

RECIPIENT



OUTCOME STUDY



DR. REINFRIED POHL
STIFTUNG

TRANSFUSIONREGISTRY.org

*for the research of
blood donor and recipient
long-term outcomes*

Prof. Dr. Dr. Zacharowski

*Dr. Jan Kloka
Dr. Benjamin Friedrichson
Dr. Elina Nürnberg-Goloub*

2011 & 2021



The urgent need to implement patient blood management: policy brief

19 October 2021 | Policy brief



Download (2.4 MB)

Overview

In the past four decades, increased awareness of the inherent risks of transfusion has resulted in major initiatives to mitigate those risks through improvements in blood component safety. The realization that the intense focus on product safety had not been matched with a similar focus on improving transfusion decisions at the bedside led to the concept of “optimal blood use”. The practice of transfusion medicine now emphasizes the judicious use of transfusion, only when clinically indicated. The concept that “our own blood is still the best thing to have in our veins” (1) has given rise to various surgical “blood conservation” techniques (for example, minimization of blood loss, blood salvage and acute isovolaemic haemodilution). Underlying these efforts is the broader concept of “patient blood management” (PBM). This is a patient-centred approach that addresses iron deficiency, anaemia, coagulopathy and blood loss, in both surgical and nonsurgical patients, as risk factors for adverse medical outcomes. Under PBM, anaemia and iron deficiency are recognized as serious global health issues in their own right, affecting billions of people worldwide. Yet, globally, there is still a gap in awareness and implementation of PBM as an overall framework to address the risks of iron deficiency, anaemia, blood loss and coagulopathy. This policy brief focuses on the urgent need to close that gap and the steps needed to

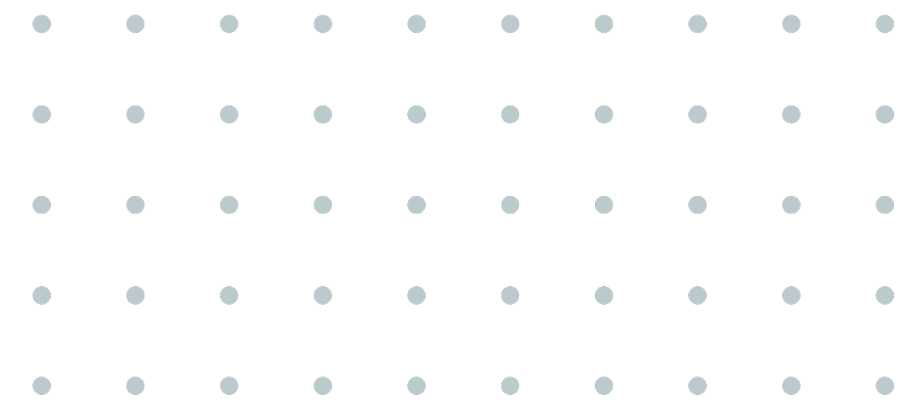
1 Patient Blood Management 2 Implementation Guidance to Improve the 3 Global Blood Health Status

4
5 *This document is to guide Health Authorities on implementing Patient Blood*
6 *Management (PBM) as a national standard of care to improve the Blood Health*
7 *status of the population in general, and to improve patient outcomes, safety,*
8 *and quality of care, while reducing the overall cost of healthcare. This guidance*
9 *also addresses the specific roles of single healthcare organisations in*
10 *conducting pilot projects as models for national PBM implementation and to*
11 *serve as national PBM reference centres.*
12

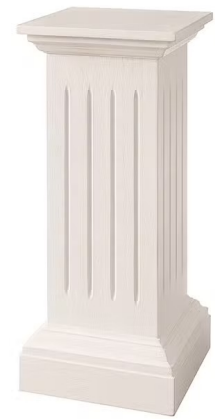
in press 2024

WHO PBM Impl. Guidan

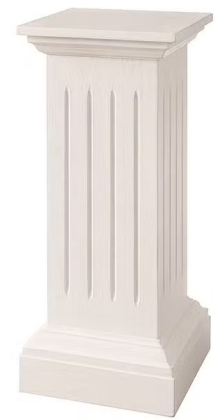




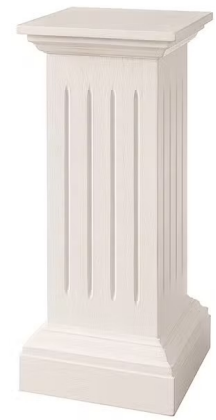
BLOOD HEALTH ENCOMPASSES CONDITIONS SUCH AS...



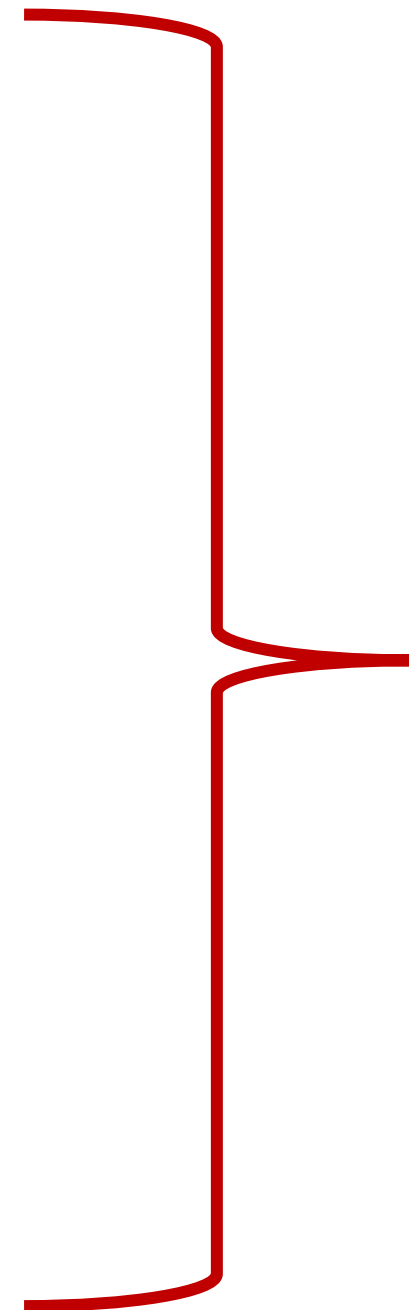
Anaemia



Blood loss



Coagulopathy

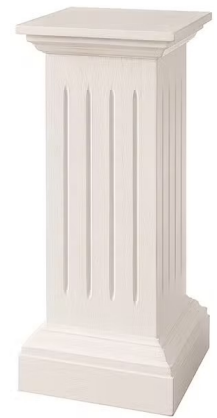
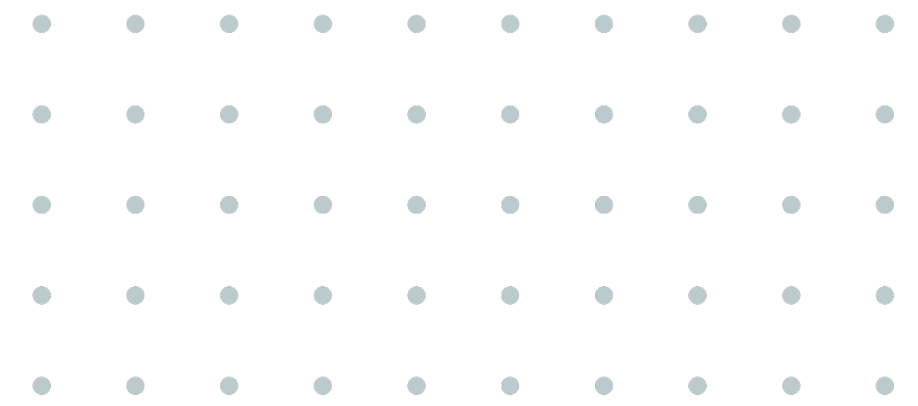


affects over 3 billion &
has significant economic and
health implications

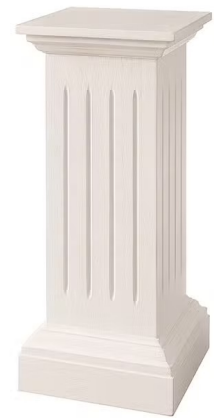
WHO PBM Impl. Guidance V.2.2 (2024) in press



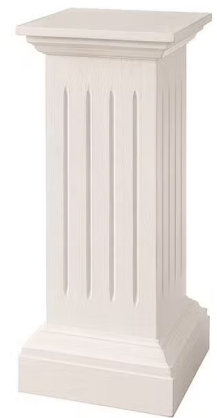
PATIENT BLOOD MANAGEMENT (PBM)



Anaemia management



Reducing blood loss



Rational use of
blood products

patient-centered approach:
improving patient outcomes
by managing & preserving
the patient's own blood

www.patientbloodmanagement.de/



BILL GATES FOUNDATION: HUMAN HEALTH CARE PROBLEMS

Leading causes 2015

% change
number
of YLDs
2005-15

% change
all-age
YLD rate
2005-15

% change age-
standardised
YLD rate
2005-15

1 Lower back and neck pain	18.6	4.9	-2.1
2 Sense organ diseases	25.2	10.8	0.6
3 Depressive disorders	18.2	4.5	1.0
4 Iron-deficiency anaemia	-3.8	-14.9	-11.6
5 Skin diseases	11.7	-1.2	0.4
6 Diabetes	32.5	17.2	5.4
7 Migraine	15.3	2.0	0.8
8 Other musculoskeletal disorders	20.5	6.6	1.3
9 Anxiety disorders	14.8	1.5	1.0
10 Oral disorders	22.4	8.2	-0.2

