



ACRON NAJAARSSYMPIOSIUM

PATIËNTENPARTICIPATIE, PATIËNTENVERGOEDING EN PATIENT ADHERENCE
IN KLINISCH ONDERZOEK

7

11

23

Locatie: Plein 7, Grand Salon | Kerkplein 18 | 3441 BG WOERDEN
Datum en tijd: dinsdag 7 november van 12:00 - 17:30 uur



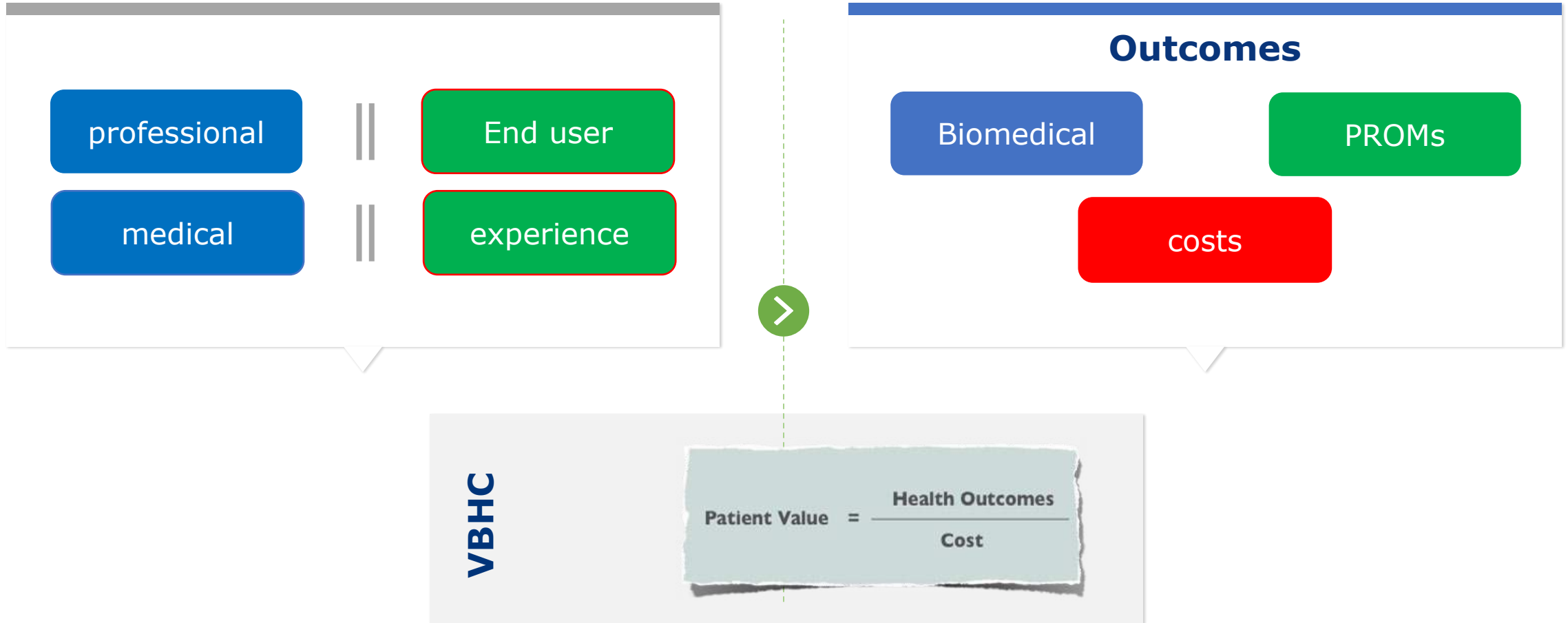
Basics of the Subjective Health Experience approach

Sjaak Bloem & Aad Liefveld



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'Subjective health experiences
in a person's life cycle'
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Outcomes are measured based on two different points of view: (bio)medical and experience



Subjective health experience – fundamentals

SHE-model



Acceptance

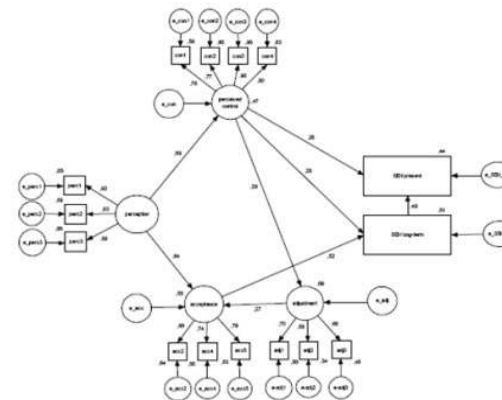
is the feeling by the individual that his health condition and the possible constraints on functioning resulting from it, are acceptable and fitting for him as a person

