PROMs –
Why, for what and how

27. Mai 2024
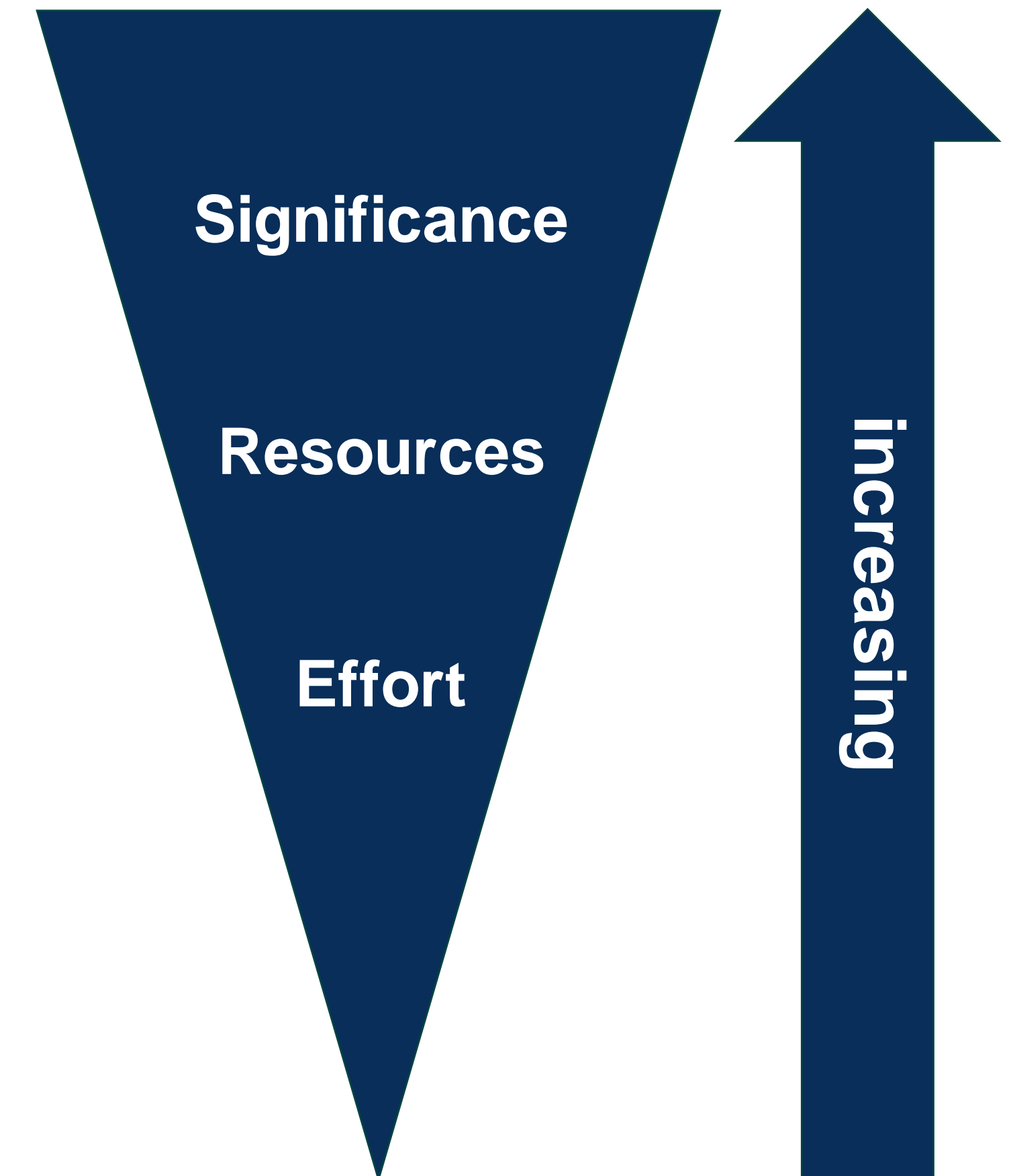Eidgenössische Qualitätskommission
Round Table, Bern

PROMs: Definition and Benefits

- **Patient Reported Outcome Measures (PROMs)**

  - Assessment of treatment success from the patient's perspective using standardized validated questionnaires

  - Generic, condition or disease-specific questionnaire

  - Measures subjective perception of quality of life and state of health

  - Measures short and long-term treatment results over a defined period of time

Patient-reported outcome measures help to practice a rational, patient-centered medicine on the way to a «value-based healthcare system»

Disease-specific PROMs

Significance

Resources

Effort

increasing

Generic PROMs (QoL)

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Why PROMs?

✓ The political framework

✓ Instrument for quality assurance

✓ Increase in treatment quality and patient satisfaction

✓ Registry requirements

    ✓ SIRIS / Siris Spine

✓ Certification requirements

    ✓ DKG Prostate Center

✓ Research interests

✓ Part of VBHC

✓ Marketing instrument

✗ Not a management tool for profit

PORTRÄT

Die Einführung der PROMs geht am Universitätsspital Basel mit einem neuen Denken einher: Die Kliniken setzen sich zum Ziel, die Behandlungsqualität zu steigern und dabei den Fokus auf die Patientinnen und Patienten zu legen.

VERSORGUNG IM UNIVERSITÄTSSPITAL

Pionierarbeit auf Schweizer Art

Von der Arzt-Patienten-Kommunikation über die Therapiesteuerung bis hin zum Qualitätsmanagement und internationalen Benchmarking: Als erste Klinik der Schweiz hat das Universitätsspital Basel PROMs systematisch eingeführt. Mittlerweile befragen die Baseler ihre Patientinnen und Patienten bei über 20 Krankheitsbildern.