GBD 2015 Disease and Injury Incidence and Prevalence
Collaborators. Lancet 2016;388(10053):1545-1602



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Leading causes 2015

% change
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1 Anaemia

1 Lower back and neck pain	18.6	4.9	-2.1
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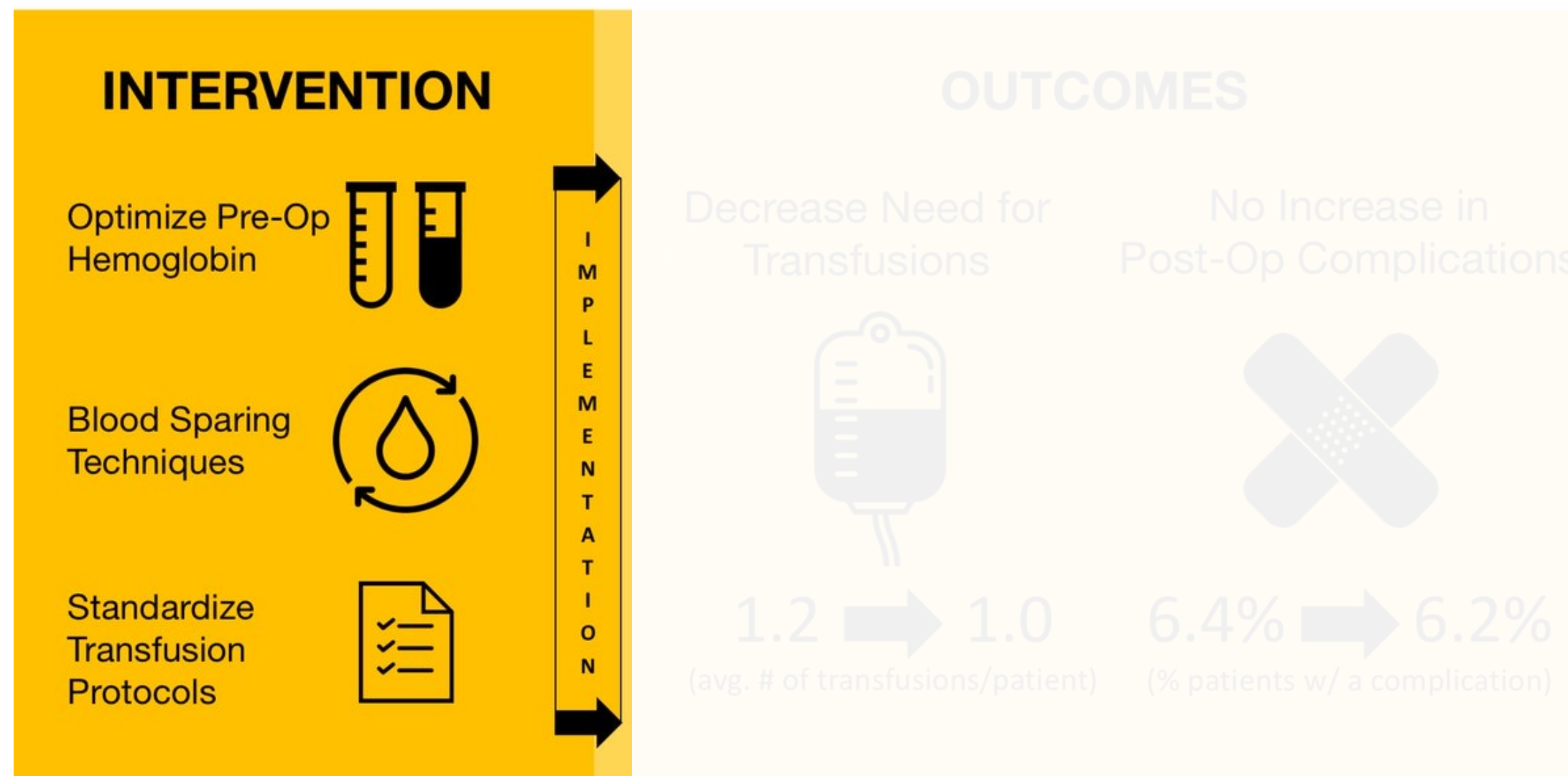
- 20-30% of you are suffering from anaemia
- 1/3 iron deficiency anaemia
- 2/3 other causes

GBD 2015 Disease and Injury Incidence and Prevalence Collaborators. Lancet 2016;388(10053):1545-1602



RESULTS IN GERMANY

Impact of Implementing a Perioperative Patient Blood Management Program



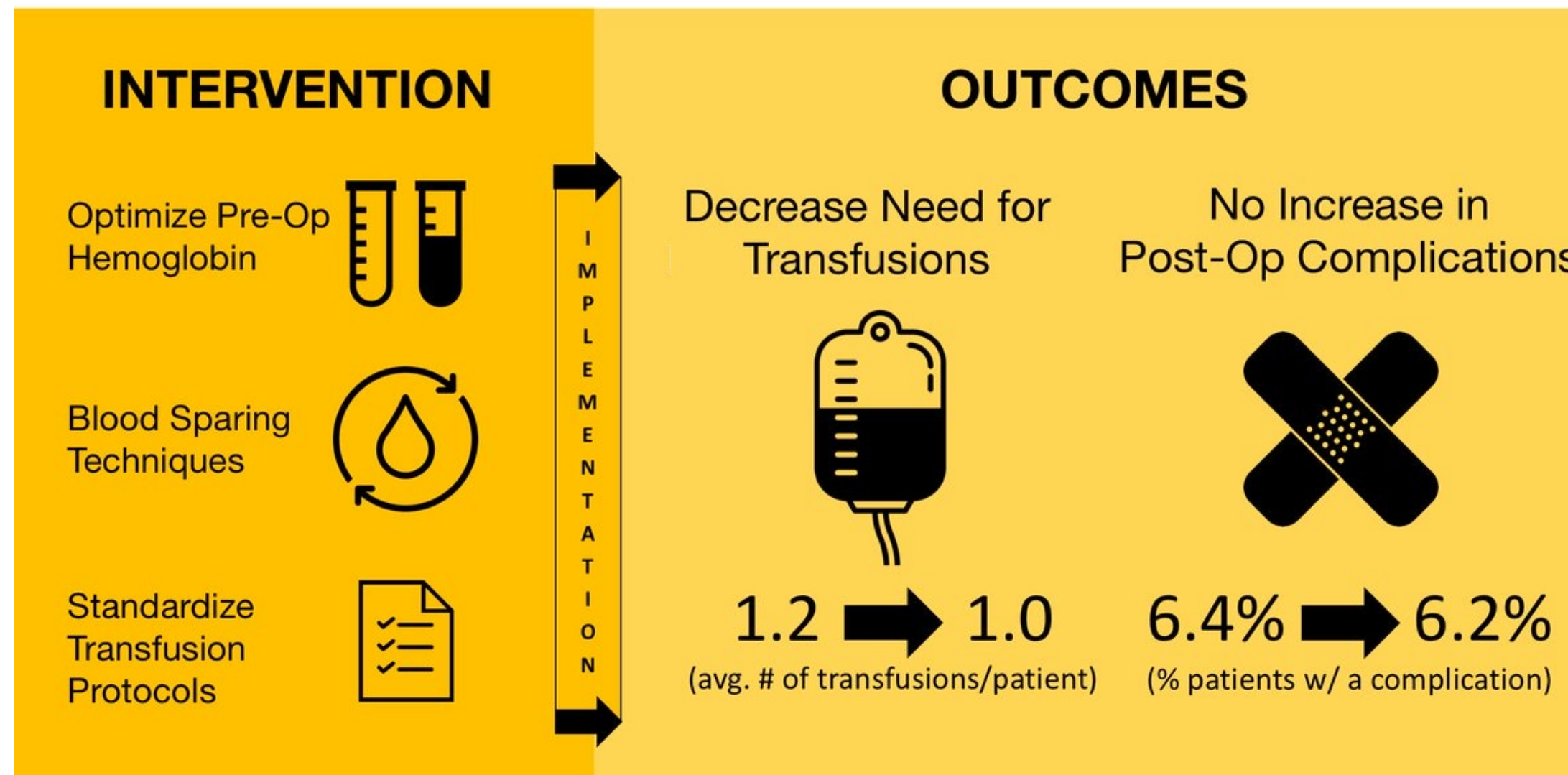
4 University Hospitals (Bonn, Frankfurt, Kiel, Münster)
Pre-PBM (n=54,513) vs. PBM (n=75,206)

ANNALS OF SURGERY
A Monthly Review of Surgical Science Since 1885

PBM, patient blood management
Meybohm et al. Ann Surg
2016;264(2):203-11

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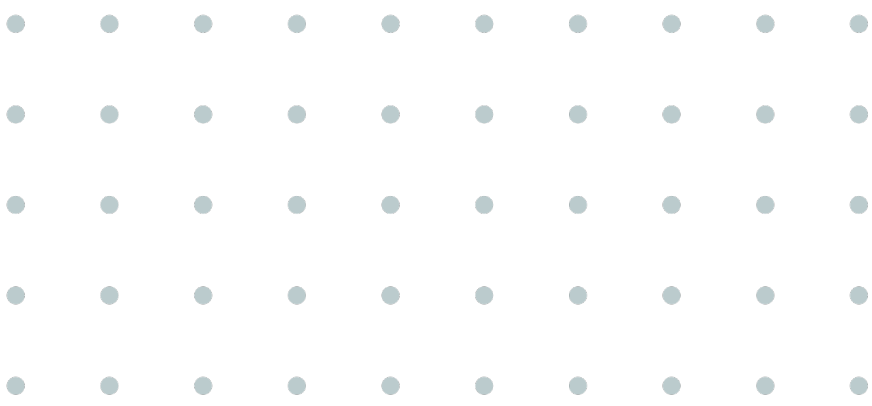