Perceived control

is the belief of the individual that his health condition, as he perceives it, can be influenced or controlled by himself or by others

Subjective experience of health (SEH)

is an individual's experience of physical and mental functioning while living his life the way he wants to, within the actual constraints and limitations of individual existence



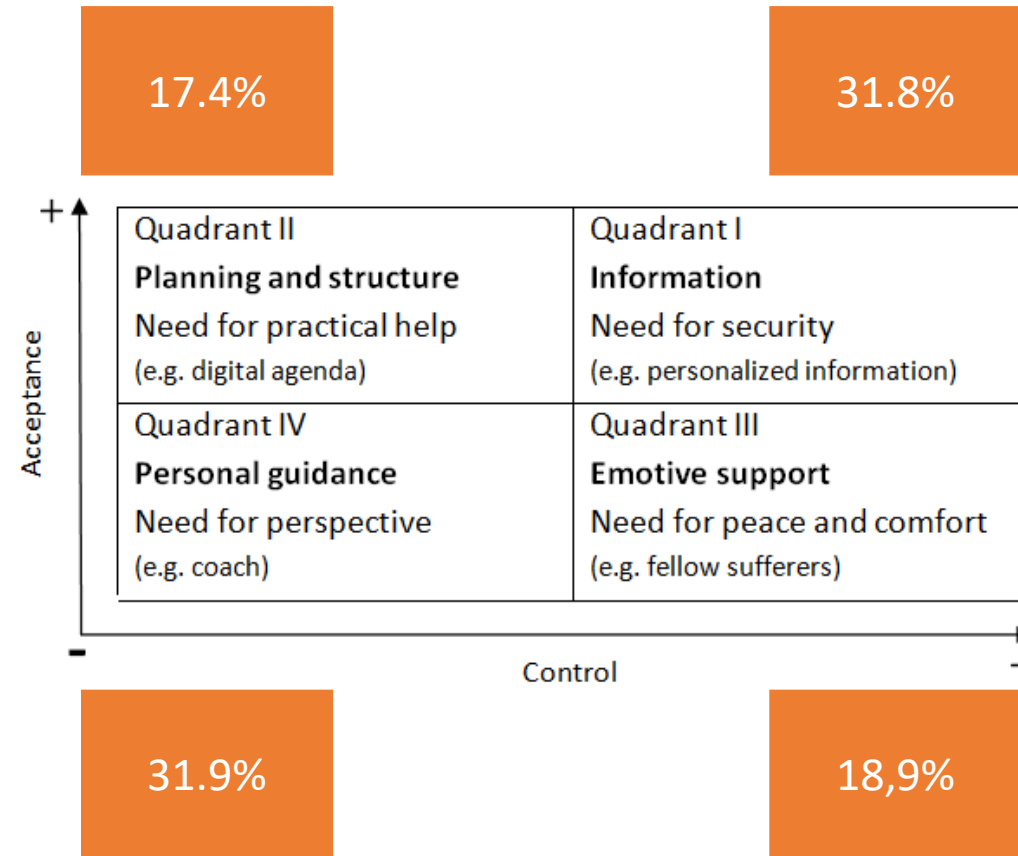
Source: Bloem (2008); Stalpers (2009) Dissertations

Source: Bloem & Stalpers, 2012
<http://dx.doi.org/10.2139/ssrn.2102513>

subjective health: ladder and segmentation



Fact & figures panels (1) N = 2450



Bloem &, Stalpers, 2016

<https://doi.org/10.1007/s40718-016-0063-5>

Source: Bloem, Stalpers, Groenland, van Montfort,
van Raaij, de Rooij (2020).

