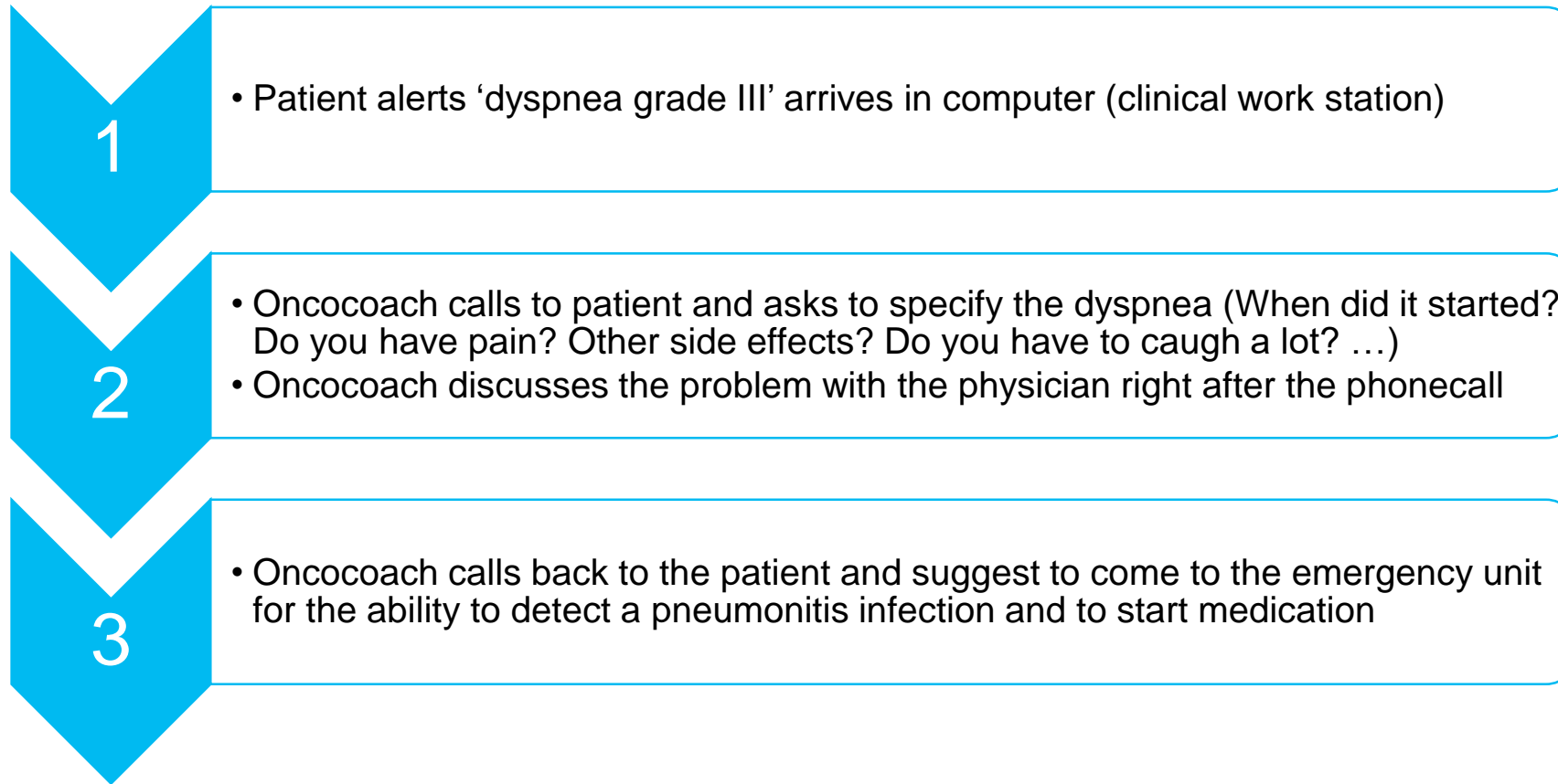
How does the treatment team (physician, nurse, oncocoach) capture and respond to patients' signals of potentially serious adverse events?