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Pre-PBM (n=54,513) vs. PBM (n=75,206)

ANNALS OF SURGERY
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PBM STUDY RESULTS

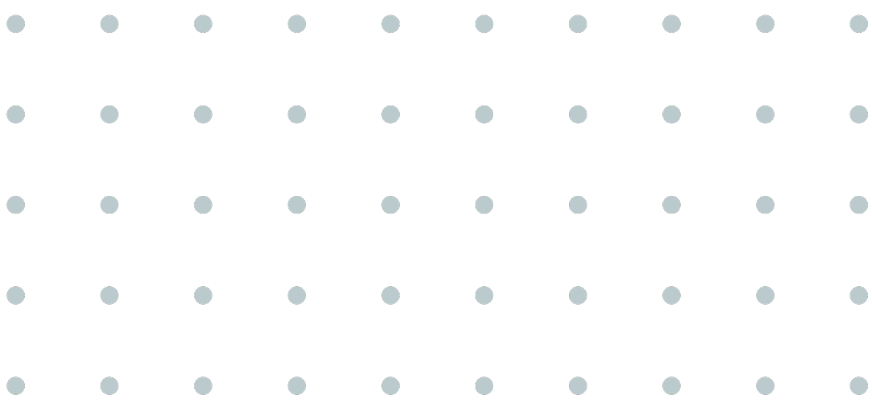


Pre-PBM

*PBM, patient blood
management
Meybohm et al. Ann Surg
2016;264(2):203-11*



PBM STUDY RESULTS



Pre-PBM










2019: ~50%
less RBCs

PBM, patient blood
management
Meybohm et al. Ann Surg
2016;264(2):203-11



German Patient Blood Management Network: effectiveness and safety analysis in 1.2 million patients

Patrick Meybohm^{1,2,*} , Elke Schmitt^{1,3}, Suma Choorapoikayil¹, Lotta Hof¹, Oliver Old¹ , Markus M. Müller^{4,5}, Christof Geisen⁵, Erhard Seifried⁵ , Olaf Baumhove⁶ , Samuel de Leeuw van Weenen⁶, Alexandra Bayer⁷, Patrick Friederich⁸, Brigitte Bräutigam⁹, Jens Friedrich¹⁰, Matthias Gruenewald¹¹, Gunnar Elke¹¹ , Gerd P. Molter¹⁰, Diana Narita¹², Ansgar Raadts¹³, Christoph Haas¹⁴, Klaus Schwendner¹⁵, Andrea U. Steinbicker^{1,16}, Dana J. Jenke¹⁶, Josef Thoma¹⁷, Viola Weber¹⁷, Markus Velten¹⁸ , Maria Wittmann¹⁸ , Henry Weigt¹⁹, Björn Lange¹⁹, Eva Herrmann³, Kai Zacharowski^{1,*}, and the German Patient Blood Management Network Collaborators[†]

RESULTS FOLLOWING PBM IMPLEMENTATION (1.2 MIO PATIENTS)

EFFECTIVE



✓ RBC-transfusion



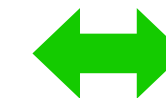
✓ Hospital length of stay



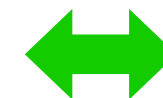
SAFE



✓ Postoperative complications



✓ Mortality

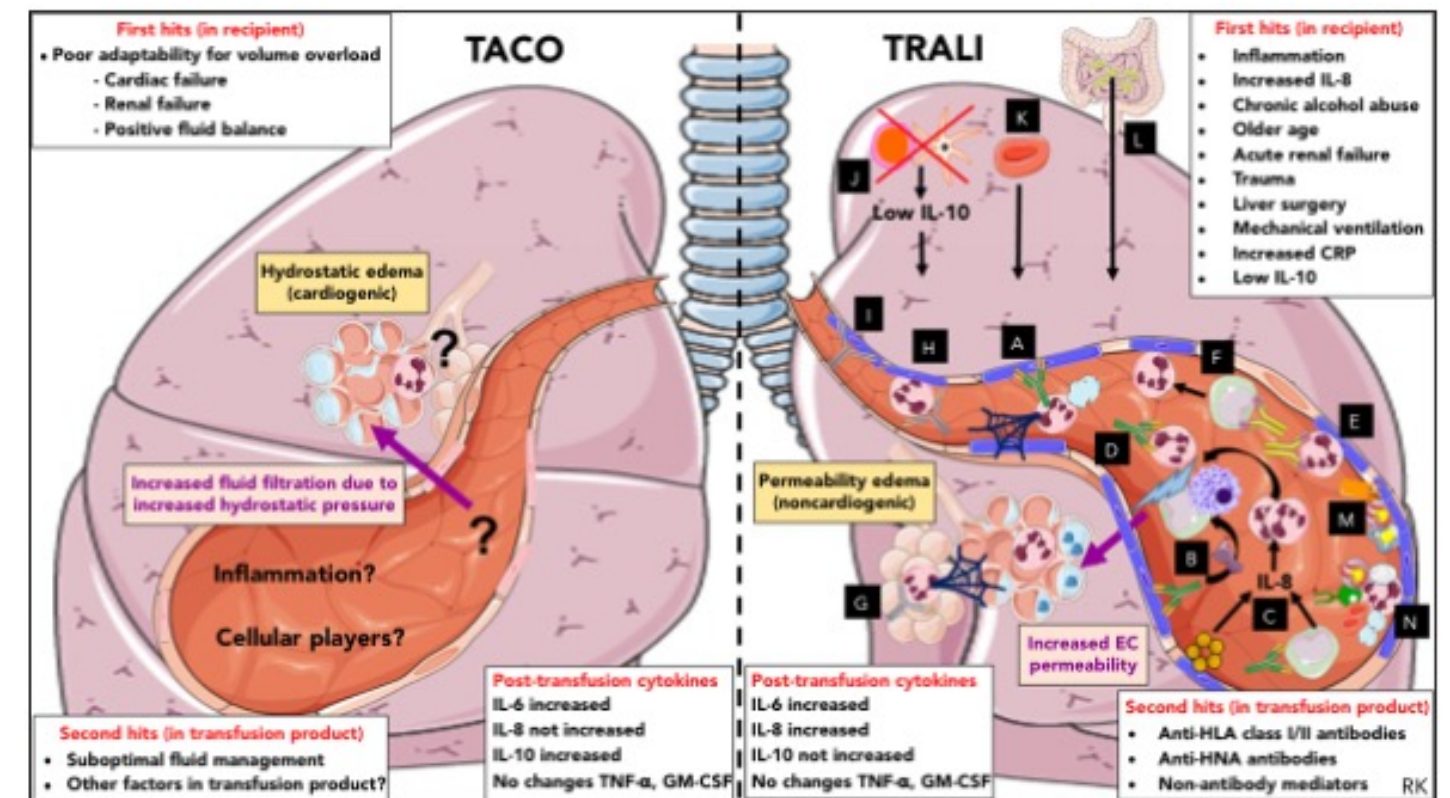


NO RELIABLE DATA TO ASSESS TRANSFUSION PRACTICE

Estimation of the prevalence and rate of acute transfusion reactions occurring in Windhoek, Namibia