<https://doi.org/10.1186/s12913-020-05560-4>

diseases (without comorbidity) (2) N = 20.000

		Segment I	Segment II	Segment III	Segment IV	Total
Psychiatric diseases	N	71	22	53	168	314
	%	22.6%	7.0%	16.9%	53.5%	100.0%
Gastrointestinal diseases	N	108	28	47	188	371
	%	29.1%	7.5%	12.7%	50.7%	100.0%
Oncological diseases	N	119	59	12	177	367
	%	32.4%	16.1%	3.3%	48.2%	100.0%
Pain diseases	N	292	113	108	448	961
	%	30.4%	11.8%	11.2%	46.6%	100.0%
Rheumatological diseases	N	436	177	107	549	1,269
	%	34.4%	13.9%	6.4%	45.3%	100.0%
Neurological diseases	N	212	73	49	318	652
	%	32.5%	11.2%	13.4%	42.9%	100.0%

Source: Broekharst, Bloem, Groenland, van Raaij, van Agthoven (2022).
<https://doi.org/10.1038/s41598-021-04070-5>

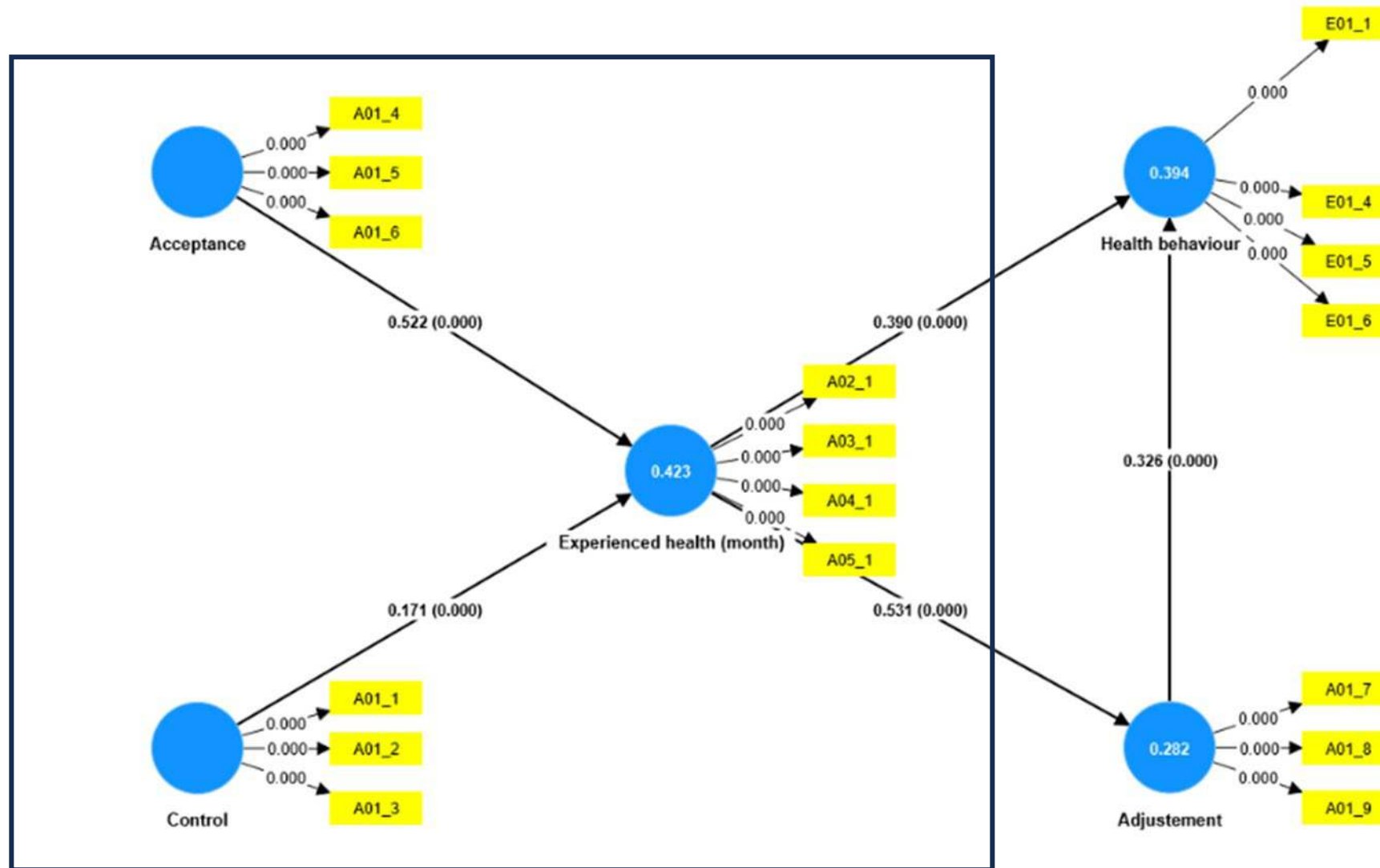
Table 1: Framework of segment characteristics in terms of behavior, queries (dilemmas), and needs.

