

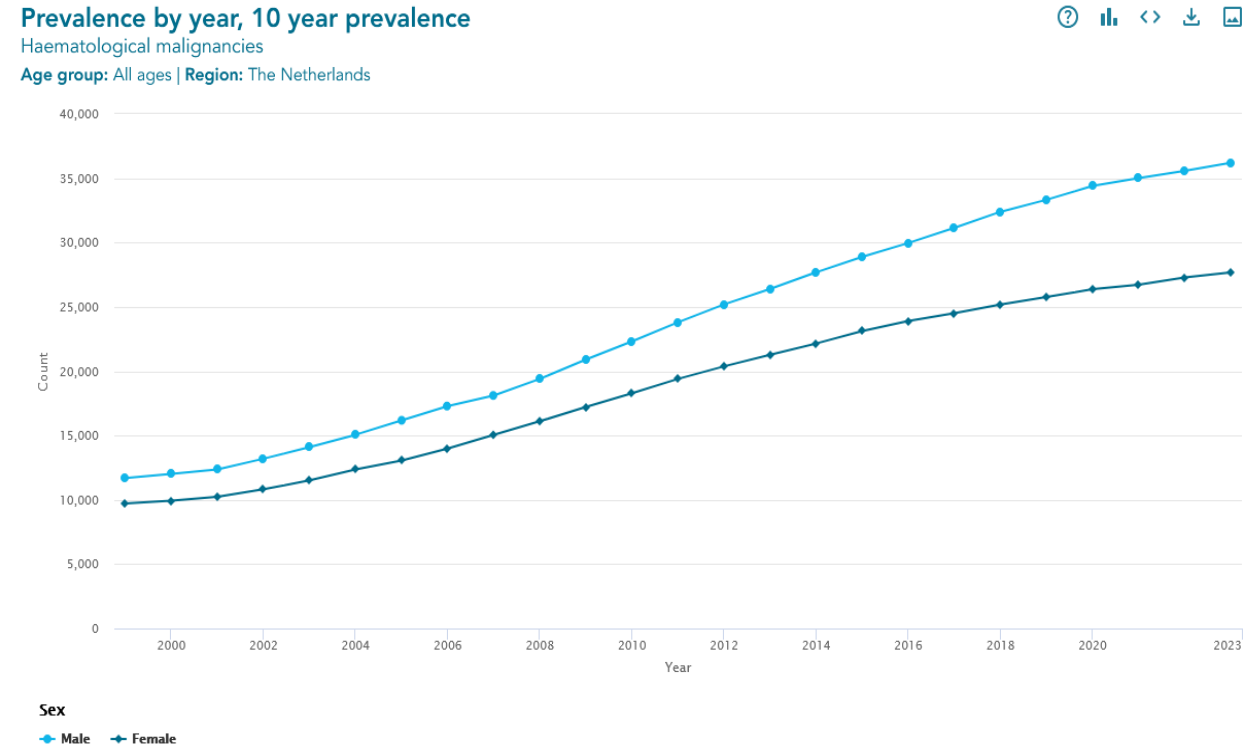
Electronic PROs and wearables in hematologic registries

Prof. dr. Lonneke van de Poll-Franse

No Conflict of Interest

Increasing prevalence of hematologic cancers

Netherlands Cancer Registry

[illegible]

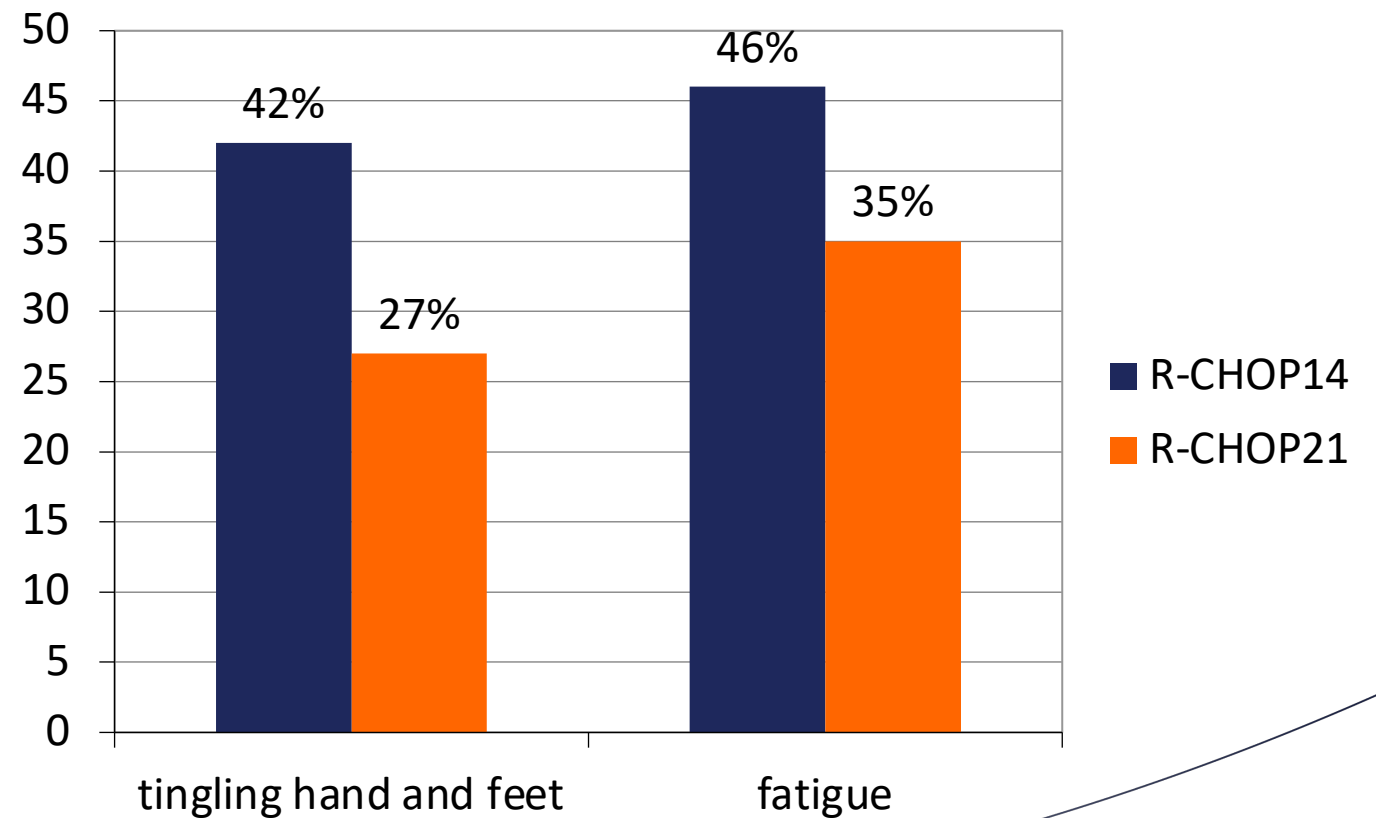
2023: Provisional figure.