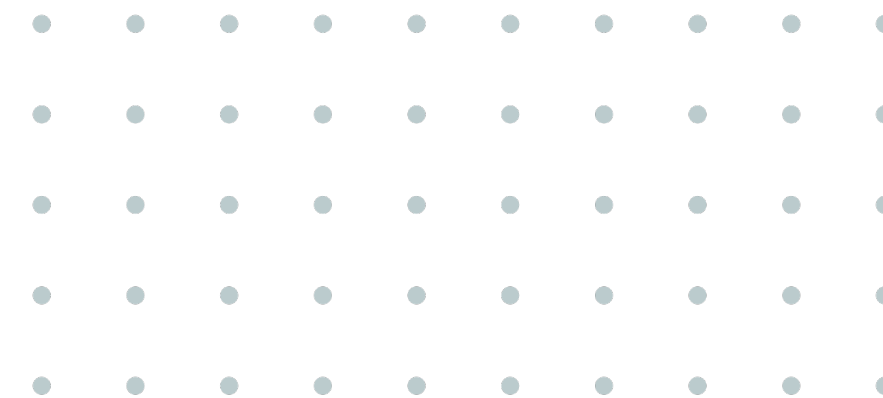
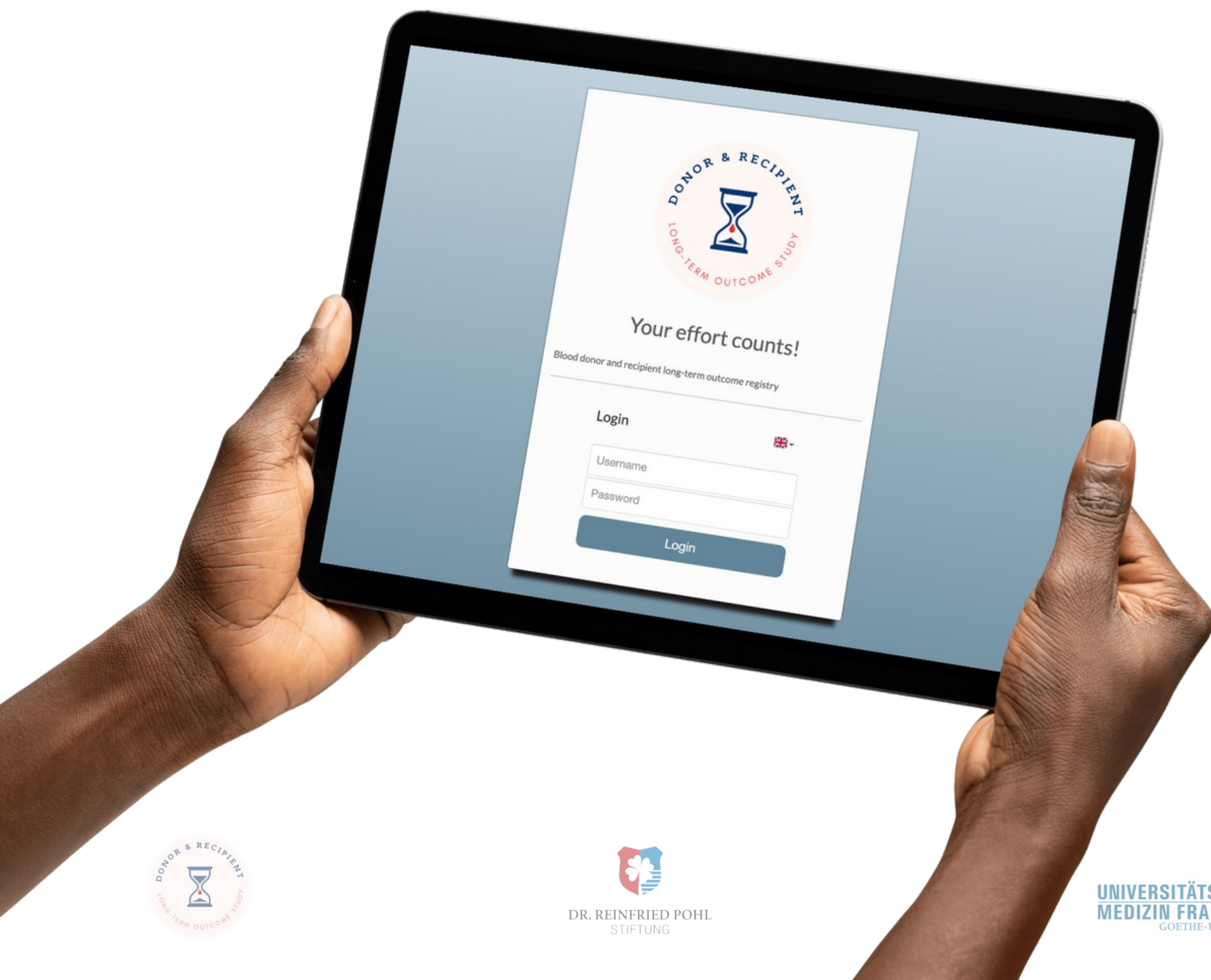
Meza et al. (2014) Blood Transfusion

- **Namibia:** 23,744 blood units transfused in 2010 (RBC, FFP, platelets, whole blood)
- **Underreported!**
 - 0.2% of serious AEs
 - 3.4% AEs
- **Long-term effects: not researched!**



Karafin et al. (2017) Transfusion
Semple et al. (2019) Blood

THE TRANSFUSION REGISTRY



**International Clinical Trials
Registry Platform**
Search Portal

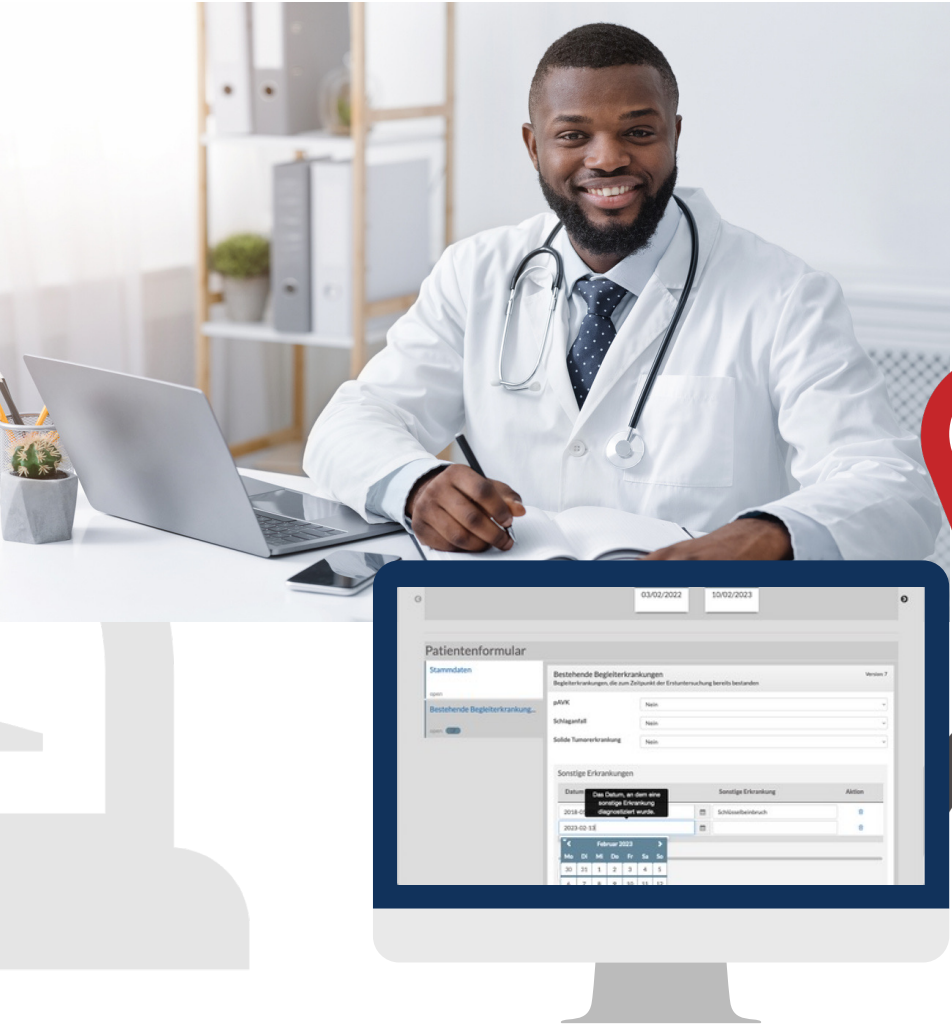
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Ethical committee – approved
Data protection – approved

HOW DOES IT WORK? – DATA COLLECTION OVER 30 YEARS

Step 1
**INITIAL PATIENT ENTRY
BY MEDICAL STAFF**



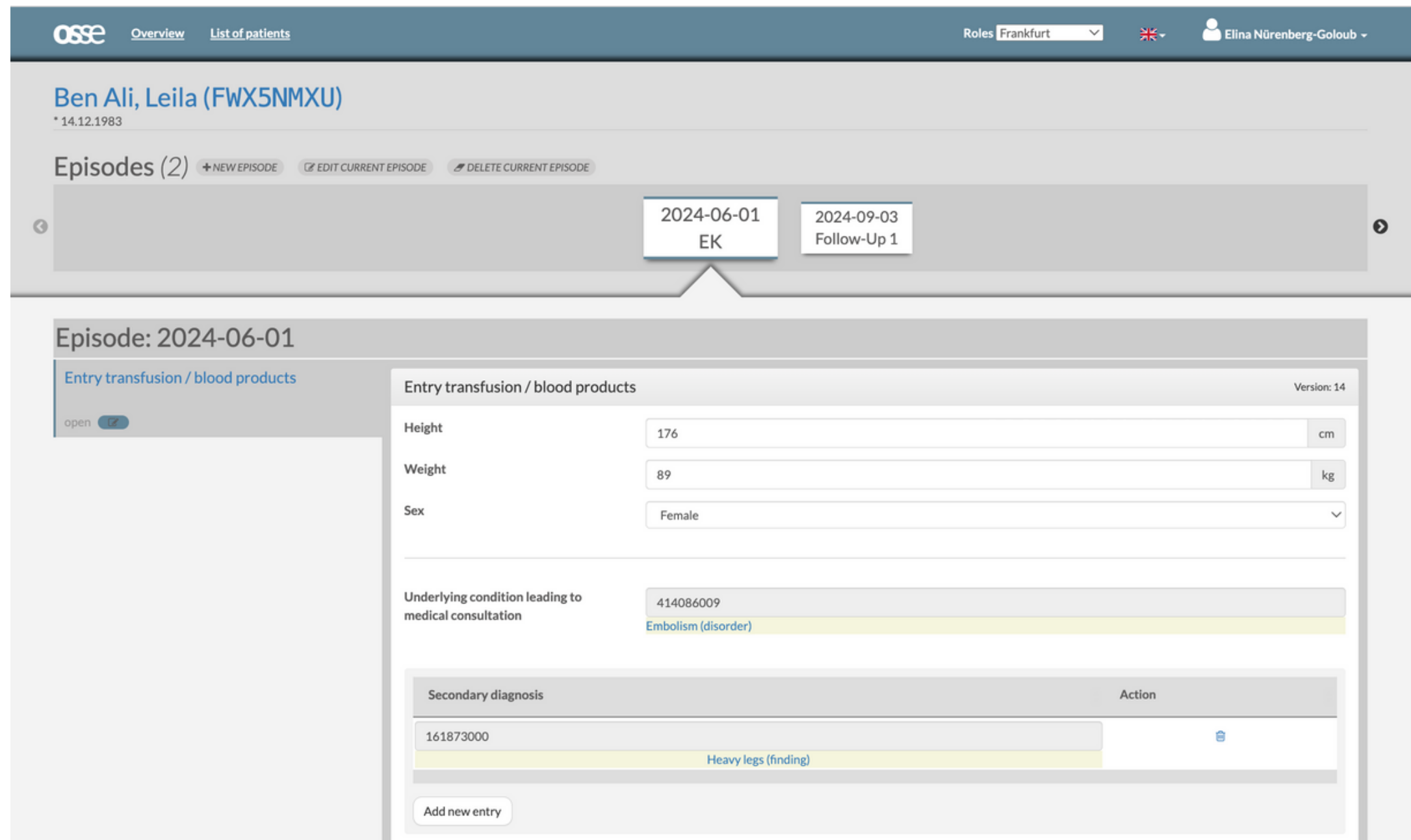
Step 3
**REPORTING,
OPTIMIZED BLOOD HEALTH,
GUIDELINES etc.**