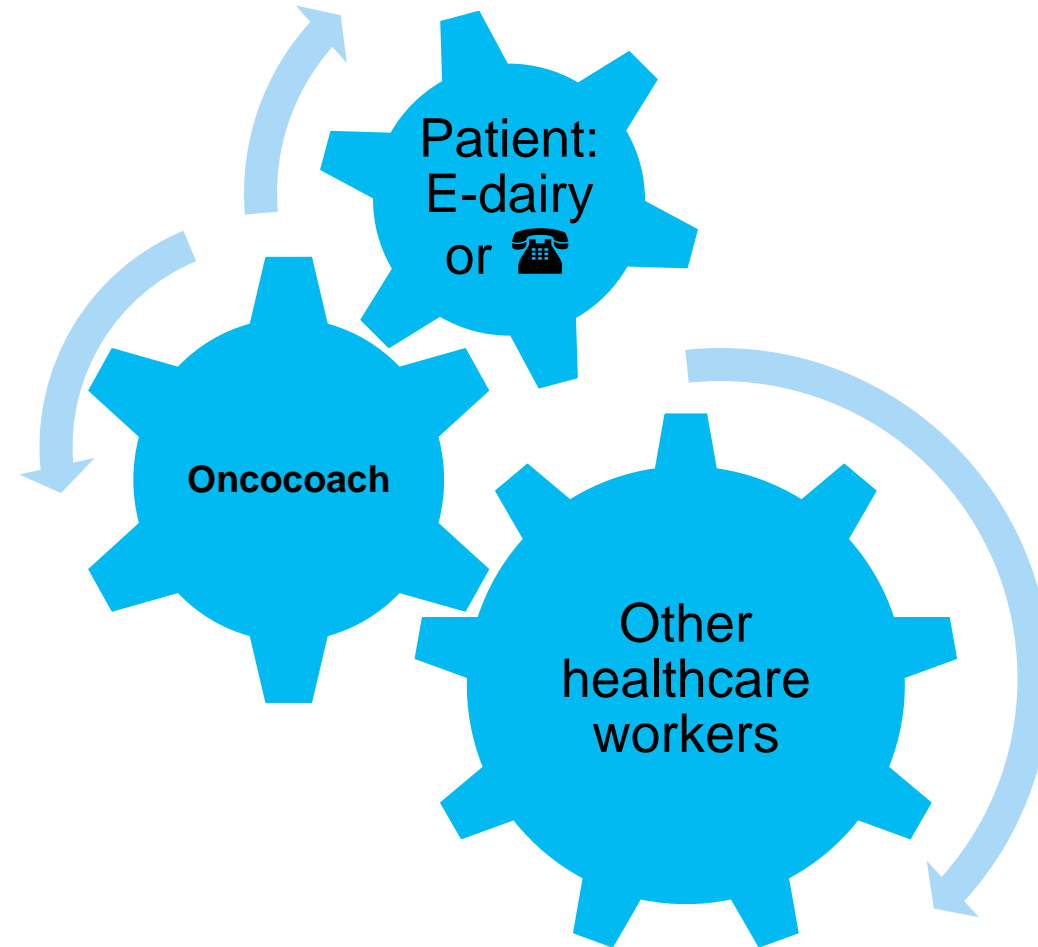
Case 1: diarrhea



Case 2: dyspnea-alert @ e-diary



Process



Thank you for your attention!
We would love to answer your questions 😊



References

Basch E., Deal, A.M., Dueck, A.C., Scher, H.I., Kris, M.G., Hudis, C. et.al. (2017). Overall Survival Results of a Trial Assessing Patient-Reported Outcomes for Symptom Monitoring During Routine Cancer Treatment. *JAMA* 318 (2), 197-98.

Castro, E.M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W. & Van Hecke A. Patient Education and Counseling (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient education and counseling*, 99 (12), 1923-39.