Source: NCR
Changed on: 27 January 2025

Source: Netherlands Cancer Registry

QoL after (R-)CHOP14 or (R-)CHOP21 in DLBCL

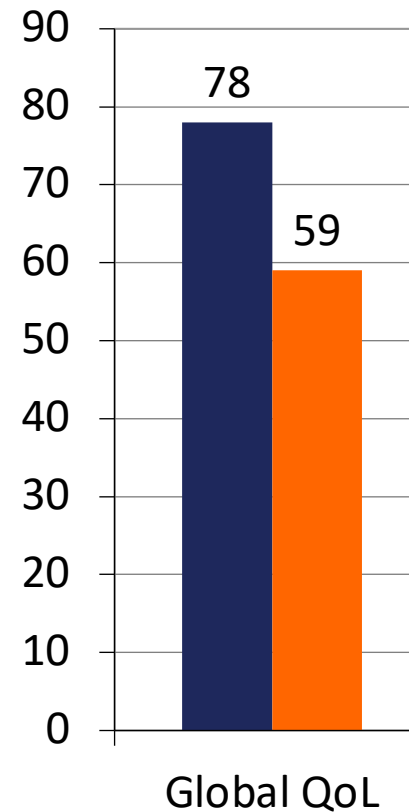
	(R-)CHOP14	(R-)CHOP21
	N=95	N=128
Age	61 yrs	67 yrs
Stage		
I	16%	43%
II	22%	26%
III	33%	15%
IV	27%	16%



Physical activity and QoL in MM survivors

‘Have you done weekly sporting activities in the past year?’

	Active	Not Active
	N=28	N=71
	4h	3,5h
	2h	0,5h
	4,25h	1,5h
	7h	5,75

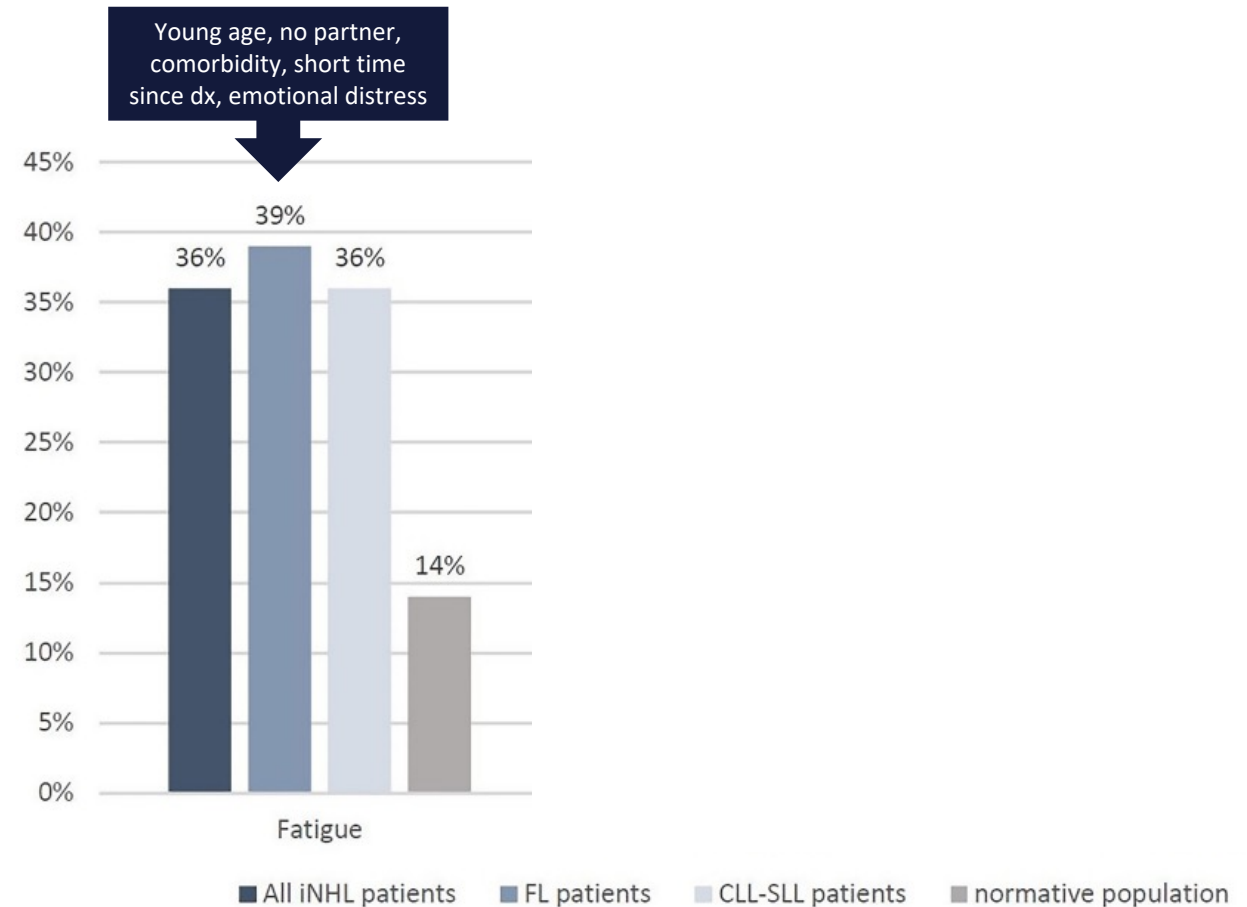
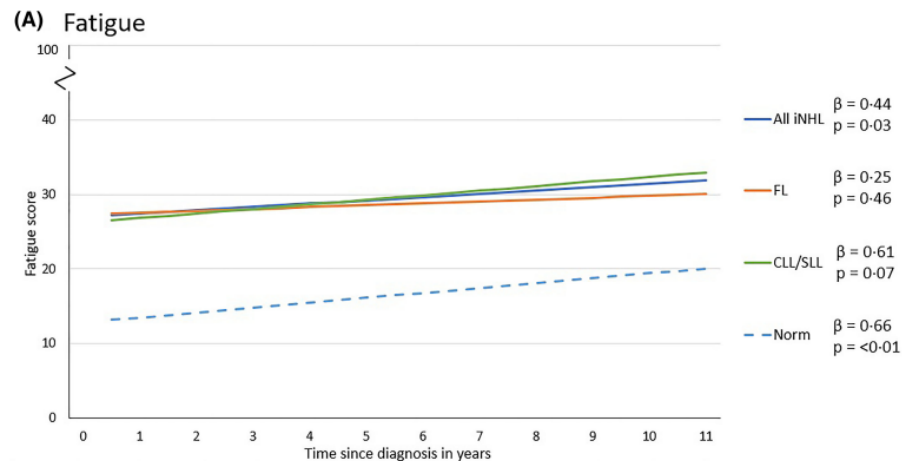