Step 2
**SELF-REPORTED HEALTH &
WELL-BEING**



STEP 1: MEDICAL QUALITY PATIENT BIOMETRICS & HEALTH STATUS



OSSE Overview List of patients Roles Frankfurt Elina Nürnberg-Goloub

Ben Ali, Leila (FWX5NMXU)
* 14.12.1983

Episodes (2) + NEW EPISODE EDIT CURRENT EPISODE DELETE CURRENT EPISODE

2024-06-01 EK 2024-09-03 Follow-Up 1

Episode: 2024-06-01

Entry transfusion / blood products

open

Entry transfusion / blood products Version: 14

Height 176 cm

Weight 89 kg

Sex Female

Underlying condition leading to medical consultation 414086009 Embolism (disorder)

Secondary diagnosis	Action
161873000 Heavy legs (finding)	

Add new entry



- demographics
- biometrics
- diagnoses
- better than ICD-10
(comparable world-wide)



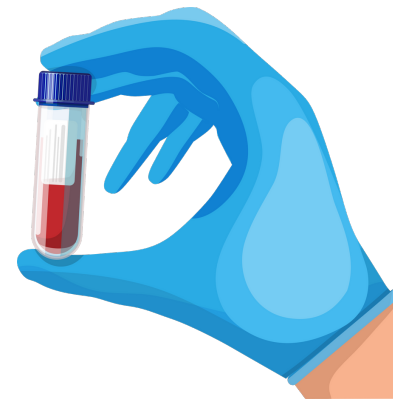
STEP 1: DETAILED THERAPY (e.g. BLOOD) RECORDING



- blood products
- iron (oral and i.v.)
- cell salvage
- exact **dosage**



exact **indication**



laboratory values
before and after
therapy

Administered (blood) products

Red cell concentrate

Date of product administration: 2024-06-03

(Blood) Product type: Red cell concentrate

Indication for transfusion / product administration:

- ☐ Hb < 7 g/dl: independent of ability to compensate
- ☒ Hb 7-8 g/dl: indications of anaemic hypoxia (tachycardia, hypotension, ECG ischaemia, lactic acidosis) or limited compensation, risk factors present (CHD, heart failure, cerebrovascular disease). Cerebro-vascular diseases
- ☐ Hb 8-10 g/dl: indications of anaemic hypoxia, individual assessment unclear risk-benefit ratio
- ☐ Massive transfusion
- ☐ Other

Blood group of product: A

Rhesus factor of product: Rh+

Dosage (value): 50

Dosage (units): ml

Hb prior to product administration: 7 g/dl

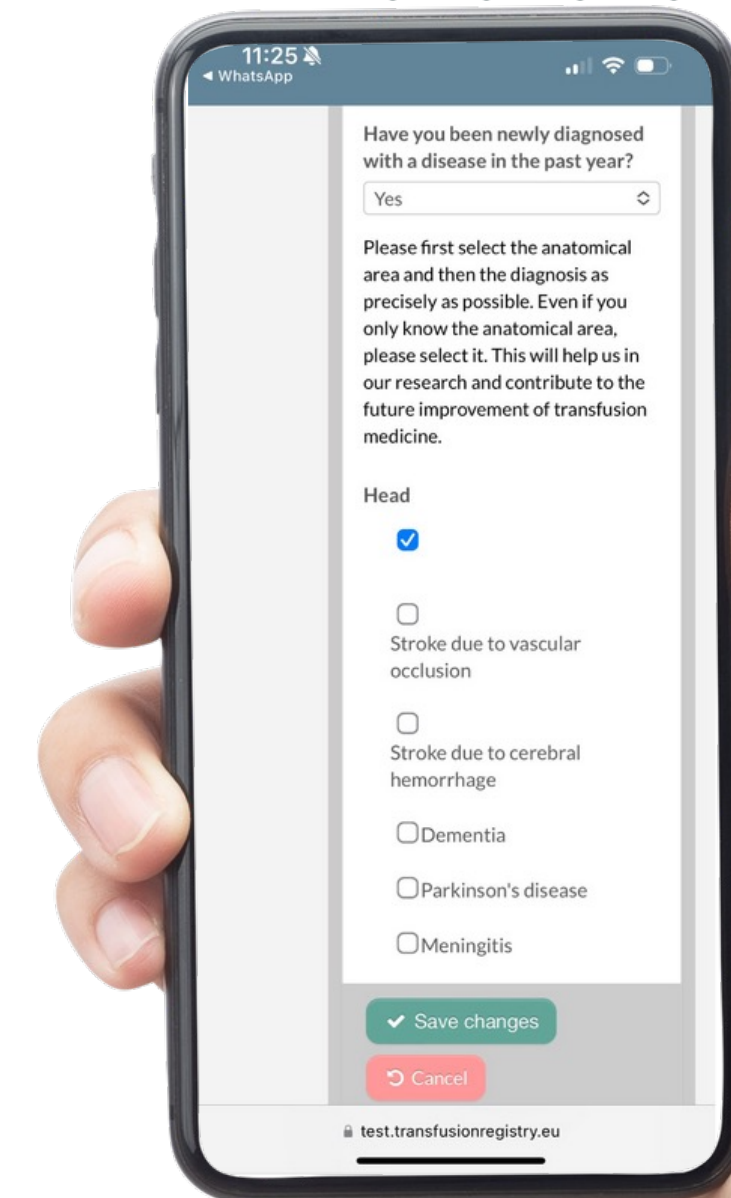
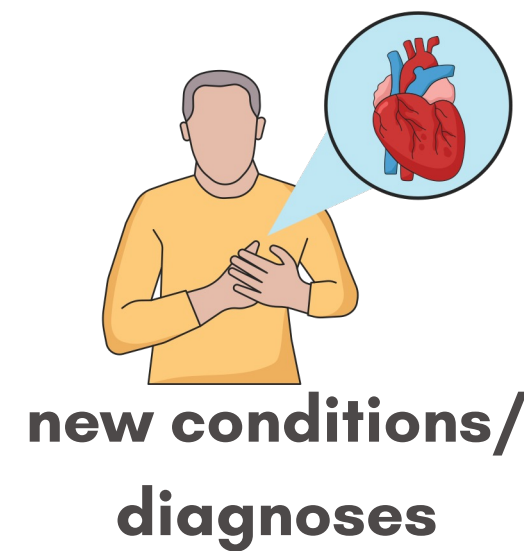
Hb after product administration: 8 g/dl

Add new entry

Connected to interventional care

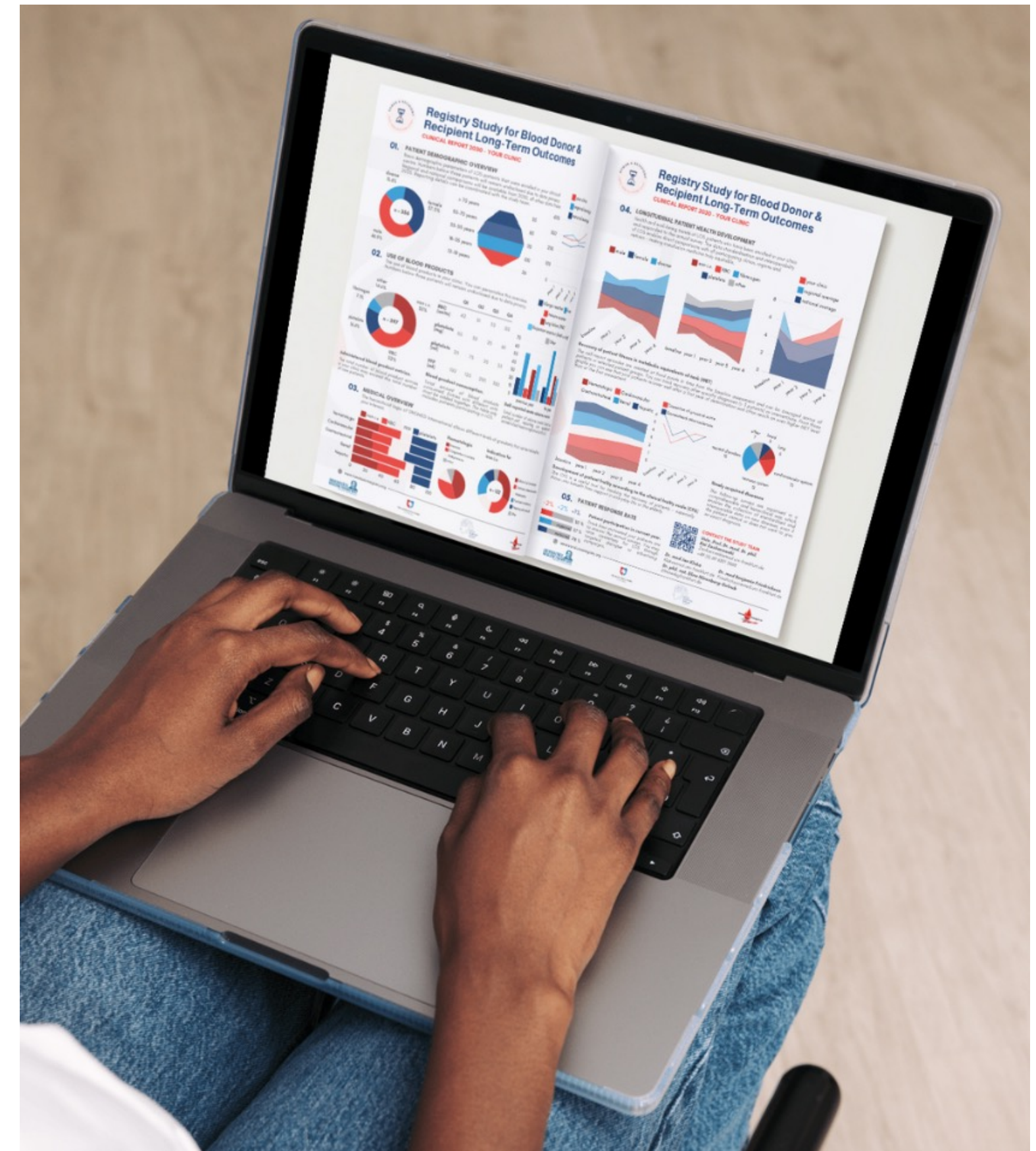
STEP 2: ANNUAL SELF REPORTING BY THE PATIENT