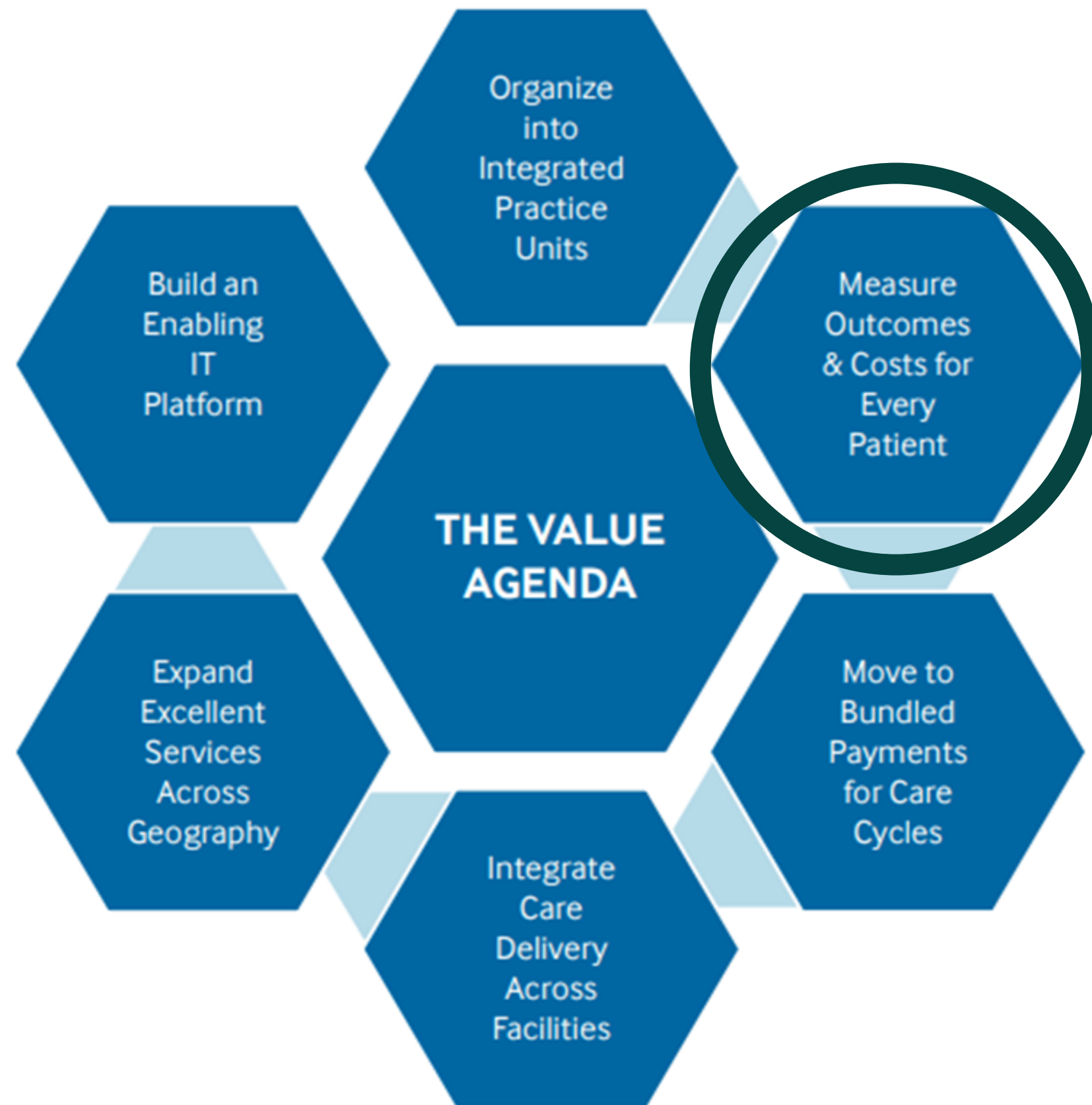42   PATIENT-REPORTED OUTCOMES

PATIENT-REPORTED OUTCOMES   43

https://www.bertelsmann-stiftung.de/de/publikationen/publikation/did/patient-reported-outcomes-3

DOI 10.11586/2023067

PROMs – Integral part of the VBHC concept

Porter ME, Lee TH. Integrated Practice Units: A Playbook for Health Care Leaders. NEJM Catal Innov Care Deliv 2021;2(1) DOI: 10.1056/CAT.20.0237

JAMA   October 1, 2014   Volume 312, Number 13

Optimal patient care

Shared decision making

Evidence-based medicine

Patient-centered communication skills

PROs

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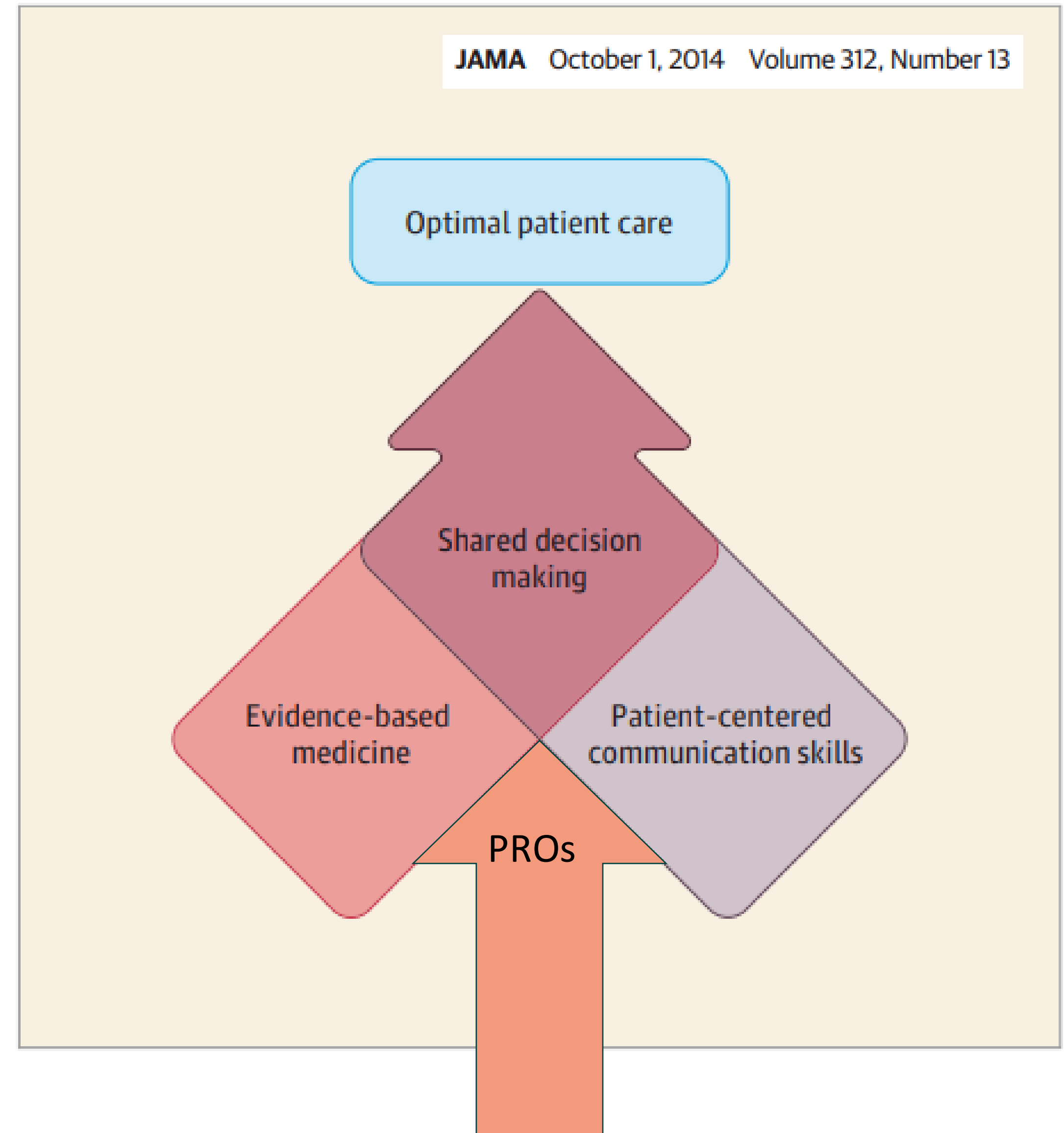
Two terms - one concept:

Value Agenda

THE VALUE AGENDA

- Organize into Integrated Practice Units
- Build an Enabling IT Platform
- Measure Outcomes & Costs for Every Patient
- Expand Excellent Services Across Geography
- Integrate Care Delivery Across Facilities
- Move to Bundled Payments for Care Cycles

Value Equation

$$Value = \frac{Treatment\ quality\ (PROMs)}{Costs}$$

The purpose of healthcare is to **deliver value to patients**

Value: Patient health outcomes per dollar spent

- In any field, value must be defined around the **customer**
- Value should be measured by **outputs**, not inputs