■ Active
■ Not Active

Long-term QoL in indolent NHL patients

Persistent symptoms of fatigue, neuropathy and impaired role functioning

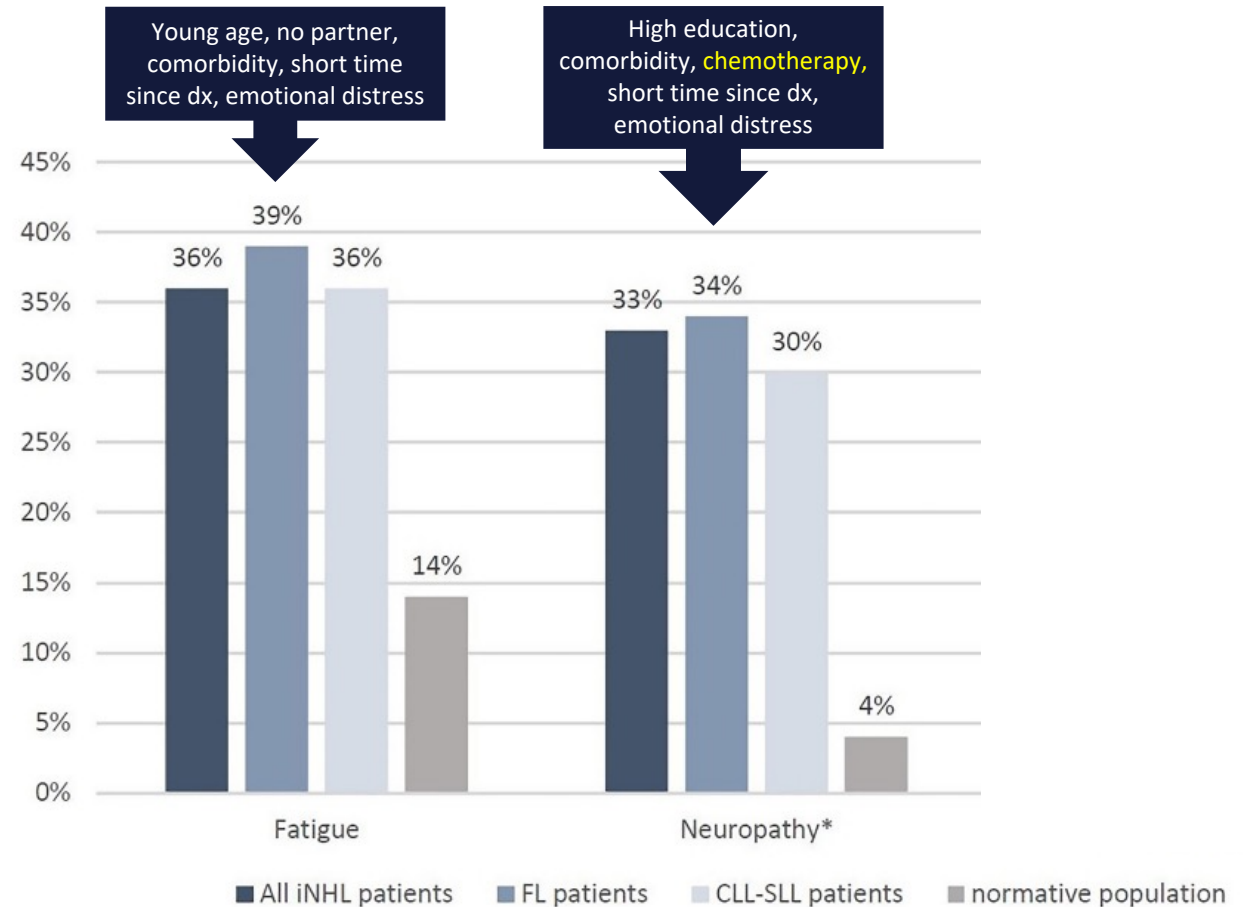
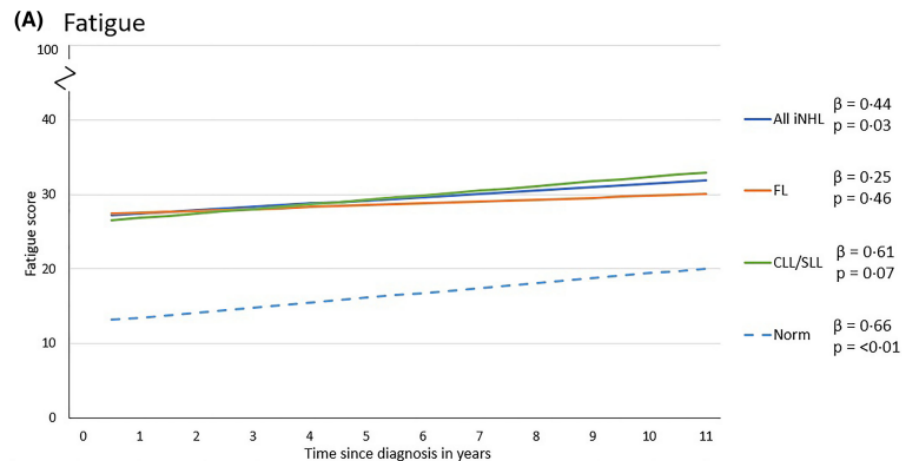
- 669 patients (74% response)
- Diagnosed 1999-2014
- Patients completed on avg 4 questionnaires