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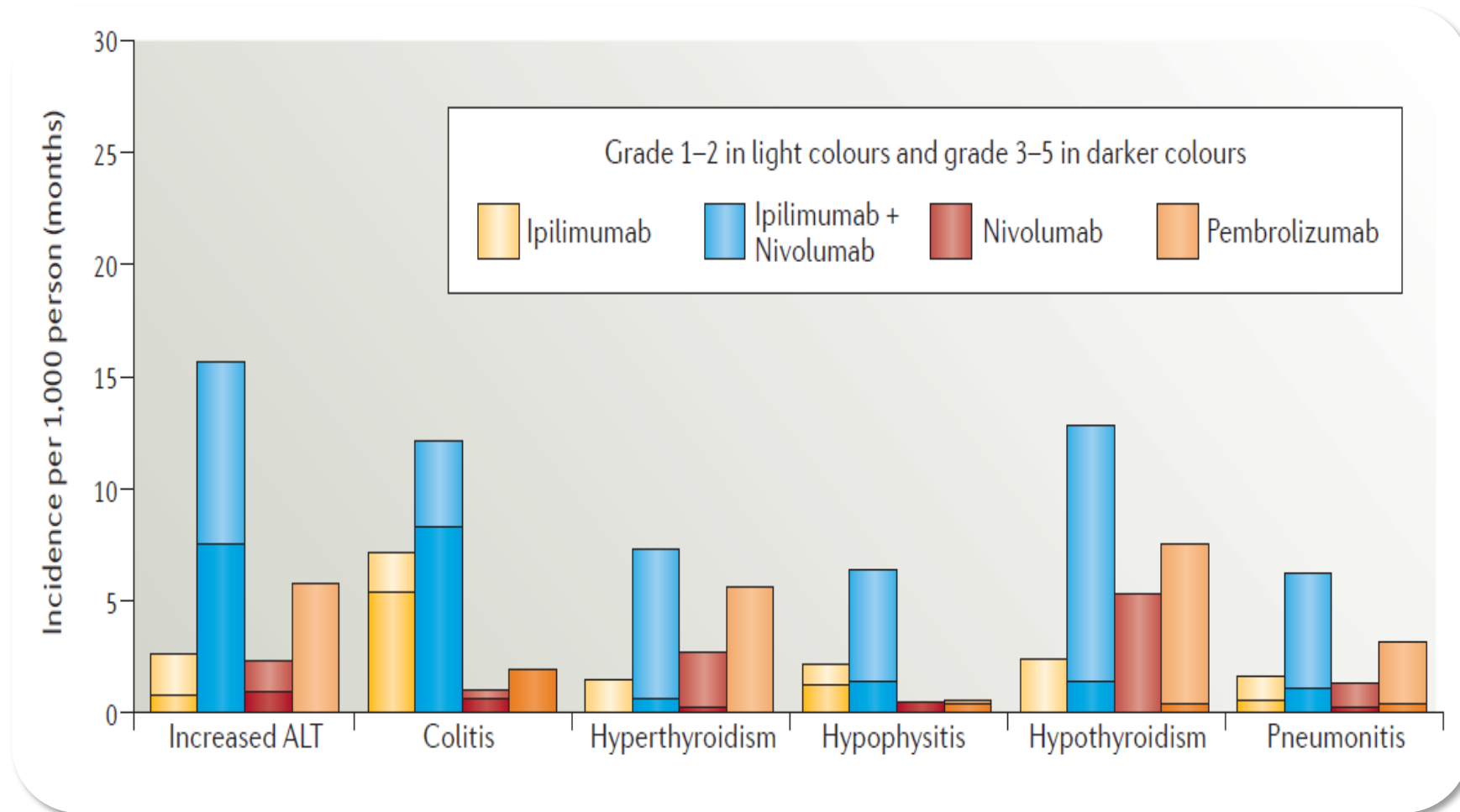
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Minimal monitoring for checkpoint toxicity