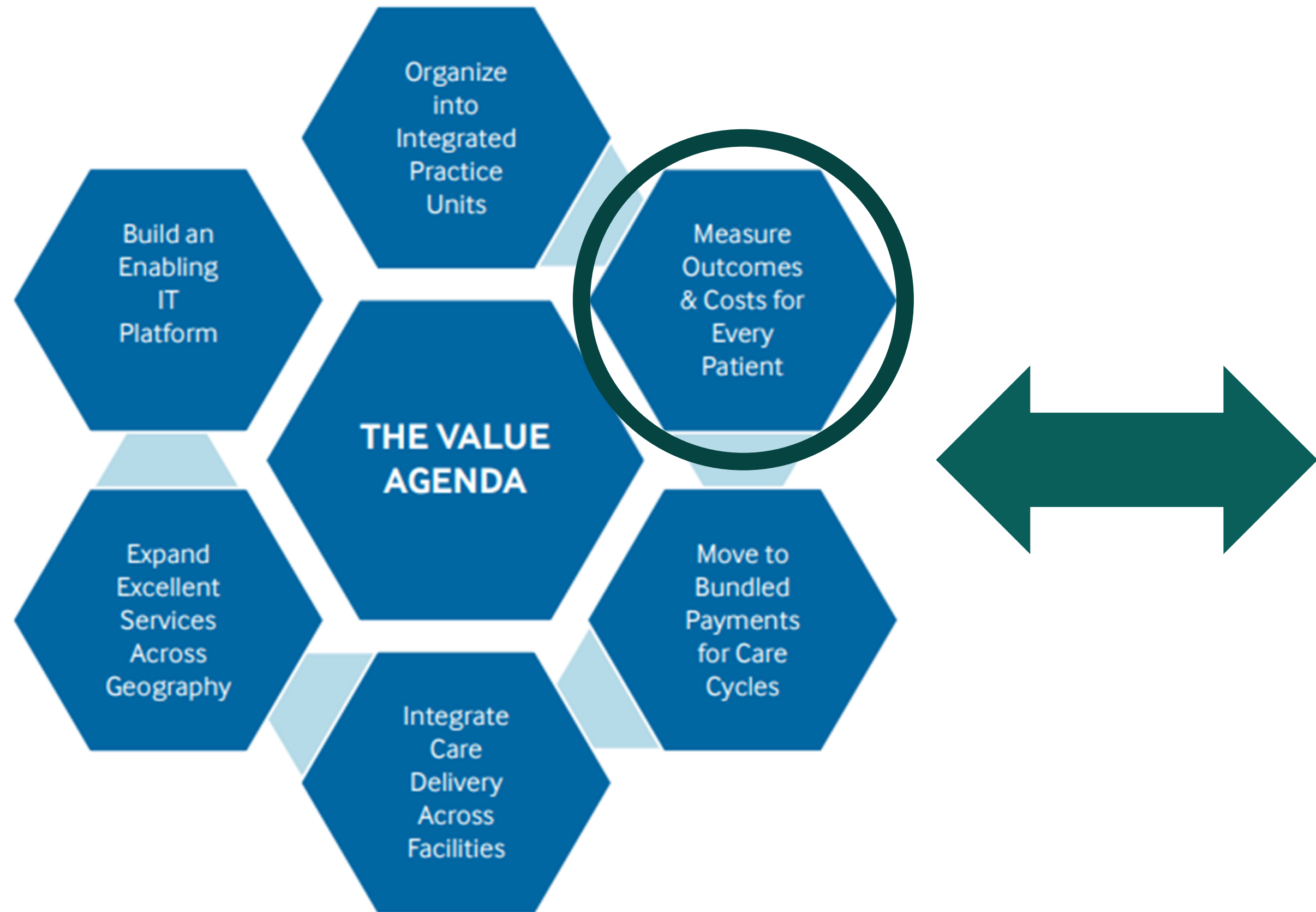Porter ME, Lee TH. Integrated Practice Units: A Playbook for Health Care Leaders. NEJM Catal Innov Care Deliv 2021;2(1) DOI: 10.1056/CAT.20.0237

Porter ME. What is Value in Health Care? 2007 https://cssnetwork.ca/wp-content/uploads/library/external/What-is-Value-in-Health-Care.pdf (abgerufen am 17.3.2024)

Porter ME. What is Value in health care? N Engl J Med. 2010 Dec 23;363(26):2477-81. doi: 10.1056/NEJMp1011024

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Disease-specific PROMs: 47 ICHOM standard sets

Cardiometabolic

ATRIAL FIBRILLATION

CORONARY ARTERY DISEASE

DIABETES

HEART FAILURE

HEART VALVE DISEASE

HYPERTENSION IN LOW- AND MIDDLE-INCOME COUNTRIES

STROKE

VENOUS THROMBOEMBOLISM

Congenital Anomalies

CLEFT LIP & PALATE

CONGENITAL HEART DISEASE

CONGENITAL UPPER LIMB ANOMALIES

CRANIOFACIAL MICROSOMIA

PAEDIATRIC FACIAL PALSY

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Disease-specific PROMs: 47 ICHOM standard sets

Mental Health

ADDICTION

AUTISM SPECTRUM DISORDER

DEPRESSION & ANXIETY

DEPRESSION & ANXIETY FOR CHILDREN & YOUNG PEOPLE

EATING DISORDERS

Musculoskeletal

HAND AND WRIST CONDITIONS

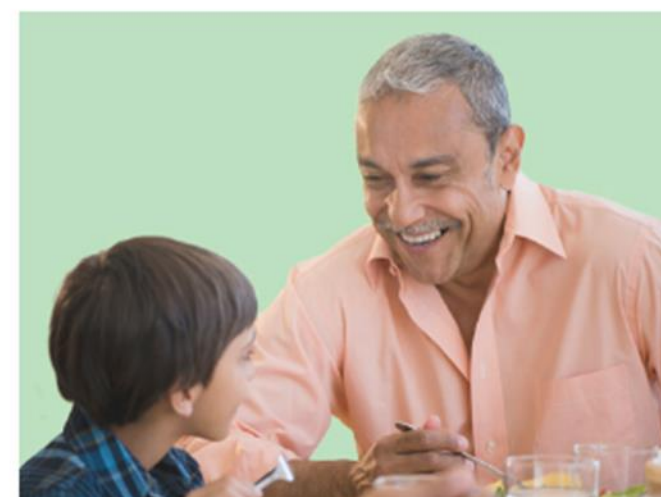**HIP & KNEE OSTEOARTHRITIS**

INFLAMMATORY ARTHRITIS

LOW BACK PAIN

Oncology

ADVANCED PROSTATE CANCER

COLORECTAL CANCER

LOCALIZED PROSTATE CANCER

LUNG CANCER

NON-METASTATIC BREAST CANCER

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Generic score as part of a disease-specific PROM-set

ICHOM

Stroke

Treatment approaches covered

IV Thrombolysis | Thrombectomy | Hemicraniectomy | Procoagulant Reversal Therapy

- PROMs & CROMs
- Up to date?
- Covers needs?
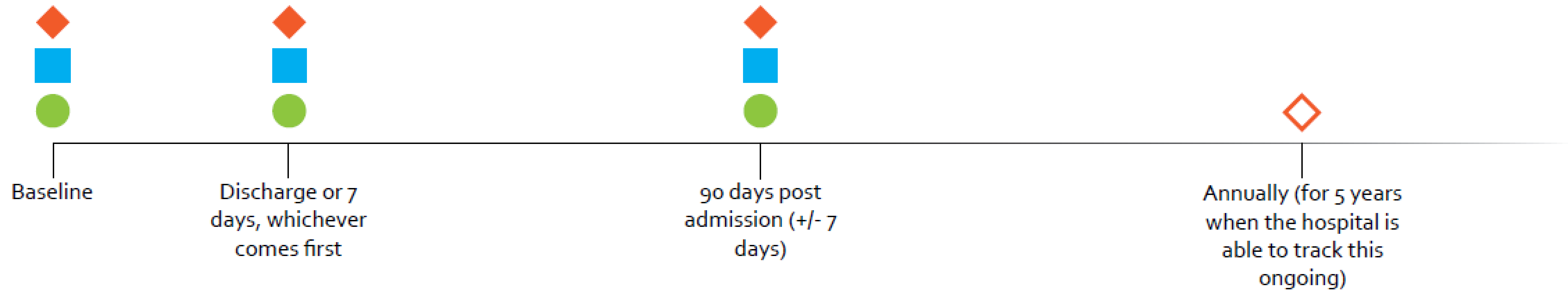- "Question load" - frequency - content

Details

1. Includes mood and global cognitive function
2. Includes pain and fatigue
3. Includes mobility, feeding, ability to return to usual activities, and self care
4. Includes social participation and ability to communicate
5. Tracked via one of the following: PROMIS GH-10 v1.2, EQ-5D-3L, WHODAS v2.0, VR-12, with additional single item questions for mobility, feeding, self care and grooming, and ability to communicate. The Simplified modified Rankin Scale questionnaire (smRSq) is recommended to be included.