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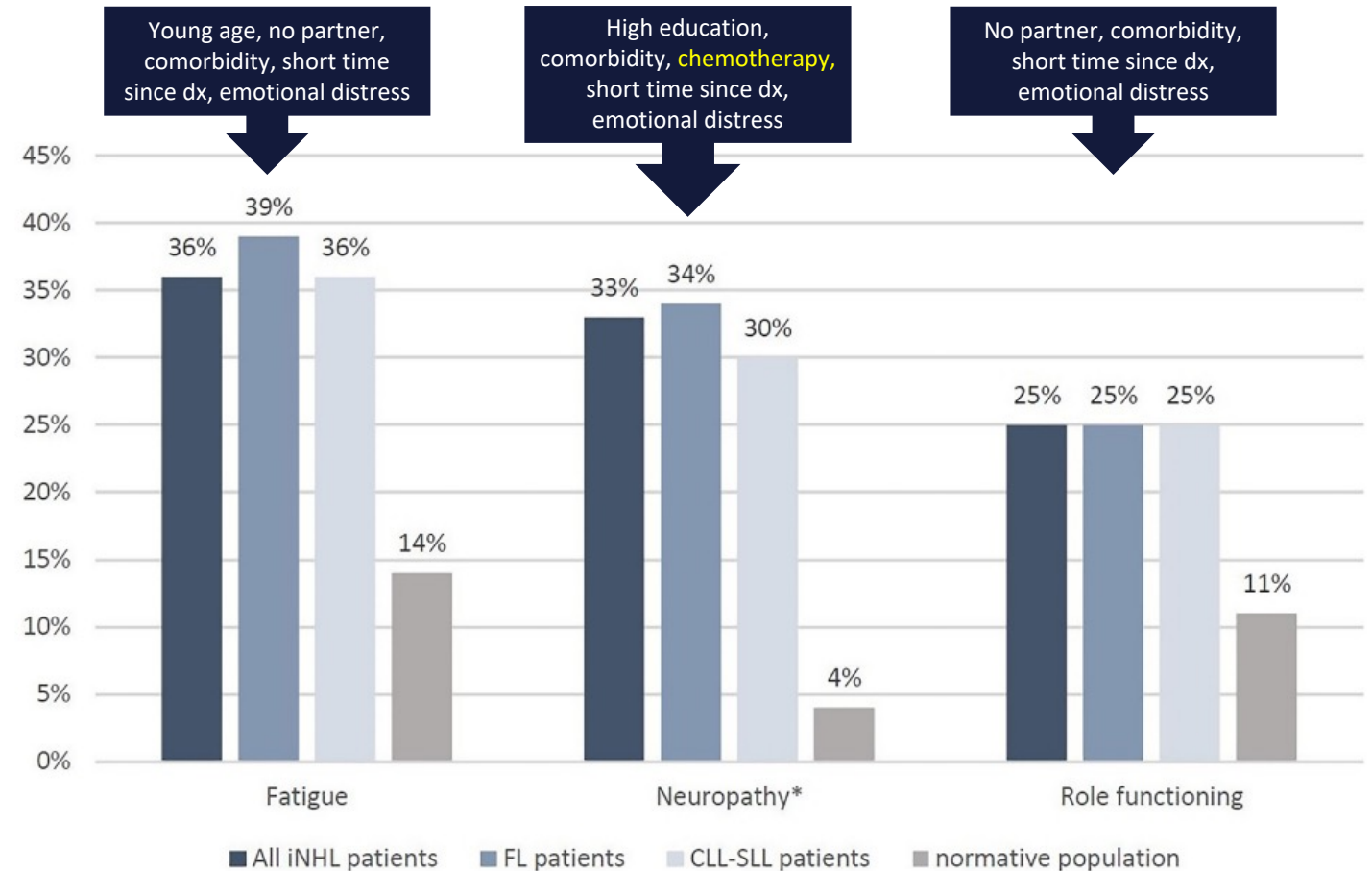
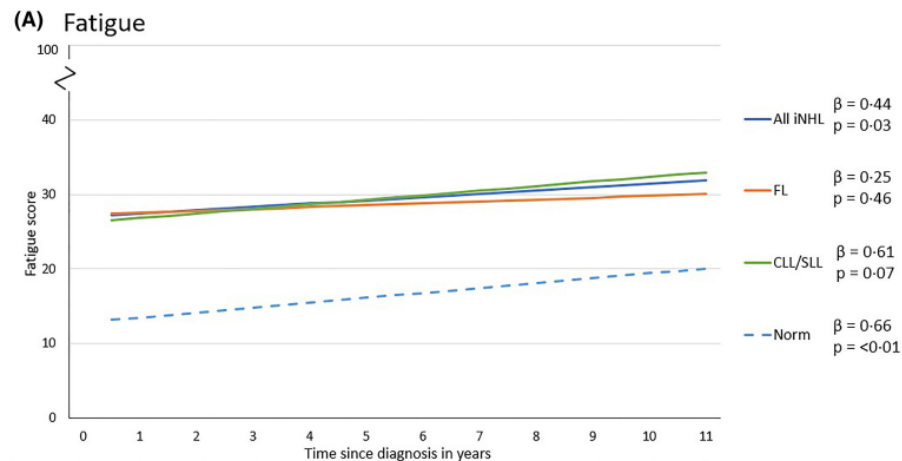
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ENGAGE PATIENTS!

- Cancer lags other chronic conditions in its provision of pro-active self-management
- Self Management = ‘the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition’
 - Monitor one’s condition
 - Healthy lifestyle behavior interventions