Segment 1		
Behaviour	Common queries	Needs
Frequently engages with <u>factual information</u> Keeps informed	"Which sources of information can I trust?"	"I need <u>certainty</u>" A desire for validation of one's own approach
Follows developments related to the condition	"What new developments are relevant to me?"	Shared decision-making
Prepares for <u>consultations</u> Copes more easily with setbacks	"What solutions am I unaware of?" "How can I manage fluctuations in intensities of my illness?"	
Segment 2		
Seeks stability to better cope with the condition	"How can I gain control?"	"I need <u>structure</u>" A need for support to gain control over the <u>situation</u> Arranging matters (themselves) with guidance
Makes efforts to prepare for consultations	"Am I doing the right things?"	Perception of attention and active listening
Consults multiple healthcare providers	"What (lifestyle) adjustments will help me manage my condition?"	Comprehensive overview of disease progression and (treatment and support) possibilities.
Open attitude towards the treatment team	"Am I doing enough?"	

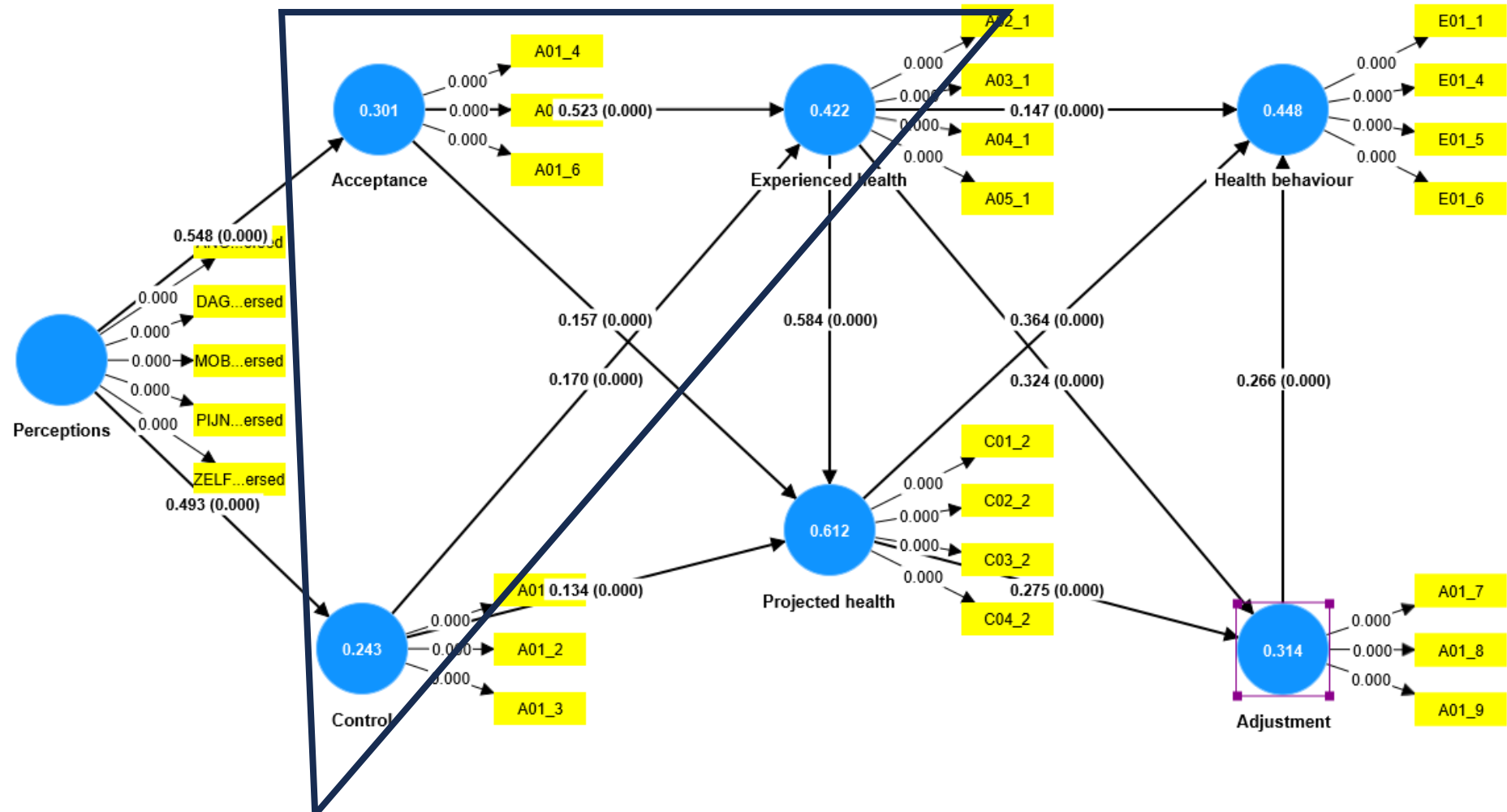
**Immunology diseases:
Behavior, dilemmas and
needs of individuals.
Example segment 1 - 2**