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Follow-Up Timeline

Content

Case-Mix Variables

Demographic Factors

Patient Population	Measure	Timing	Reporting Source
	Age	Admission for index stroke event	Clinical
	Sex		
	Gender	Baseline	
	Ethnicity	Admission for index stroke event	Patient-reported
All patients	Living location	Admission for index stroke event;	
	Living alone	90 days + 7 days post admission for index event	
	Comorbidities	Baseline and annually	Clinical

Stroke Type

Patient Population	Measure	Timing	Reporting Source
All patients	Stroke type	Admission for index stroke event	Clinical
	Stroke severity		
	Duration of symptoms		Patient-reported

Vascular and Systemic

Patient Population	Measure	Timing	Reporting Source
	Prior Stroke		
	Prior TIA		
	Prior MI		
	Coronary artery disease		Clinical
	Atrial fibrillation	Admission for index stroke event	
All patients	Diabetes mellitus		
	Hypertension		
	Hyperlipidemia		
	Smoking status (current or in past year)		Patient-reported
	Alcohol use (>1 drink a day)		

Treatment/Care Related

Patient Population	Measure	Timing	Reporting Source
	Diagnostic evidence base	Admission for index stroke event	
All patients	Length of stay		Clinical
	Rehabilitation	Discharge + 7 days	
	Discharge destination		

Treatment Variables

Patient Population	Measure	Timing	Reporting Source
Ischemic stroke patients	Thrombolytic therapy	Discharge + 7 days	Clinical
	Thrombectomy		
Intracereberal hemorrhage patients	Hemicraniectomy		

Outcomes

Acute Complications

Patient Population	Measure	Timing	Reporting Source
Patients who received thrombolytic therapy or thrombectomy	Symptomatic intracranial hemorrhage after thrombolysis or thrombectomy	Discharge + 7 days	Clinical

Survival and Disease Control

Patient Population	Measure	Timing	Reporting Source
All patients	Overall survival	Discharge + 7 days; 90 days + 7 days post admission for index event; Annually	Clinical
	Ability to return to usual activities	Discharge + 7 days; 90 days +/- 7 days post-discharge	

Patient-Reported Health Status

Patient Population	Measure	Timing	Reporting Source
	Health-related Quality of Life	Discharge + 7 days post admission for index event	
	Feeding		
	Ability to communicate		
All patients	Mobility	Admission for index stroke event: Discharge + 7 days; 90 days +/- 7 days post-discharge	Patient-reported
	Self care (including grooming, toileting & dressing)		
	Self-reported new stroke	90 days + 7 days post admission for index event	
	Smoking cessation		

Disease-specific questions: patient-reported «PROMs»

Patient-reported health status

Variable ID:	poststrokeamb
Variable:	Poststroke functional status - Ambulation
Definition:	Are you able to walk?
Supporting Definition:	This item is also measured at baseline, as PRESTROKEAMB
Displayed Value:	None
Inclusion Criteria:	All patients
Timing:	Discharge or 7 days post admission, whichever comes first; 90 days post admission
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = Able to walk without help from another person with or without a device
	2 = Able to walk with help from another person
	3 = Unable to walk

Variable ID:	WHODAS_Q02
Variable:	Question 2 of WHODAS 2.0
Definition:	S2: Taking care of your household responsibilities?
Supporting Definition:	None
Displayed Value:	S2: Taking care of your household responsibilities?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Discharge or 7 days post admission, whichever comes first; 90 days post admission
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None
	1 = Mild
	2 = Moderate
	3 = Severe
	4 = Extreme or cannot do

Variable ID:	WHODAS_Q03
Variable:	Question 3 of WHODAS 2.0
Definition:	S3: Learning a new task, for example, learning how to get to a new place?
Supporting Definition:	None
Displayed Value:	S3: Learning a new task, for example, learning how to get to a new place?
Inclusion Criteria:	If answered "2 = WHODAS V2.0-12" to HR-HSQoL
Timing:	Discharge or 7 days post admission, whichever comes first; 90 days post admission
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	Code
Response Options:	0 = None
	1 = Mild
	2 = Moderate
	3 = Severe
	4 = Extreme or cannot do

Variable ID:	MH3
Variable:	Question 6a of VR-12
Definition:	These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks: a. Have you felt calm and peaceful?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Discharge or 7 days post admission, whichever comes first; 90 days post admission
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = All of the time
	2 = Most of the time
	3 = A good bit of the time
	4 = Some of the time
	5 = A little of the time
	6 = None of the time

Variable ID:	MH4
Variable:	Question 6c of VR-12
Definition:	c. Have you felt downhearted and blue?
Supporting Definition:	None
Displayed Value:	None
Inclusion Criteria:	If answered "3 = VR12" to HR-HSQoL
Timing:	Discharge or 7 days post admission, whichever comes first; 90 days post admission
Reporting Source:	Patient-reported
Type:	Single answer
Value Domain:	code
Response Options:	1 = All of the time
	2 = Most of the time
	3 = A good bit of the time
	4 = Some of the time
	5 = A little of the time
	6 = None of the time

Variable ID:	PF2
Variable:	Question 2a of VR-12
Definition:	The following items are about activities you might do during a typical day. Does our health now limit you in these activities? If so, how much? a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

Generic score as part of a disease-specific PROM-set

PROMIS® Scale v1.2 – Global Health

Global Health

Please respond to each question or statement by marking one box per row.

		Excellent	Very good	Good	Fair	Poor
Global01	In general, would you say your health is:	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
Global02	In general, would you say your quality of life is:..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
Global03	In general, how would you rate your physical health?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
Global04	In general, how would you rate your mental health, including your mood and your ability to think?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
Global05	In general, how would you rate your satisfaction with your social activities and relationships?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
Global09r	In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)......	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

		Completely	Mostly	Moderately	A little	Not at all
Global06	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

PROMIS® Scale v1.2 – Global Health

In the past 7 days…

		Never	Rarely	Sometimes	Often	Always
Global10r	How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

		None	Mild	Moderate	Severe	Very severe
Global08r	How would you rate your fatigue on average?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

Global07r	How would you rate your pain on average?	☐ 0 No pain	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10 Worst pain imaginable

Patient-Reported Outcomes Measurement Information System PROMIS®

Key points about PROMIS measures:

- **Comparability** - PROMIS offers standardized measurement instruments and thus allows the comparison of patients over time (interpersonal comparison, i.e. longitudinal comparison), the comparison between different patients (intrapersonal comparability) and across different disease groups or cultures.

- **Reliability & validity** - So far, it has been shown that the instruments developed to date have a high psychometric quality due to the strict methodological specifications.

- **Flexibility** - PROMIS items can be used in static questionnaires as well as in computer-adaptive tests. Unlike in a classic questionnaire, the items can be selected freely, i.e. according to need (e.g. only difficult items for use in a highly stressed group).

- **Inclusive** - PROMIS collects data from all population groups without having to take into account reading ability, language, physical functioning or individual life history.

Patient-Reported Outcomes Measurement Information System PROMIS®

PROMIS measures include item banks, short forms, and computer adaptive tests (CATs).

- **Item banks** are collections of carefully selected and tested items all measuring the same construct. Any subset of items can be administered and produce a score on the same metric. In some administration platforms, an item bank defaults to being administered as a computer adaptive test. Item banks are not intended to be administered in their entirety.

- **Short forms** are subsets of items selected from a larger collection of items (e.g., from an item bank). A short form usually generates a single score for a construct. Sometimes short forms are called fixed length forms or fixed forms.

- Scales are complete collections of scored items to be administered in their entirety.

- Profiles measure multiple constructs through a fixed collection of short forms or **CATs**.

- Pools are collections of related items not intended to produce a summary score, but to be used as single items.