Prepare patients, survivors and caregivers for active involvement in care



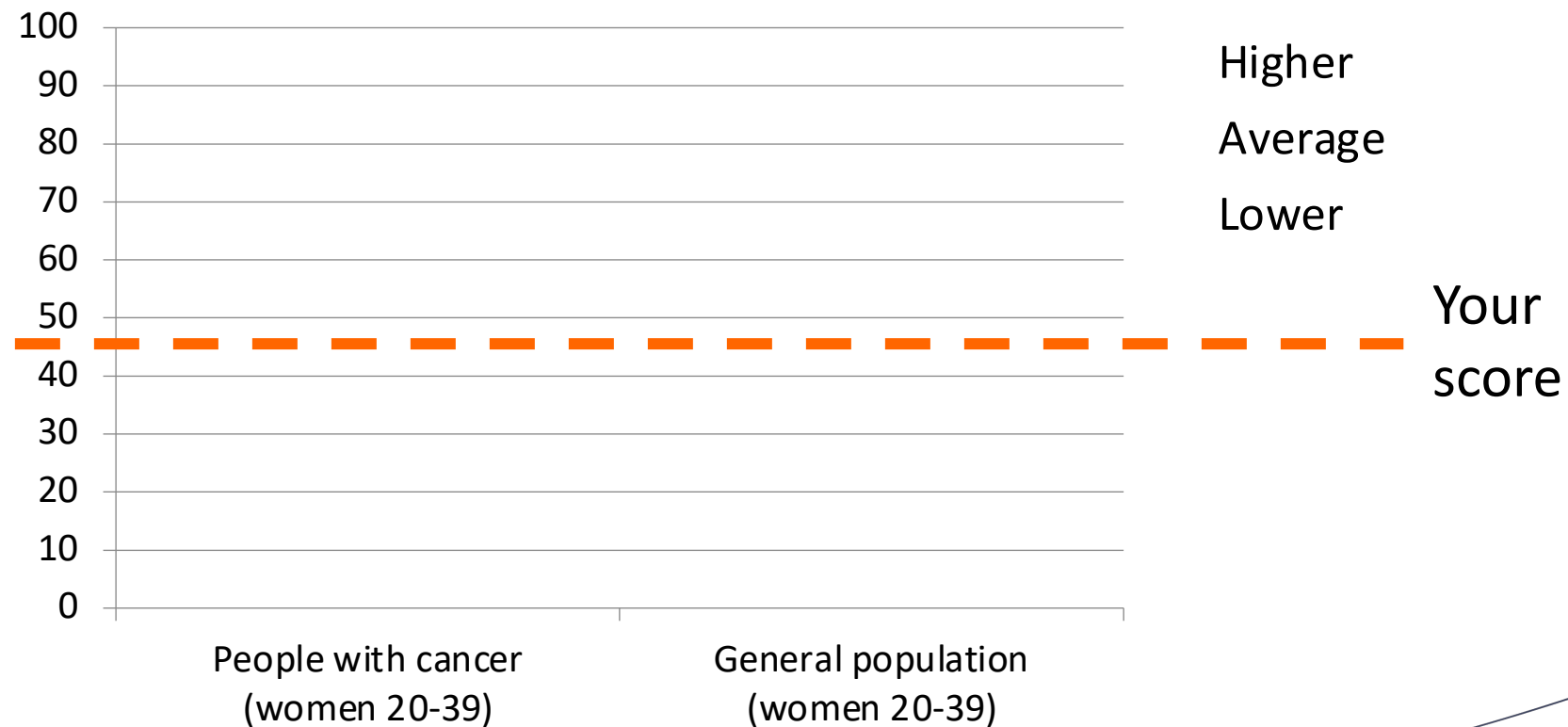
Return of individual PRO results to patients (and providers)

Yes, I want
feed back
about my
symptoms
and QoL



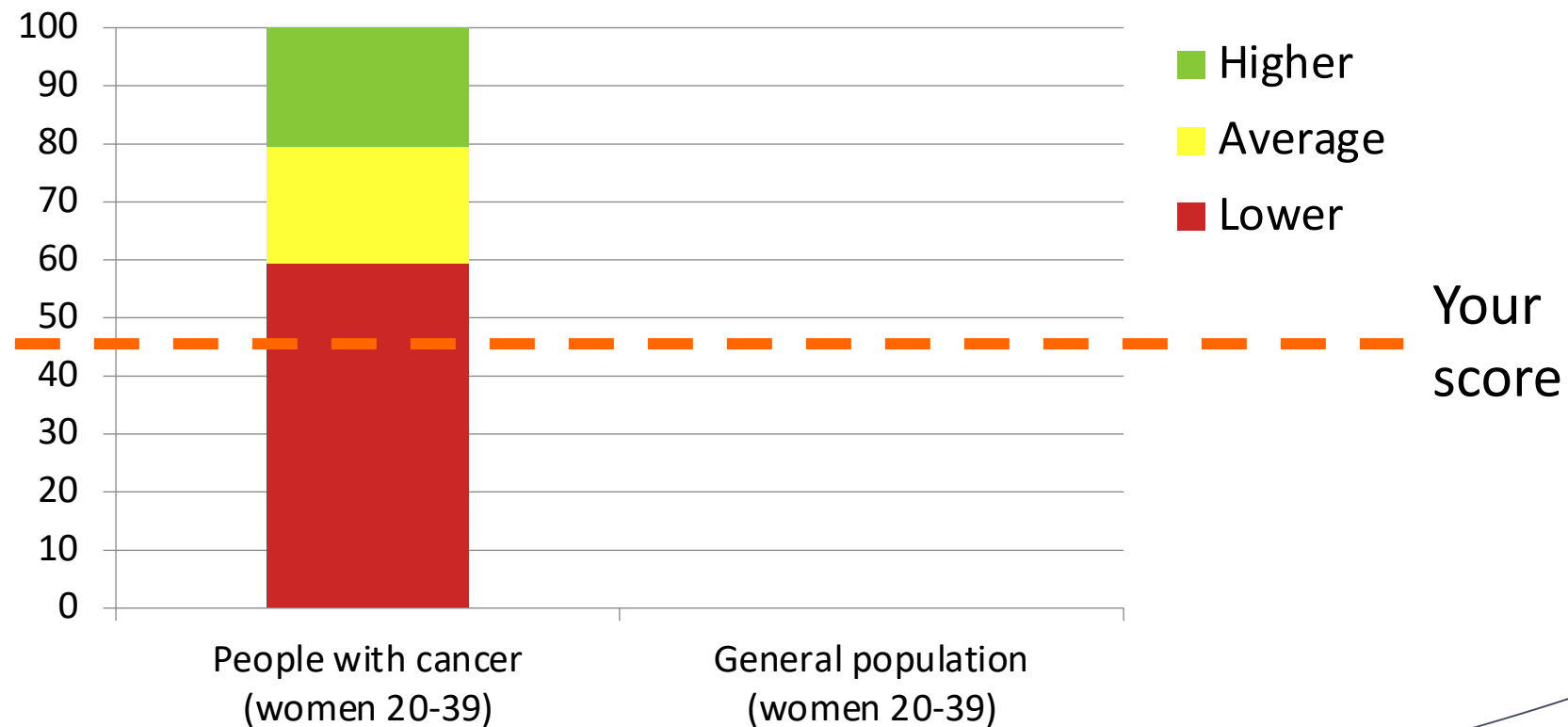
Return of individual PRO results to patients (and providers)