Source: Tack, Bos, Vodegel, Folkertsma, Broekharst, Liefveld, Bloem (2023). Personalizing supportive healthcare for individuals with immunological disorders A qualitative study in clinical practice. Submitted

SHE model and health behavior



SHE model and health behavior (extended)



Summary

Disease agnostic model – Subjective Health Experience

Fact & Figures *(examples of recent publications)*

Theory & Basics

Bloem & Stalpers, 2012
<http://dx.doi.org/10.2139/ssrn.2102513>

Broekharst, Bloem, Groenland, et al. (2022).
<https://doi.org/10.1038/s41598-021-04070-5>

Validity

Broekharst, Thomas, Russel, West, Jansen, Bloem, Römken (2023)
<https://doi.org/10.1016/j.gastha.2023.03.020>

van Erp, Thomas, Groenen, Bloem, Russel, Römken, Wahab. (2023)
doi.org/10.15403/jgld-4855

Segmentation: Needs & support

Bloem, Stalpers, et al (2020)
<https://doi.org/10.1186/s12913-020-05560-4>

Tack, Bos, Vodegel, Folkertsma, Broekharst, Liefveld, Bloem (2023 – submission)

All relevant platforms
(EPR, apps ,Link2Trials
and so on)

How to embed a treatment in a person's daily life?

Research topics

Older adults: vitality

Broekharst, Bloem, Blok, Raatgever, Hanzen, de Vette (2023).
<https://doi.org/10.3390/ijerp-h20116052>

Chronic illness and work

Dona, Peters, Senden, Kaal, Bloem, Hoevelaken, Bartstra, Derikx, Jacobs – Middelkoop, Schaafsma, Jeurissen (2023). In preparation

Adherence (EFPIA – IMI2)

IMI Beamer – development of a new adherence model. SHE approach = backbone

HTA: Expected and experienced utility

Broekharst, Bloem, Groenland, van Raaij, Jeurissen and van Agthoven (2023)
<https://doi.org/10.3389/fpsyg.2023.1139931>

Next Phase

Older adults: frailty, In - out hospital

Valid outcome indicators

Testing model in 6 disease areas (clinical trials)

Translation experienced utility into Qualys

Personalized care (effectivity and efficiency), monitoring, digitalization, real world evidence

Outcomes: positive impact SHE on:

SHE: strong association with

Determinants SHE

#representative sample population; different subgroups: sex, age, income, education, (no) disease (with comorbidity)

Health behavior#	Projected health#
e.g., healthier food intake, more mobility, better rest/ sleep, better health	e.g., health expectations (next 4 weeks, next year)
Adjustment#	Satisfaction
e.g., successful change, using support	e.g., service and support HCP
Adherence & retention	Next: time, people, work (productivity), and so on
e.g., compliance – medicine intake; less drop-outs in (clinical) studies	

Disease specific measures
e.g., handle with side effects, symptoms; physical, mental, social functioning because of disease
General (HR)QoL measures
e.g., anxiety/ depression, mobility, daily activity, mental, physical and social functioning
But a unique position

Acceptance and control
e.g., dynamic model, changes in time, causal relation SHE, differences in score profile for diseases
Segmentation model Supportive care
4 segments, each segment specifies a need which gives direction to the type of support (6 reliable/ valid questions)
Several platforms
e.g., electronic patient record, Link2trials, and so on



Questions - discussion

Sjaak Bloem & Aad Liefveld