- **Simple:** Patients automatically receive a health link once a year
- **Fast:** max. 5 minutes
- **Safe:** highest data safety & full legal compliance

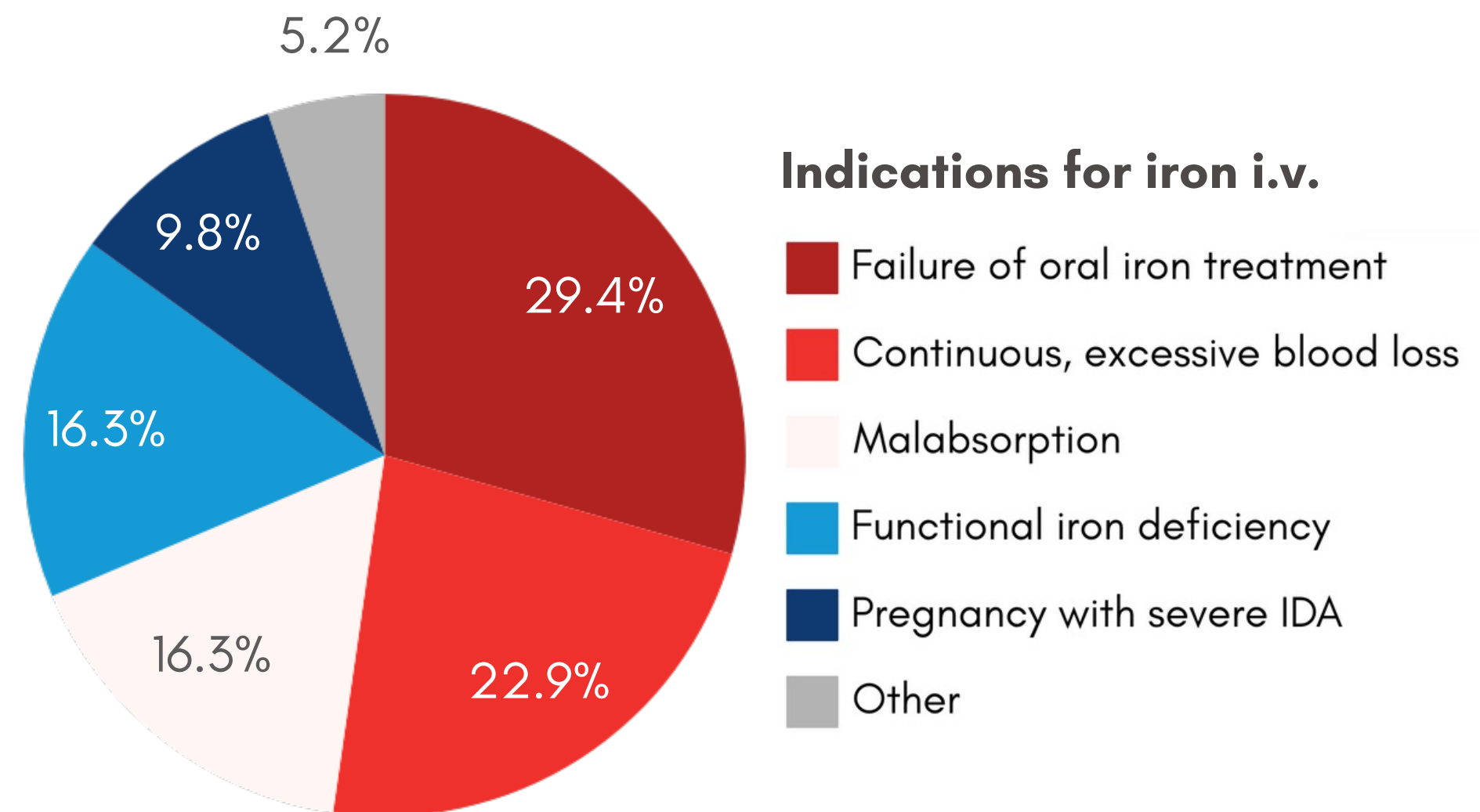
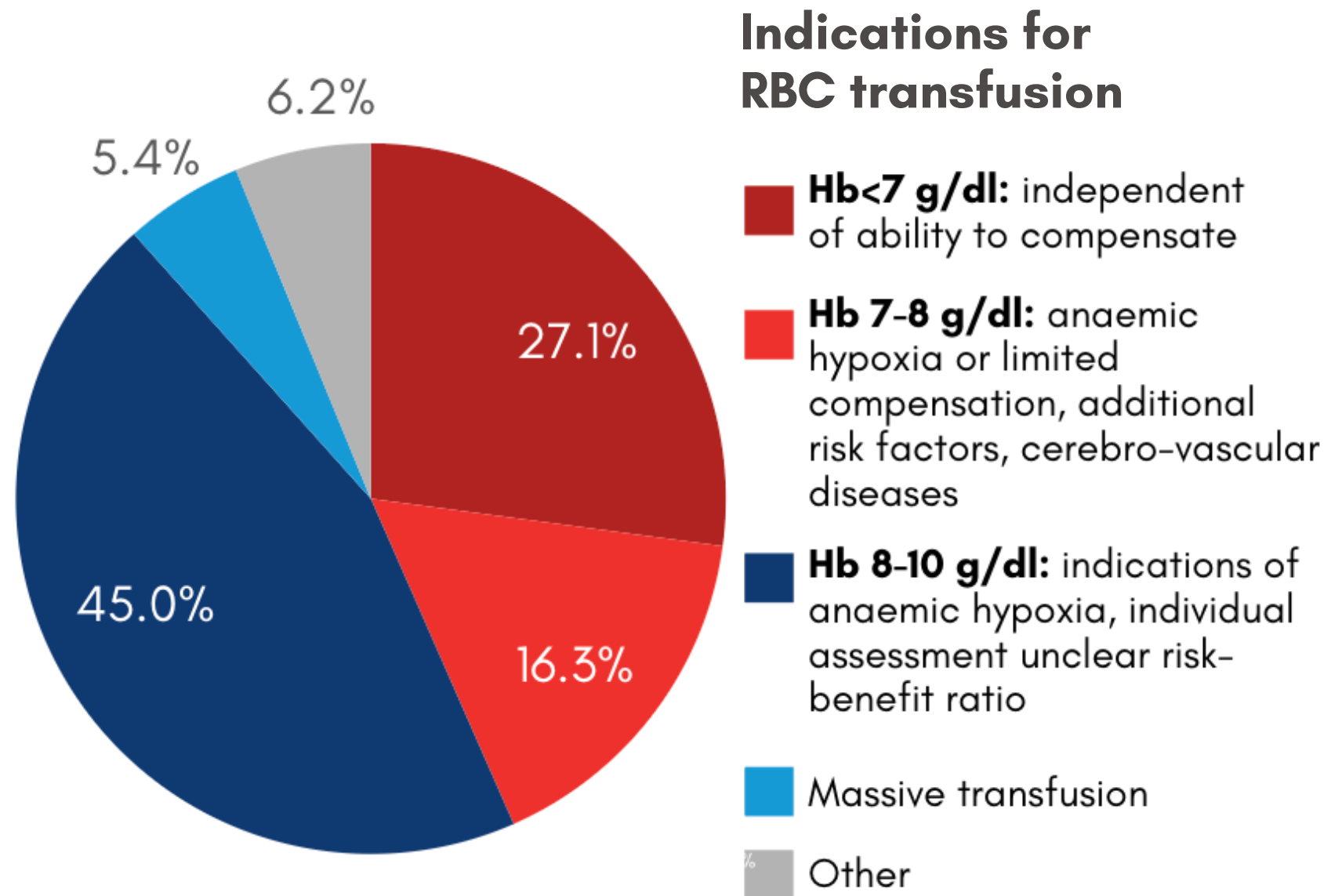


STEP 3: CLINICAL REPORTING transparent & standardized (personalized as you wish...)