Physical functioning



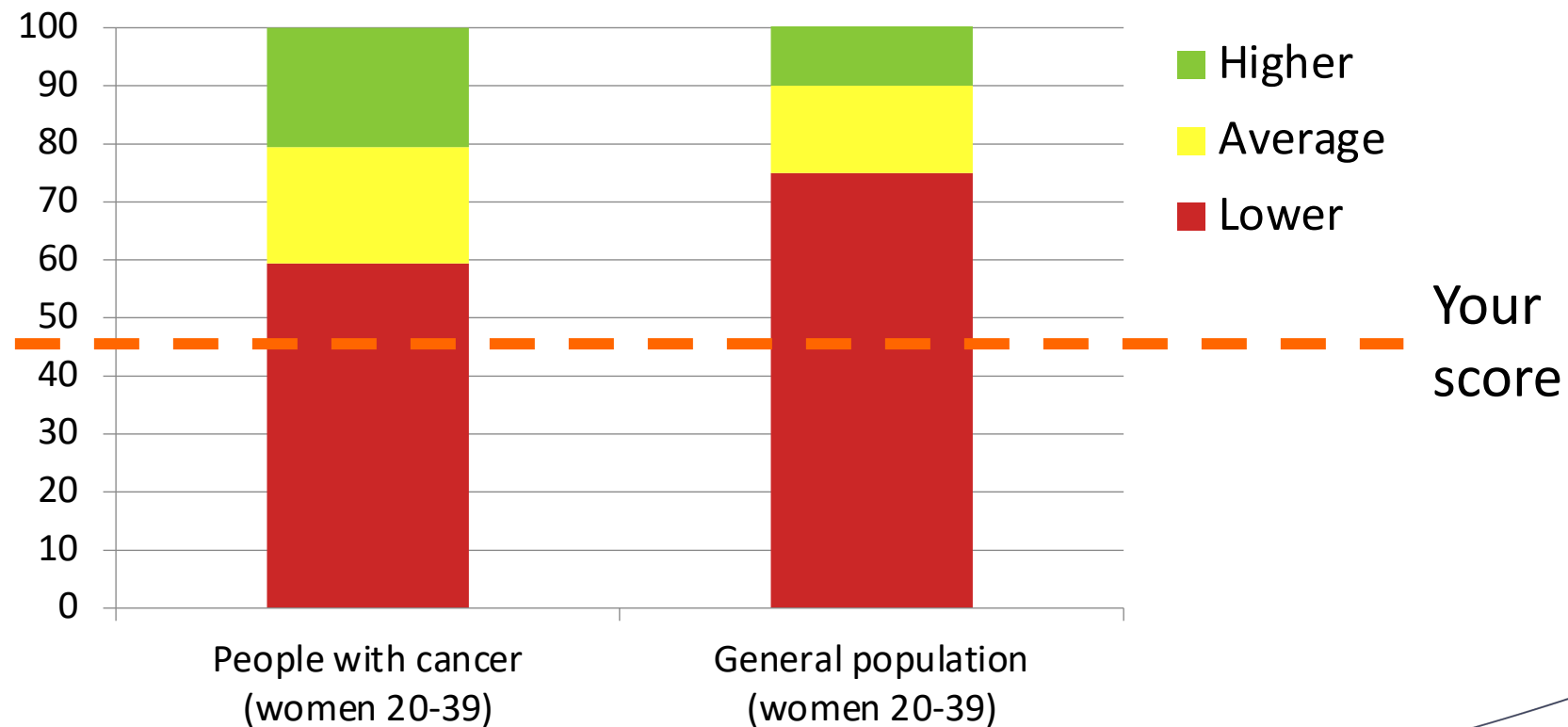
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Physical functioning



Return of individual PRO results to patients (and providers)

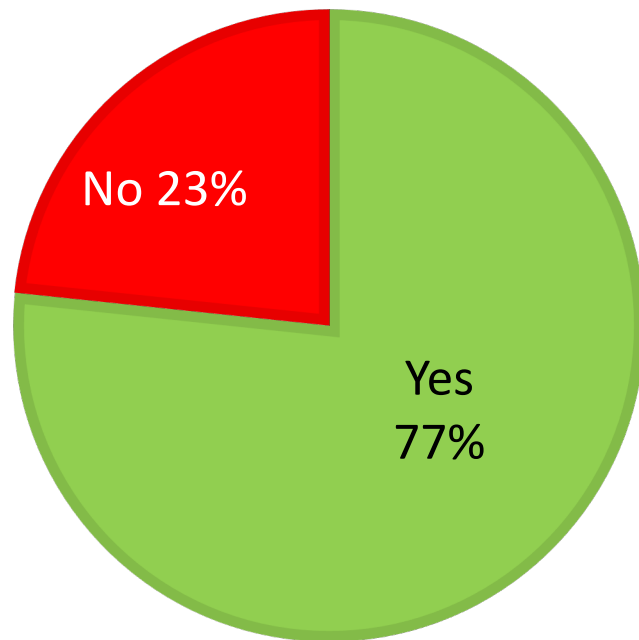
Physical functioning



Return of individual PRO results to patients (and providers)

Results of RCT in lymphoma patients (n=456)

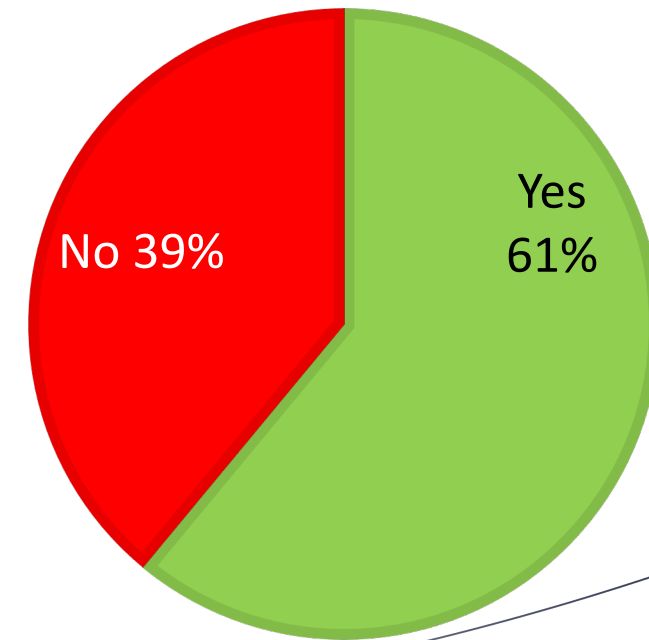
VIEWED INDIVIDUAL FEEDBACK



Oerlemans, J Med Internet Res 2021

Observational findings in CRC patients (n=484)

VIEWED INDIVIDUAL FEEDBACK



Visser, Support Care Cancer 2022

[illegible]

A collage of images representing various aspects of health and lifestyle. The collage includes: a close-up of a hand typing on a white keyboard; a close-up of a hand holding a blue pen over a survey form with questions about life satisfaction and social support; a close-up of a hand holding a syringe; a plate of food featuring bread, cheese, fruit, and vegetables; a black Fitbit smartwatch displaying the time 12:58 PM and distance 1.63mi; a computer monitor displaying a tic-tac-toe game; and a yellow measuring tape coiled around a black digital scale showing 293.