IQM PROM Standardset: Orthopädie (Endoprothetik)/Unfallchirurgie

Krankheitsbild	Generisches Instrument	+	Krankheits-spezifisches Instrument	Erläuterung Akronyme	Befragungszeitpunkte
Wirbelsäule	PROMIS29	+	ODI, COMI	Oswestry Disability Index Core Outcome Measures Index	1 - 6
Hüft-TEP	PROMIS29	+	HOOS-12	Hip disability and Osteoarthritis Outcome Score	1 - 6
Knie-TEP	PROMIS29	+	KOOS-12	Knee disability and Osteoarthritis Outcome Score	1 - 6
Oberes Sprunggelenk	PROMIS29	+	FAAM, FFI	Foot and Ankle Ability Measure Foot Function Index	1 - 6

*Befragungszeitpunkte

1) Baseline bei Aufnahme

2) Nach Entlassung

3) 6 Monate nach Behandlung

4) 12 Monate nach Behandlung

5) 24 Monate nach Behandlung

6) 36 Monate nach Behandlung

IQM PROM Standardset: Onkologie

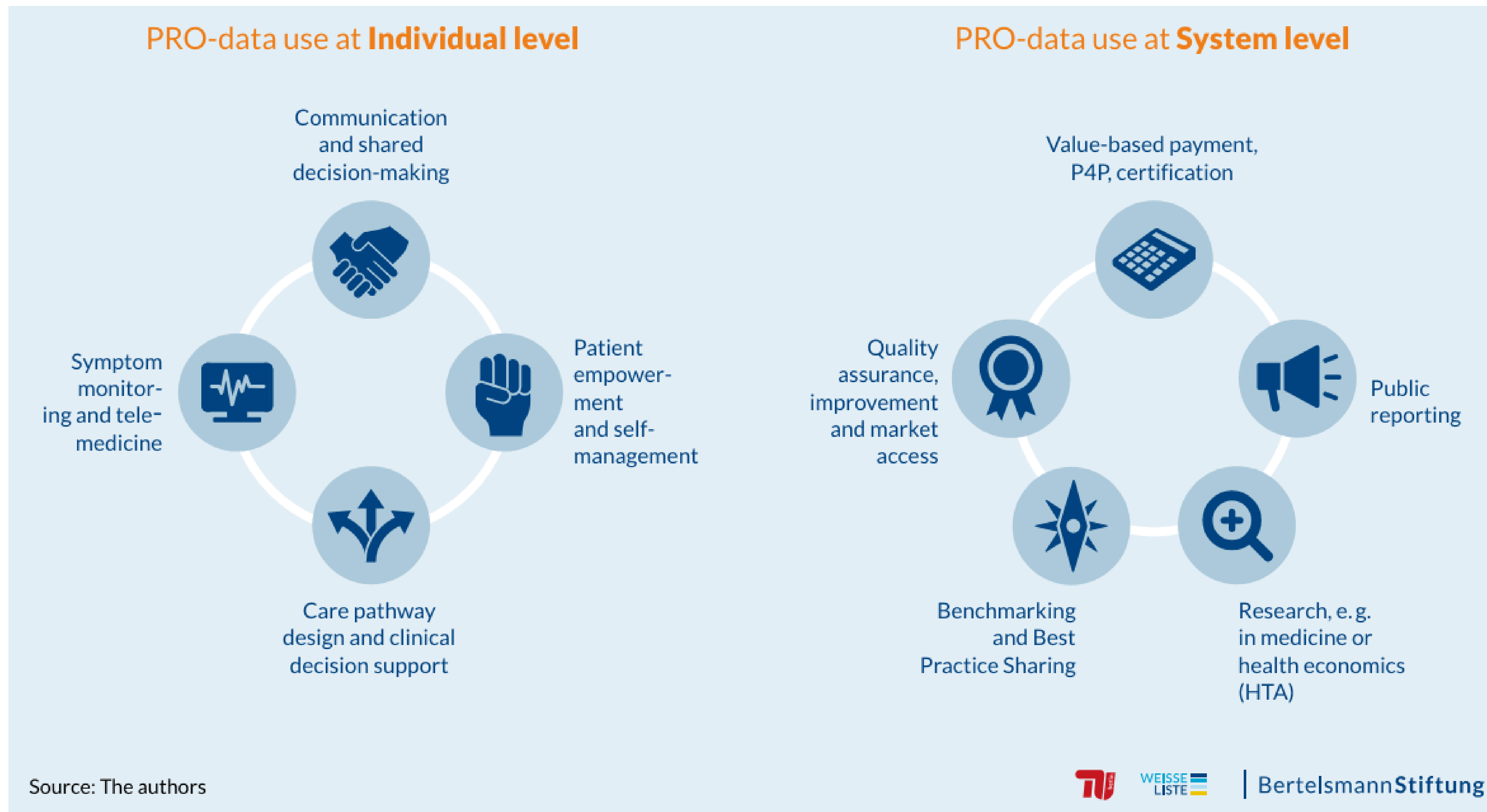| Krankheitsbild	Generisches Instrument	+	Krankheits-spezifisches Instrument	Erläuterung Akronyme	Befragungszeitpunkte
Brustkrebs	PROMIS29	+	EORTC QLQ BR23	European Organisation for Research and Treatment of Cancer: Quality of Life Questionnaire BReast Cancer mit 23 Fragen	1 - 6
Prostatakrebs	PROMIS29	+	EPIC-26	Expanded Prostate Cancer Index Composite mit 26 Fragen	1 - 6
Darmkrebs	PROMIS29	+	EORTC QLQ CR29	European Organisation for Research and Treatment of Cancer: Quality of Life Questionnaire ColoRectal Cancer mit 29 Fragen	1 - 6
Lungenkrebs	PROMIS29	+	EORTC QLQ LC13	European Organisation for Research and Treatment of Cancer: Quality of Life Questionnaire Lung Cancer mit 13 Fragen	1 - 6

*Befragungszeitpunkte

1) Baseline bei Aufnahme

2) Nach Entlassung

3) 6 Monate nach Behandlung

4) 12 Monate nach Behandlung

5) 24 Monate nach Behandlung

6) 36 Monate nach Behandlung

PROMs – for what?

PRO-data use at Individual level

Communication and shared decision-making

Symptom monitoring and tele-medicine

Patient empower-ment and self-management

Care pathway design and clinical decision support

PRO-data use at System level

Value-based payment, P4P, certification

Quality assurance, improvement and market access

Public reporting

Benchmarking and Best Practice Sharing

Research, e. g. in medicine or health economics (HTA)

Source: The authors

BertelsmannStiftung

https://www.bertelsmann-stiftung.de/fileadmin/files/user_upload/BSt_PROMs-Implementation_final.pdf

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PROMs – how? – Software Set-Up

✓ Expectation Management

✓ Clearly define content, processes,
 wishes and goals

✓ Ongoing change requests

✓ Intuitive handling of the system

✓ Integration into ICT landscape
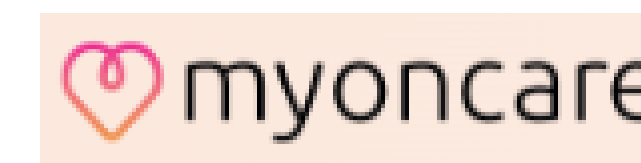
Collecting information about VBHC initiatives in Switzerland

Goal : make all listed projects available to VBHC Suisse members and facilitate the exchange among practitioners

Survey May to September 2023

What tools do you use for outcome collection?	
Medidux patient and provider apps	cenplex, own material
software	OpenPROMS solution, Brightfish front-end, MIDATA back-end
Heart Beat	Patient Journey, Questionnaires, Interviews, Gemba Walks, Software, Process Cost Analysis (Prozesskostenrechnung)
heartbeat, EQ-5D-5L, HOOS-PS, KOOS-PS, OKS, OHS, Forgotten Joint Score, Revisionsrate, Komplikationen	VR-12, SurveyMonkey, Integromat, Google Data Studio
Revisionsrate, ungeplante Rehospitalisation, ASA Score, HOOS-PS, KOOS-PS, Numeric Pain Rating Scale	Probably the ICHOM Set for Hypertension (or a part of it)
mobile app, in-app questionnaires, out-of-app questionnaires for PREMs	PROMIS-10, Zedoc (Software by "The Clinician")
We use Engage from Exolis	
Lyfgen	