Stefan Rauh
Centre Hospitalier Emile Mayrisch
Esch LU



Immunotoxicity adverse events¹

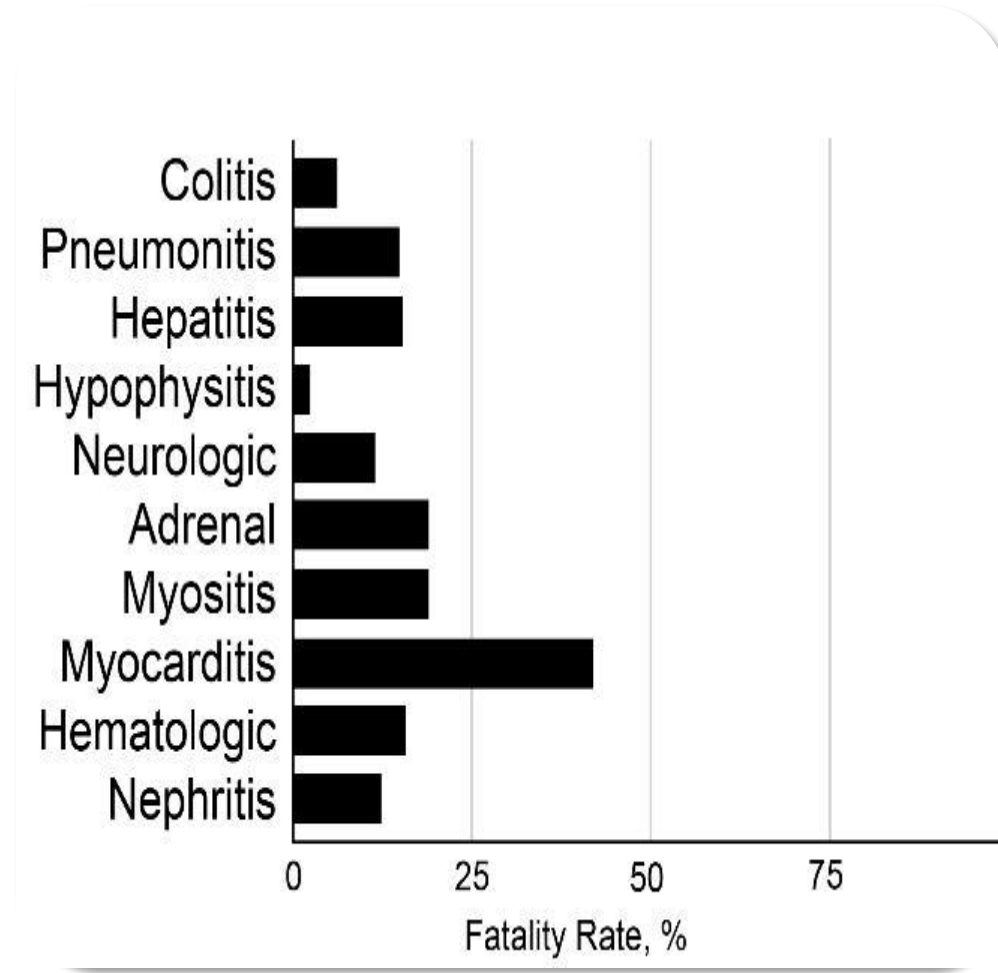


1. Boutros et al. Nat Rev Clin Oncol 2016;13:473–86.

Any off-label data shown are used to support the educational message of the presentation and not intended to endorse use of any drug in any way



Fatal toxic effects associated with immune checkpoint inhibitors a systematic review and meta-analysis¹



My mini checklist for immuno toxicity

- ▶ (Ask for new symptoms before every visit)
- ▶ Ask for diarrhea, dyspnea and weakness
- ▶ Check satO₂
- ▶ Control liver values
- ▶ Check periodically tsh, cortisole
- ▶ **O₂LDE.** (**O**xygen saturation/respiratory sypmtoms , **L**iver enzymes, **D**iarrhea, **E**ndocrine symptoms)



My « card » for patients

- ▶ You receive immunotherapy with an anti-PD 1 agent
- ▶ Any new symptom/ complaint might be a side effect
- ▶ Rarely, side effects may become life threatening in very short time (days)
- ▶ Report immediately if you note: shortness of breath, cough or chest pain, jaundice , diarrhea (more than 4 stools/d), trouble walking or making movements
- ▶ Report immediately in case of any other complaint which you consider serious or worrysome



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