Physical activity (measured with Fitbit) and QoL



- 314 patients completed baseline questionnaire (74% response);
- N=129 (41%) also had compliant Fitbit data: 2 weeks at dx, 3m, 6m, 12m; 10h per day; 2 week days, 1 weekend day)



Fitbit users were on average 4 years younger (61 vs 65) than non users!



Physical activity (measured with Fitbit) and QoL

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	Q1 N=38	Q2 N=33	Q3 N=28	Q4 N=30
Median # daily steps				
- At diagnosis	3.131	5.932	8.113	11.893

Physical activity (measured with Fitbit) and QoL



	Q1 N=38	Q2 N=33	Q3 N=28	Q4 N=30
Median # daily steps				
- At diagnosis	3.131	5.932	8.113	11.893
- 3 mo after diagnosis	3.301	5.879	8.064	10.920

Physical activity (measured with Fitbit) and QoL



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Median # daily steps				
- At diagnosis	3.131	5.932	8.113	11.893
- 3 mo after diagnosis	3.301	5.879	8.064	10.920
- 6 mo after diagnosis	3.132	6.075	8.537	11.027



Physical activity (measured with Fitbit) and QoL

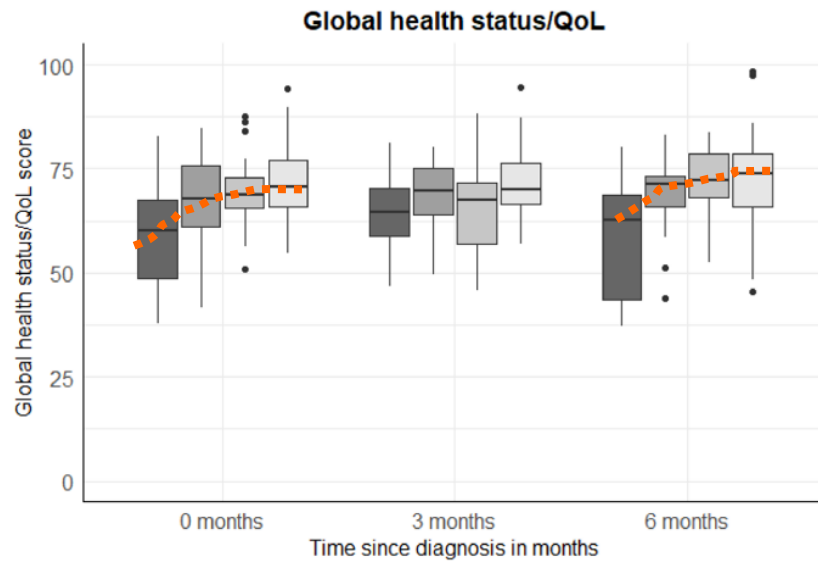
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- 3 mo after diagnosis	3.301	5.879	8.064	10.920
- 6 mo after diagnosis	3.132	6.075	8.537	11.027
- 12 mo after diagnosis	3.539	5.887	7.933	10.806

MM, SCT
older age, male sex,
lower education and/or income,
overweight, current smoker, comorbidities