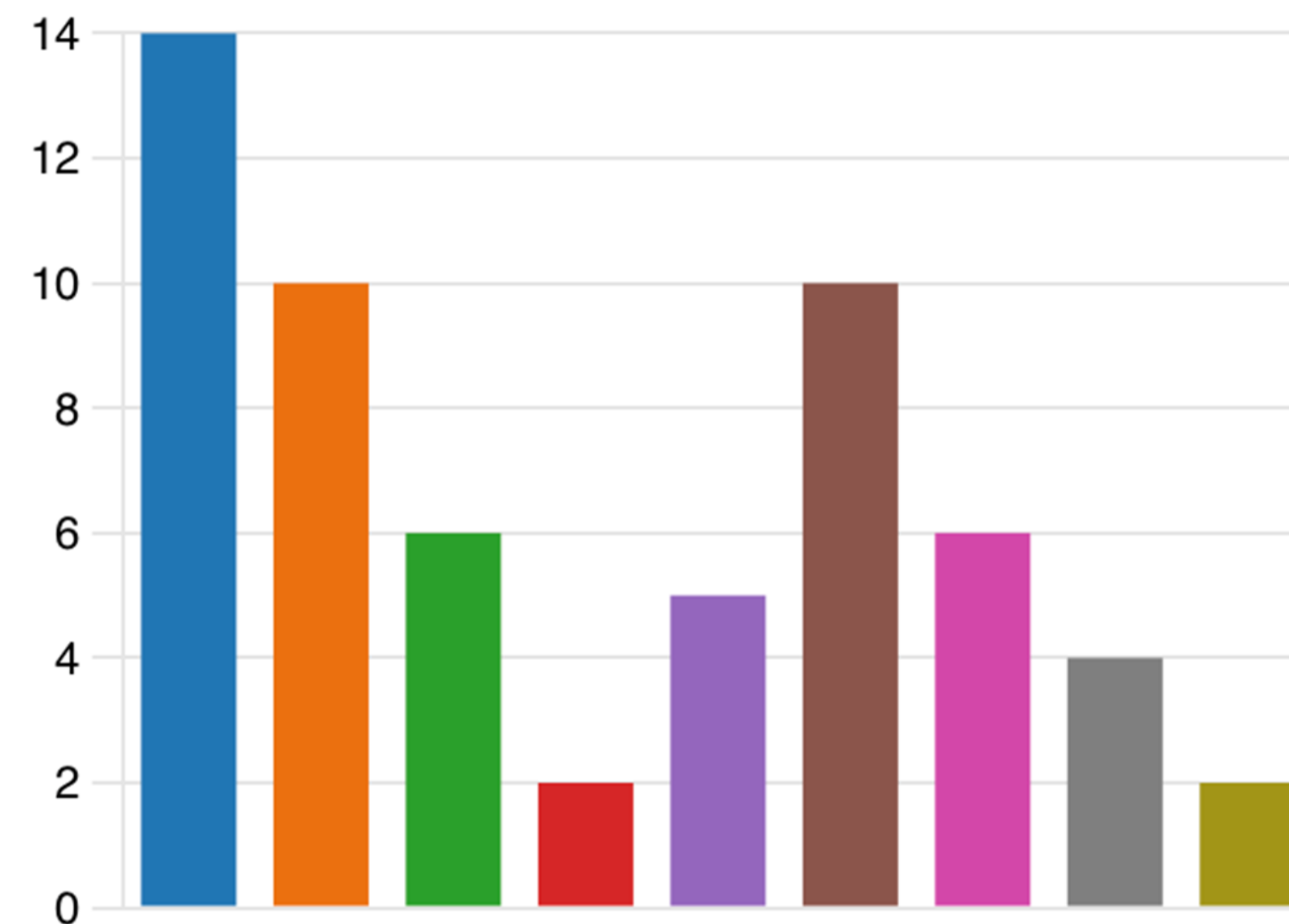# Collecting information about VBHC initiatives in Switzerland

Goal : make all listed projects available to VBHC Suisse members and facilitate the exchange among practitioners

Survey May to September 2023

3. What of the following elements are included in your initiative?

Plus de détails

Element	Count
Collection of PROMs	14
Collection of CROMs	10
Collection of PREMS	6
Integrated practice unit (within i...	2
Care cycles / pathways	5
Information technology platform	10
New payment mechanisms (incl....	6
Integrated care delivery (across i...	4
Autre	2

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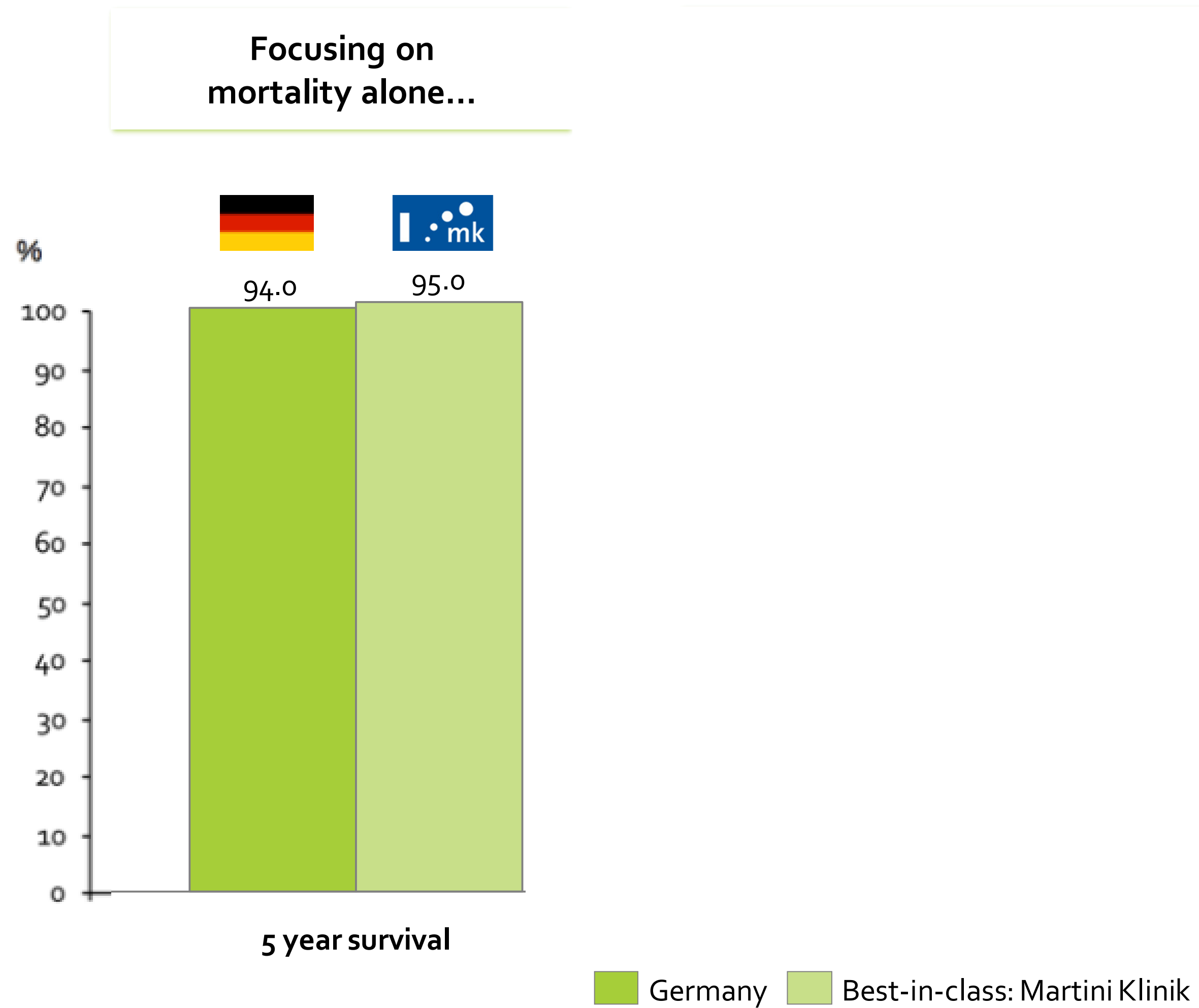Swiss Society for Value Based Healthcare

Collecting information about VBHC initiatives in Switzerland

Goal : make all listed projects available to VBHC Suisse members and facilitate the exchange among practitioners

Survey May to September 2023

What is the name of the institution(s) involved?	
3 hospitals with pilot projects in Kanton Wallis	T-Physio GmbH
Zurich University of Applied Sciences, Unisanté, BFH, University of Basel	BFH, MIDATA, Brigthfish, Inssel group, HUG, further clinics
KSW, USB, CSS, Swica (PwC)	Stadtspital Zürich and Novartis
FHNW, Hochschule für Wirtschaft / Reha Klinik Bellikon	EQUAM Stiftung, ZHAW, Pilatus Praxis (Luzern), Praxis Morillon (Bern), Innosuisse
mobile Health AG and partners in the healthcare system in CH and DE	BIHAM, HEIG-VD, PharmaSuisse, EQUAM Stiftung and others
Groupe Mutuel, DELTA, HSG	mediX Zürich, Spitex Zürich, EQUAM Stiftung, Ecoplan, an unnamed Hospital, SPO
USB & Roche	Hôpital de La Tour
Groupe Mutuel, Hôpital de La Tour, Universitätsspital Basel	Hôpital de La Tour, J&J, Lyfgen
KSW, CSS, SWICA, USB, PWC	
Hopital de La Tour, USB, Groupe Mutuel	
KSSG, USZ	

How do patients benefit from PROMs?