- Patient demographics
- Medication & blood product use
- High-quality medical data
- Longitudinal outcome data
- Transparent regional & national benchmarking

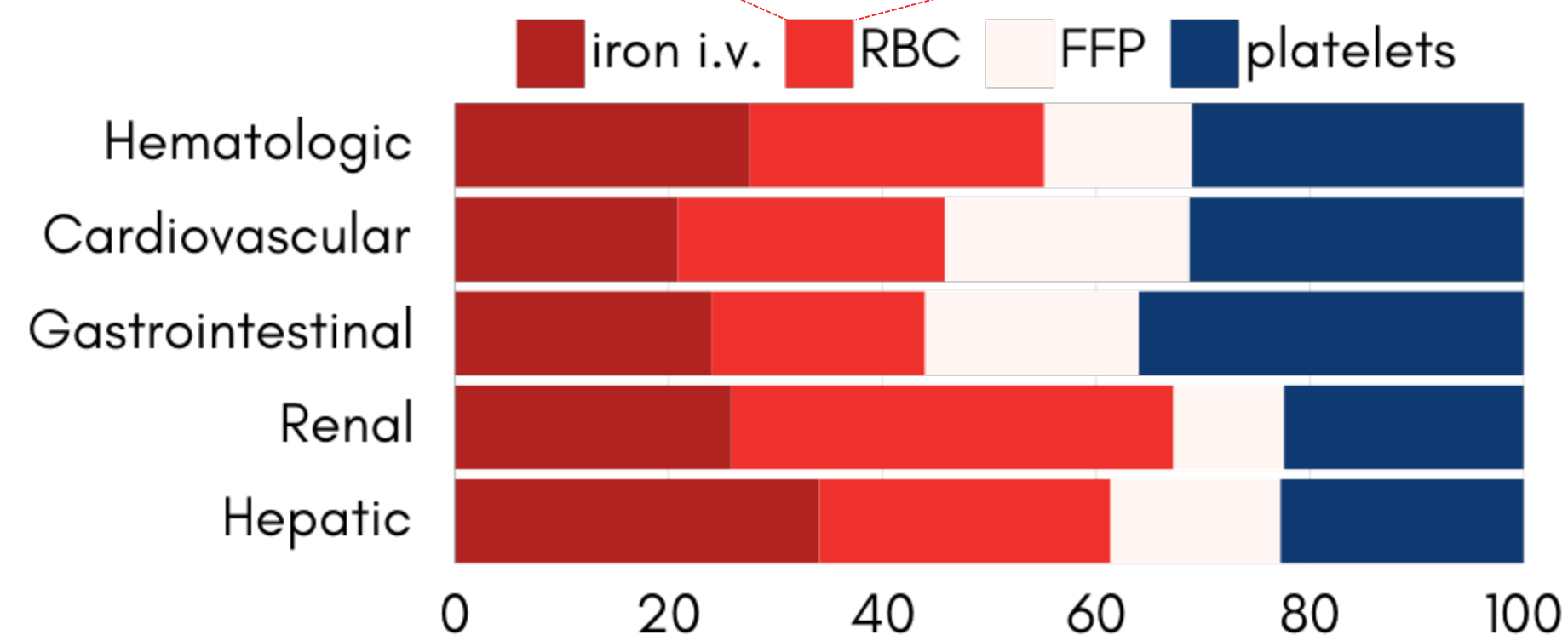
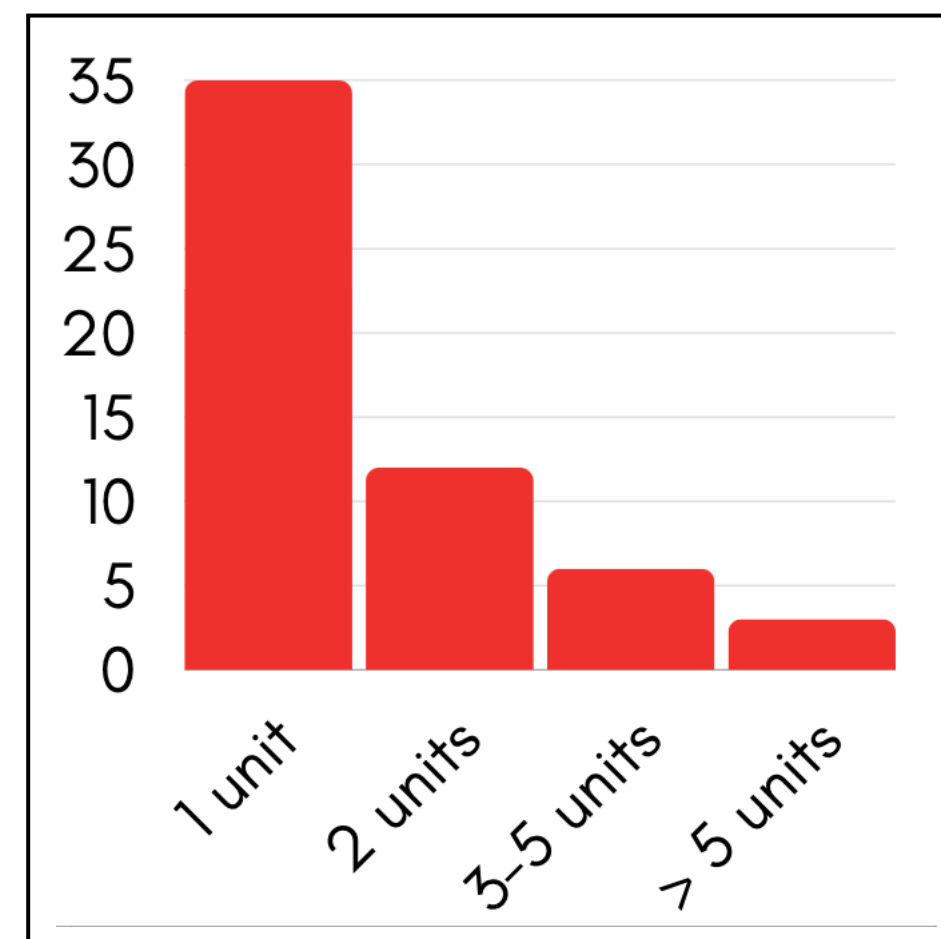


OVERCOMING MAJOR LIMITATIONS OF LARGE COHORT STUDIES: TRANSFUSION INDICATIONS



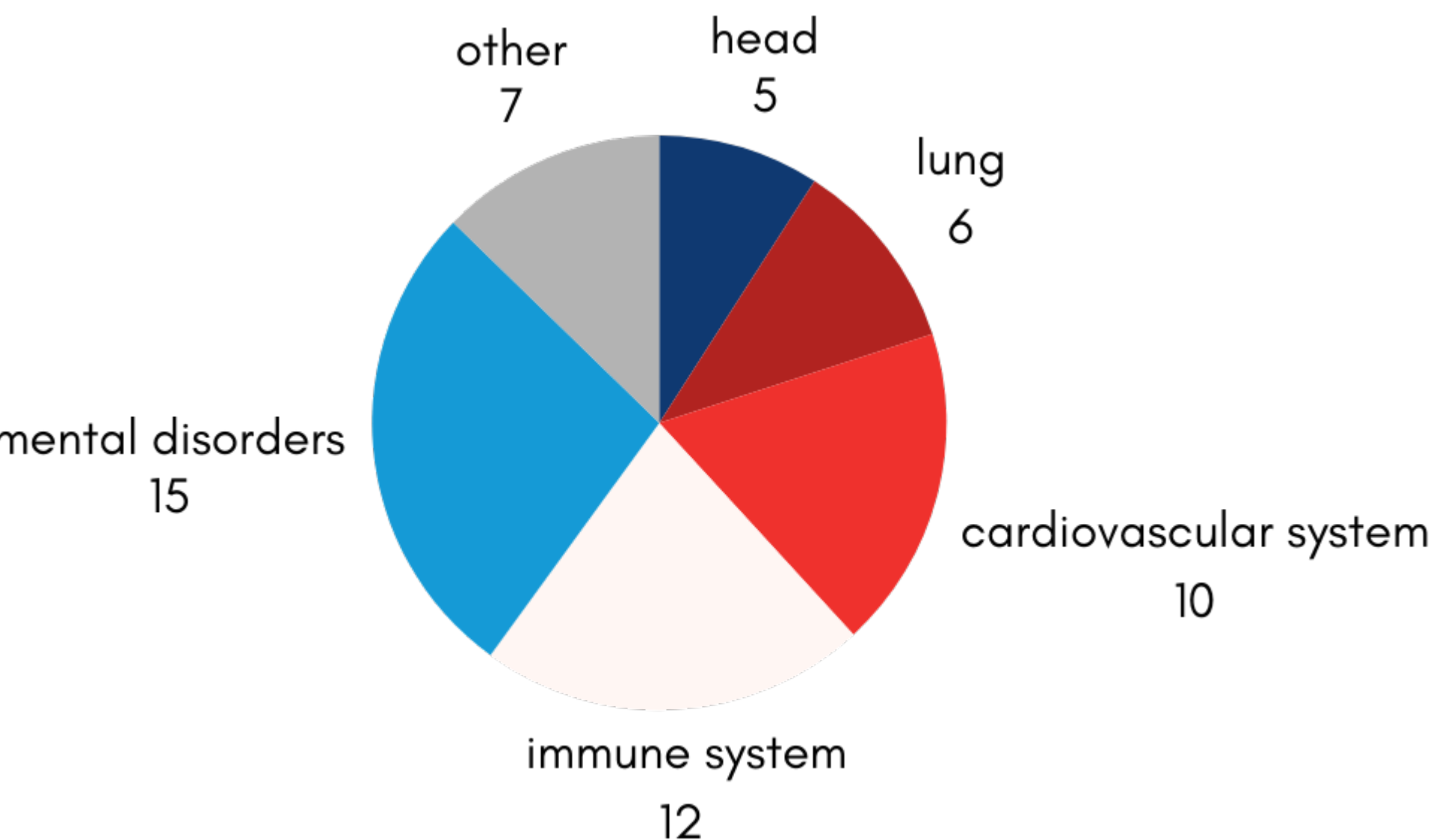
UNDERLYING CONDITIONS & TRANSFUSION QUANTITY