Physical activity (measured with Fitbit) and QoL



Q1 Q2 Q3 Q4

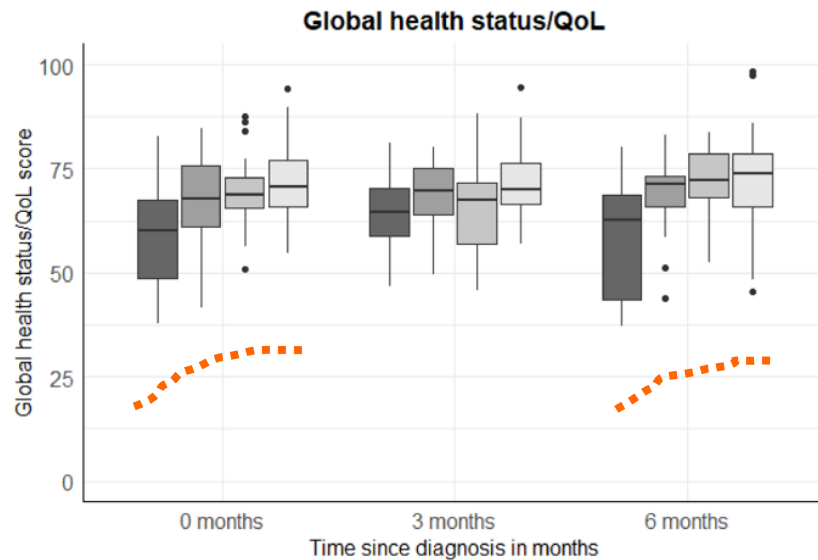


$P < 0.001$

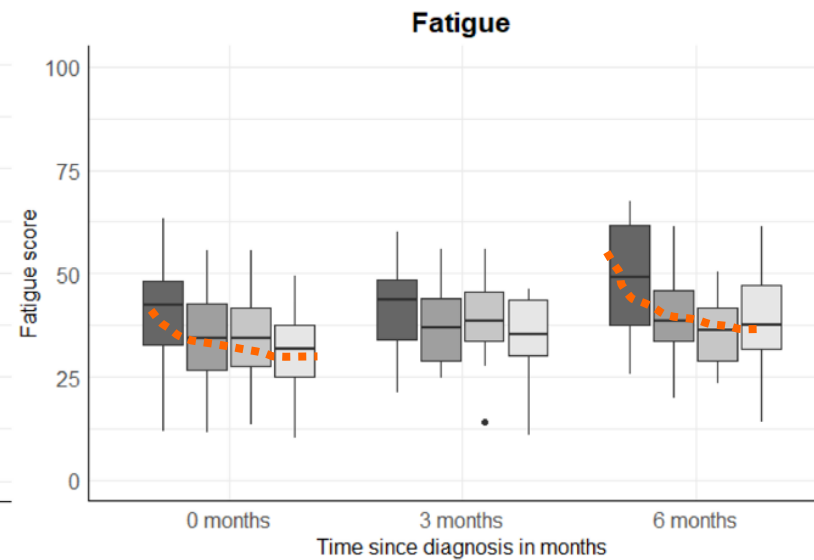


Physical activity (measured with Fitbit) and QoL

Q1 Q2 Q3 Q4



$P < 0.001$

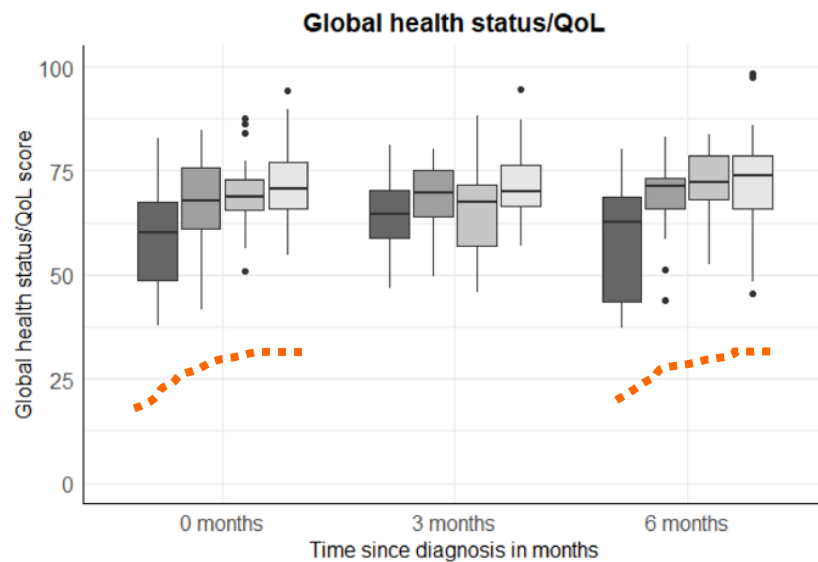


$P = 0.03$

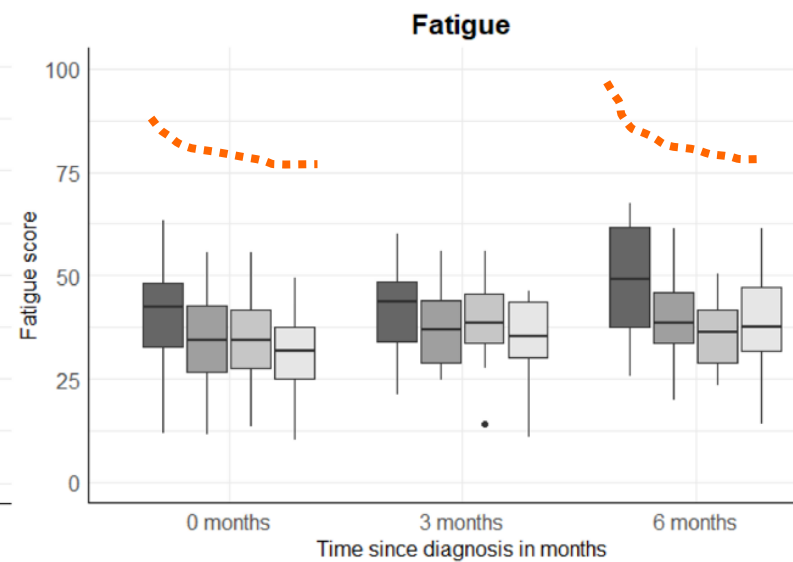
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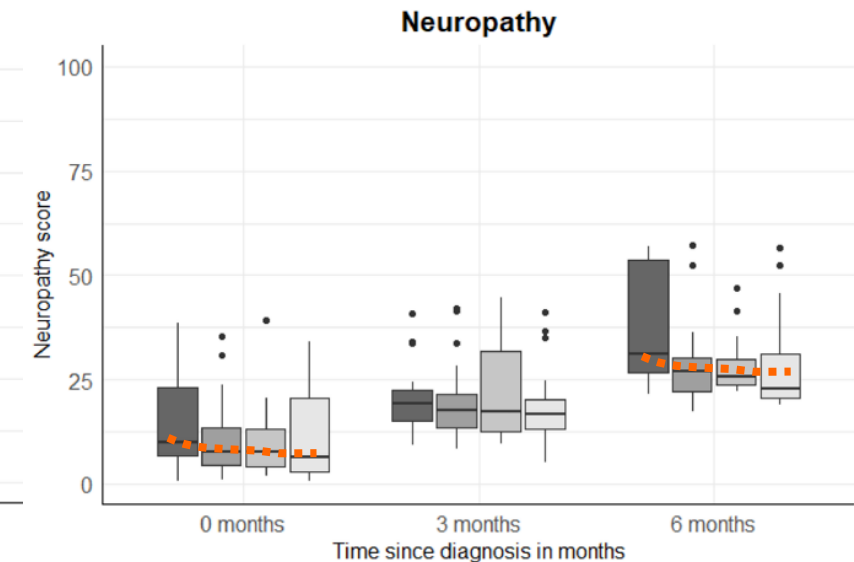
Q1 Q2 Q3 Q4



$P < 0.001$



$P = 0.03$



$P = 0.89$

Conclusion: more steps → better QoL, but better outcomes plateau at >8.000 steps

Take home message

What have we learned?

- ePROMs and wearables provide important insights
- Enable personalized care and self-management
- But... patients (and doctors!) are not always ready

What does this mean for the future?

- From isolated (paper) questionnaires to integrated monitoring
- Improving outcomes through feedback loops and self-management
- Collaboration between patients, clinicians, and researchers is key!



By integrating ePROMs, wearables and clinical data, we truly make the patient's voice part of clinical decision-making and survivorship care

Balancing the promise and pitfalls of wearables

Opportunities

- More objective measurement (of physical activity)
- Continuous, real-time monitoring
- Earlier detection of decline in QoL or complications
- Empowering patients through feedback
- Integration PROs with clinical data for holistic patient profiles
- Personalized survivorship care and targeted interventions

Challenges

- Selection bias: (younger patients more likely to wear devices)
- Digital divide (esp. older patients)
- Compliance over time
- Privacy and data security concerns
- Data integration
- Data handling and analyses
- Risk of information overload for patient and clinician