Focusing on mortality alone…

%

94.0   95.0

5 year survival

Germany   Best-in-class: Martini Klinik

Source: Martini Klinik, BARMER GEK Report Krankenhaus 2012, Patient-reported outcomes (EORTC-PSM), 1 year after treatment, 2010

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Figure. Overall Survival Among Patients With Metastatic Cancer Assigned to Electronic Patient-Reported Symptom Monitoring During Routine Chemotherapy vs Usual Care

JAMA July 11, 2017 Volume 318, Number 2

Patient-reported symptom monitoring

Usual care

Log-rank test: $P = .03$
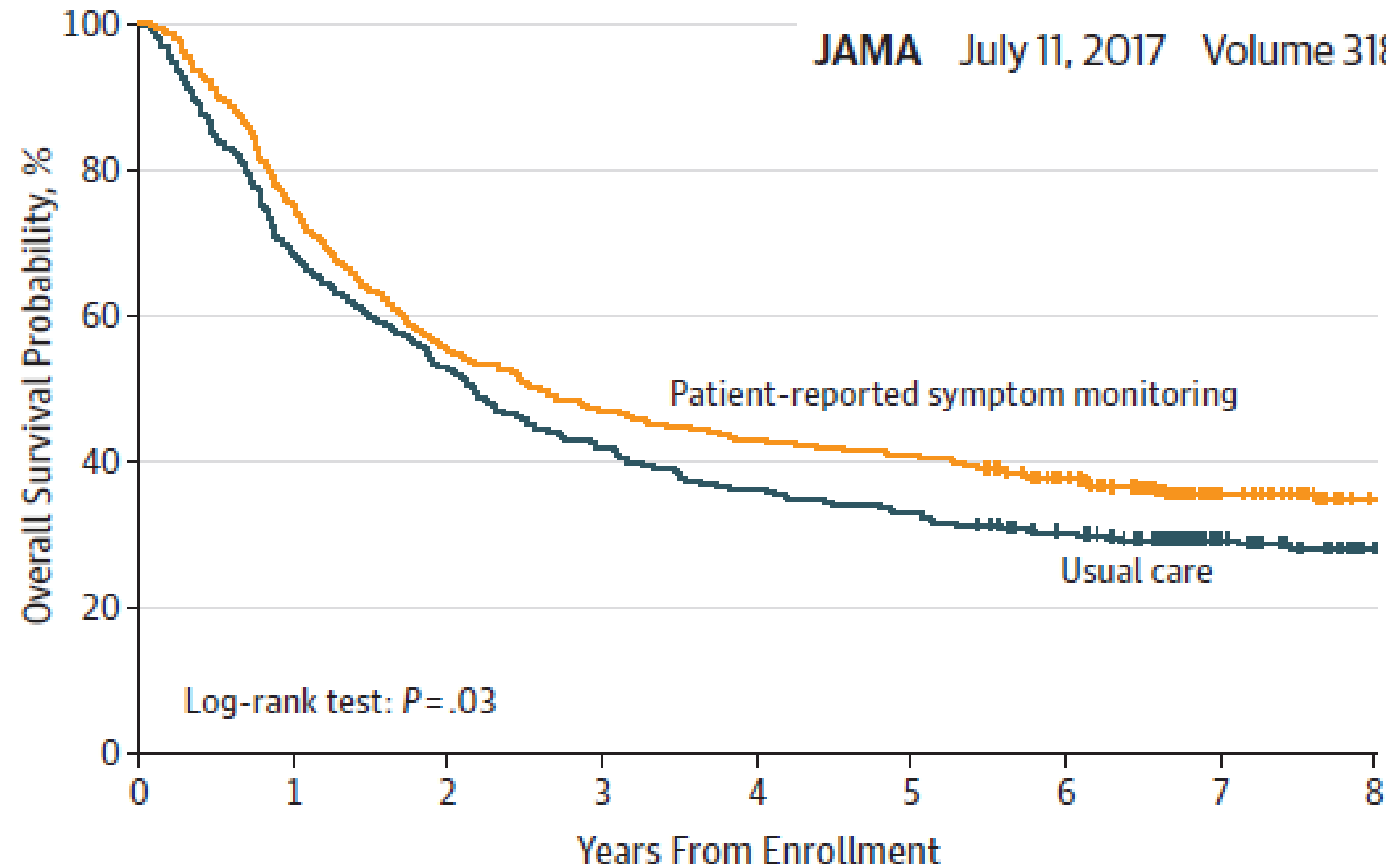
No. at risk									
Patient-reported symptom monitoring	441	331	244	207	190	181	148	65	33
Usual care	325	223	171	137	118	107	89	50	27

Figure 2. Kaplan-Meier Curves for the Overall Survival (OS) Analysis

A Intention-to-treat analysis

HR, 0.59 (95% CI, 0.37-0.96); P = .03
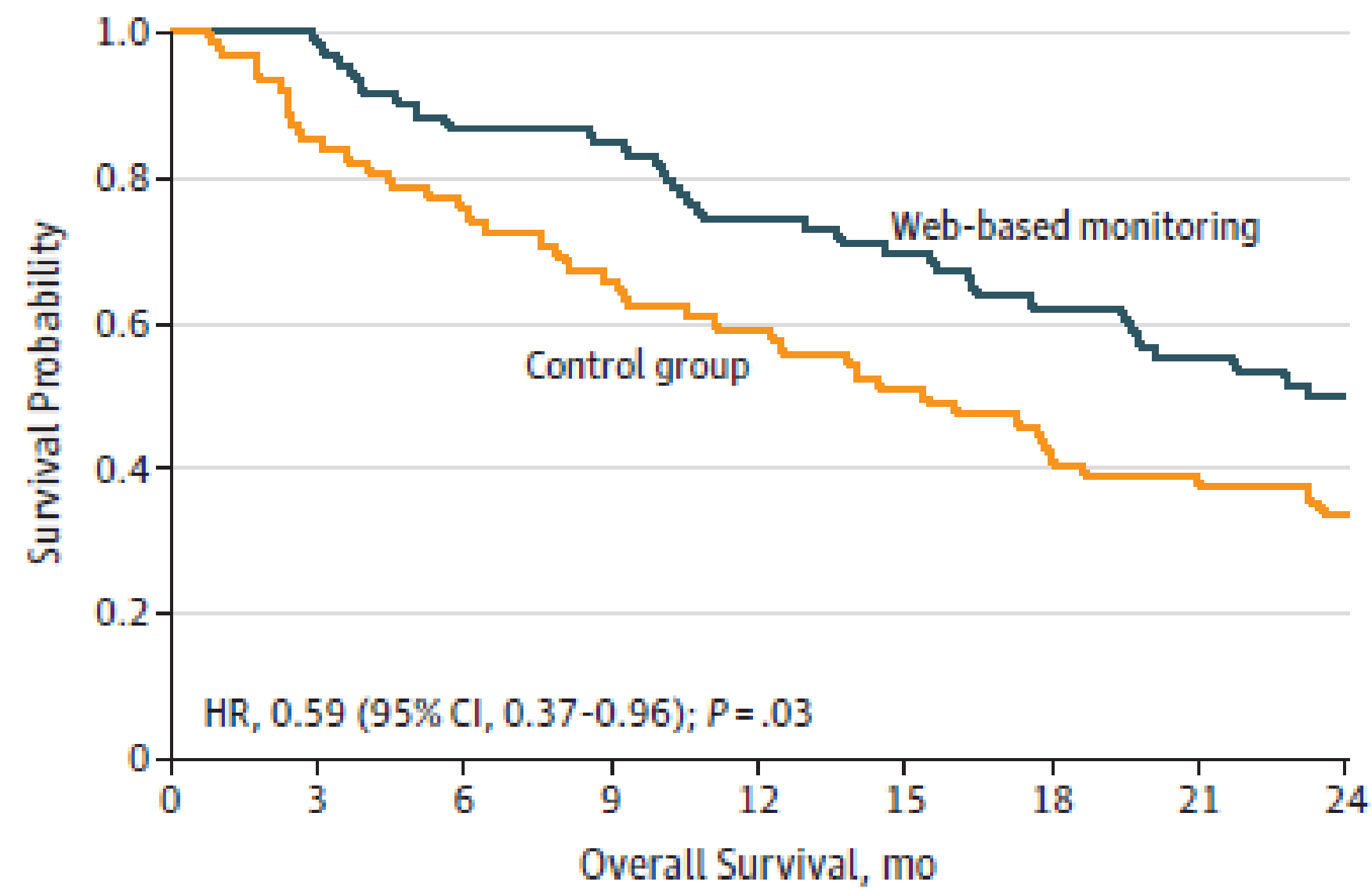
No. at risk

	0	3	6	9	12	15	18	21	24
Web-based monitoring	60	60	51	48	43	39	35	31	27
Control	61	52	45	38	34	29	24	22	19

Source	Median OS	12-mo OS, %	24-mo OS, %
Web-based monitoring	22.5 mo	75	50
Control	14.9 mo	56	34

B Censoring of crossover analysis

Log-rank P = .004

HR, 0.50 (95% CI, 0.31-0.81); P = .005
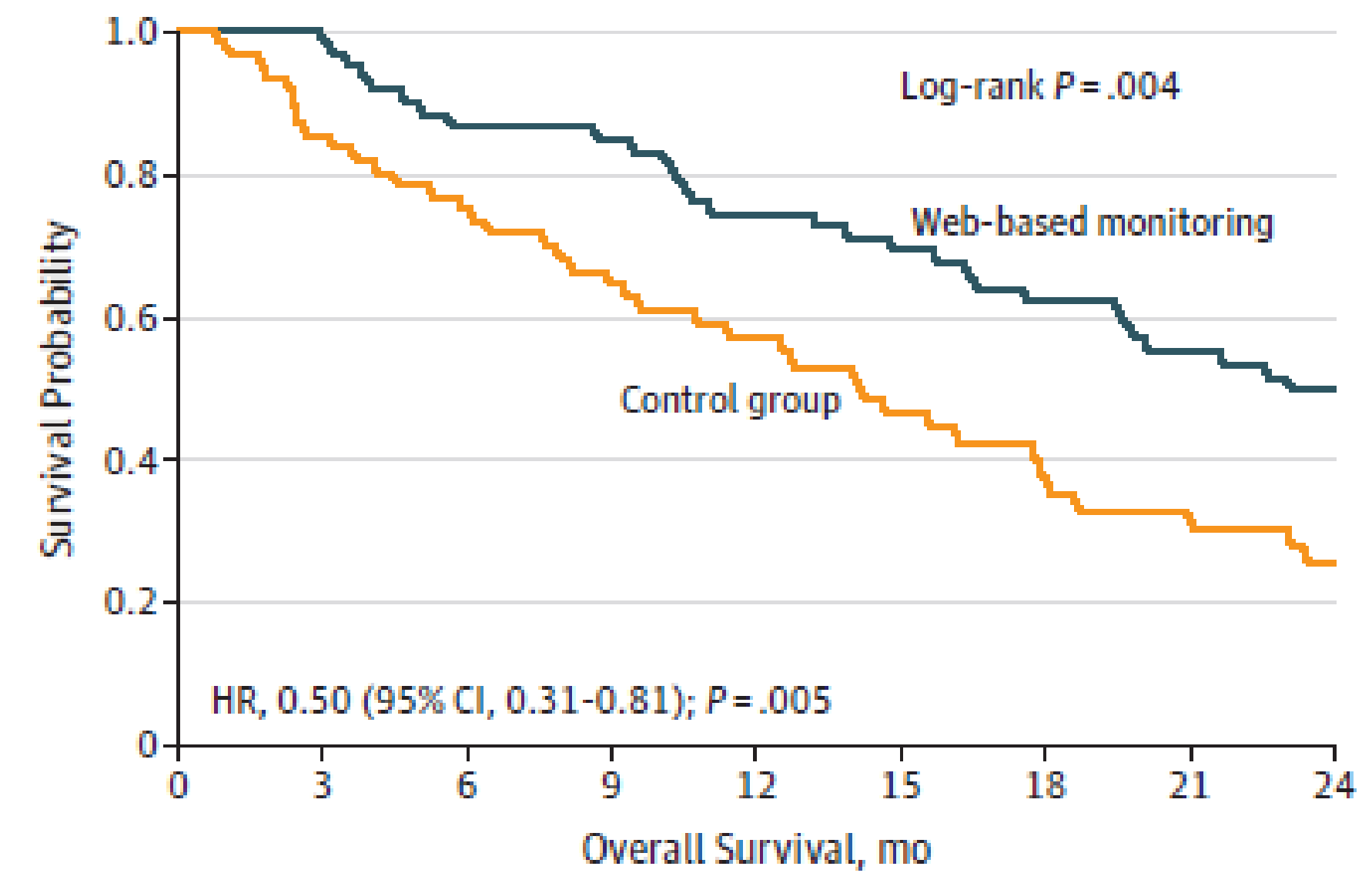
No. at risk

	0	3	6	9	12	15	18	21	24
Web-based monitoring	60	60	51	48	43	39	35	31	27
Control	61	52	43	33	26	20	15	13	11

Source	Median OS	12-mo OS, %	24-mo OS, %
Web-based monitoring	22.5 mo	75	50
Control	13.5 mo	53	26

A total of 121 patients were included in the intention-to-treat survival analysis. Ten of 34 living patients in the control group were eligible to cross over following the interim analysis. HR indicates hazard ratio.

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Discussing a system-wide approach for Value-Based Healthcare

Annual Meeting VBHC Suisse with Swiss Patient Compass

When: Thursday 27 June 2024, 10 am   **Where:** Hotel Bern, Zeughausgasse 9, CH-3011 Bern

Attendance: Members of the VBHC Suisse association (100+ members), leaders and change agents of the Swiss healthcare system

Time	Topic	Speakers
10:00 – 11:00	**Keynotes** Combining a top-down and bottom-up approach to VBHC in the Netherlands - the role of the Linnean Initiative Value-based Healthcare in clinical practice: The nursing care perspective	Prof Willem Jan Bos Isabelle Gisler
11:00 – 11:15	Swiss Declaration on VBHC	Daniel Schmutz
11:15 – 12:00	**Round table** Discussion of the keynote and the Swiss declaration on VBHC Moderated by Prof Christoph A. Meier	Keynotes speakers: Prof Willem Jan Bos & Isabelle Gisler Swiss Patient Compass: S. Wyss, R. Eurin, T. Huggler, U. Martin, D. Schmutz Patient representative: Chantal Britt Insurance representatives: tbd
12:00 – 13:00	**Break** Lunch break	
13:00 – 14:30	**Discussion** Population-based Healthcare - Chances and Risks • Medix' approach to population health • Réseau de l'Arc's capitation model Moderated by Susanne Gedamke	Dr Leander Muheim Dr Alain Kenfak
14:30 – 15:00	**Break** Coffee break	
15:00 – 16:30	**General assembly** VBHC Suisse General Assembly (for members)	Dr Florian Rüter & Board

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Q & A