**Data clustering
(personalized as You wish!)**



MAXIMUM INFORMATION FROM SELF-REPORTING: SMART FILTER OPTIONS & MULTIPLE CHOICE

Number of patients with newly acquired diseases



HIGH-QUALITY LONGITUDINAL PROFILING: VALIDATED SCALES

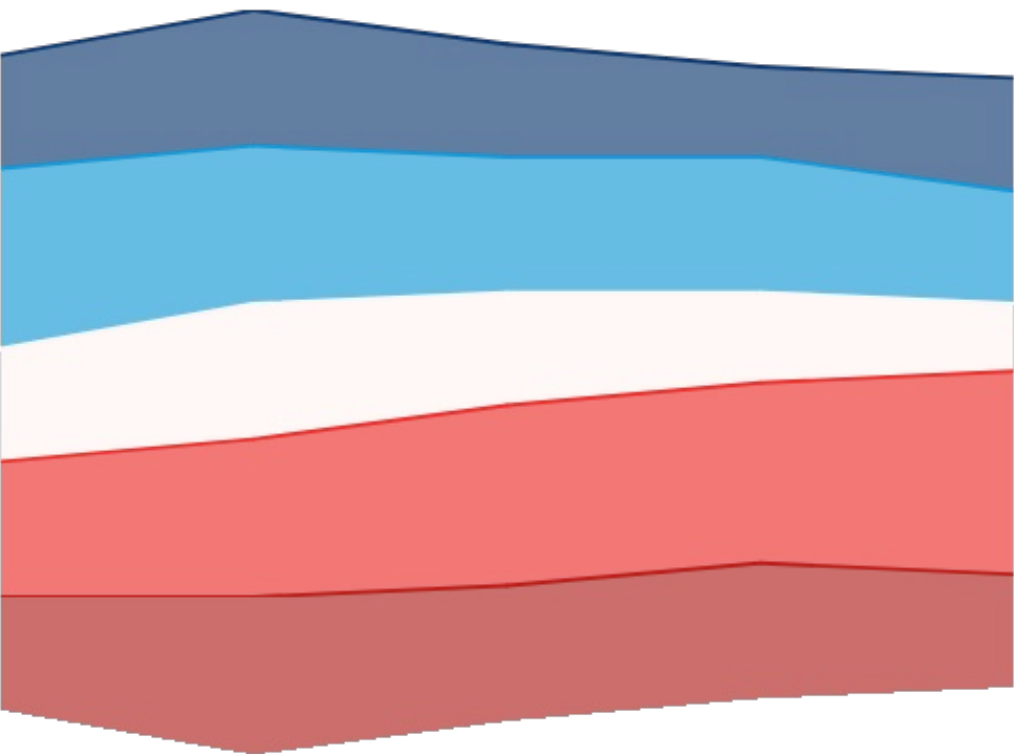


1 - very fit



10 - terminally ill

 Hematologic  Cardiovascular
 Gastrointestinal  Renal  Hepatic



baseline year 1 year 2 year 3 year 4

Have you had a blood test in the past year?

Have you been newly diagnosed with a disease in the past year?

Please first select the anatomical area and then contribute to the future improvement of treatment

Current physical capacity

How would you describe your current state of health?

General level of fitness or frailty according to CFS

☐ I cannot / do not want to answer

☒ 1 - Very Fit. People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

☐ 2 - Well. People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

☐ 3 - Managing Well. People whose medical problems are well controlled, but are not regularly active beyond routine walking.

☐ 4 - Vulnerable. While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

☐ 5 - Mildly frail. These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

☐ 6 - Moderately frail. People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

☐ 7 - Severely frail. Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

☐ 8 - Very severely frail. Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

☐ 9 - Terminally ill. Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

☒ I cannot / do not want to answer

☐ I can eat, drink, use the toilet independently (1 MET)

☐ I can walk one to two blocks at slow speed (3 MET)

☐ I can do light housework and climb stairs (4 MET)

☒ I can do moderately strenuous sports (bowling, golf) (10 MET)

☐ I can do strenuous sports (football, athletics) (> 10 MET)

NAMBTS – PARTNERSHIP FOR BLOOD HEALTH

Contact Us On +264 61 386-300 Or Email pro@bts.com.na

NamBTS News And Events

DARE TO CARE

MONDAY, 30 September 2024

Centre Tal Street (Windhoek)	07:00-16:00
Integrated Dental Holdings (Windhoek)	09:00-15:30
NBC Headquarters (Windhoek)	09:00-15:30
Nampharm (Windhoek)	09:00-15:30
Oshakati Centre (Hospital Grounds)	10:00-18:00
Swakopmund Town (Ferdinand Stieh Street No 4)	10:00-18:00

TUESDAY, 01 October 2024

Centre Tal Street (Windhoek)	07:00-18:00
Sanlam (Windhoek)	09:00-15:30
Trustco (Windhoek)	09:00-15:30
WHK Consulting Engineers (Windhoek)	09:00-15:00
Ondangwa Centre (Gweshamba Mall)	10:00-18:00
Walvis Bay Town (Behind Welwitschia Medipark)	10:00-18:00

WEDNESDAY, 02 October 2024

Centre Tal Street (Windhoek)	07:00-16:00
Namibian Oncology Centre (Eros)	08:30-16:00
Windhoek Afrikaans Privatskool (Windhoek)	08:30-14:00
Nedbank (Windhoek)	09:00-15:30
Andimba Tolo Ya Tolo Secondary School	09:00-14:00
Coastal High School (Swakopmund)	09:00-14:00

THURSDAY, 03 October 2024

Centre Tal Street (Windhoek)	07:00-18:00
Namibia Training Authority (Windhoek)	09:00-15:30
Standard Bank Kleine Kuppe (Windhoek)	09:00-15:30
Brilliant Star Diamond Namibia (Windhoek)	09:00-15:30
Ongulil Secondary School (Okavango)	09:00-14:00
Westside High School (Walvis Bay)	09:00-14:00

FRIDAY, 04 October 2024

Okavango Secondary School (Oshakati)	09:00-14:00
Hangana Seafood (Walvis Bay)	10:00-15:30

YOU HAVE THE POWER TO SAVE A LIFE. DONATE BLOOD.

#daretoshare

NAMBTS donate life

t: 061 386 300 e: pro@bts.com.na www.bts.com.na

GIVE BLOOD SAVE LIVES

Donate 4 times and receive a gift!

Every donor who donates blood 4 times within a year receives this complimentary beach towel for saving lives.

Qualifying period 1 April 2024 – 31 March 2025.

NAMBTS donate life

t: 061 386 300 e: pro@bts.com.na www.bts.com.na

CRITICAL BLOOD SHORTAGE

PLEASE DONATE BLOOD TODAY.

NamBTS has implemented all necessary safety measures needed during this COVID-19 pandemic and would like to assure our donors that it is safe to donate blood.

NAMBTS donate life

The Blood Transfusion Service of Namibia, @NamBTSservice
t: 061-386 300 e: pro@bts.com.na www.bts.com.na

Our registry will help to...



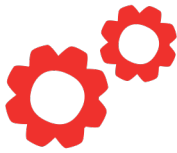
- Monitor donor health
- Rise awareness & remind of annual donations
- Save blood
- Collaborate internationally

bts.com.na

20



BLOOD DONOR REGISTRY

- 01. START-UP FINANCING** 
Dr. Reinfried Pohl Stiftung
- 02. IT AND REGULATORY FRAMEWORK** 
Data protection – consent – ethical approval
- 03. DONOR HEALTH CONCERNS?** 
Evidence-based research & collaboration
- 04. LAUNCH IN 2025**
Inform partners and start patient enrollment

LANDMARK SIGNIFICANCE FOR NUMEROUS STAKEHOLDERS

PATIENTS AND DONORS

Patient safety
Awareness-raising
Participation



SCIENTISTS

Unique dataset
Sophisticated infrastructure
FAIR principles

CLINICIANS

Evidence-based practice
Innovative guidelines
Benchmarking & Blood product
consumption tracking



Republic of Namibia
Ministry of Health & Social Services

POLICYMAKERS

Regular reports
Health policy
Collaboration with organisations



CONTACT & FURTHER INFORMATION



TRANSFUSIONREGISTRY.ORG



STUDY DIRECTOR

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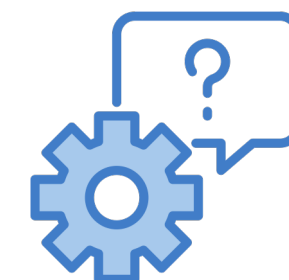
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STUDY MANAGER

Dr. phil. nat. Elina Nürenberg-Goloub
elina@dsgfrankfurt.de



DEPUTY STUDY DIRECTOR

Dr. med. Benjamin Friedrichson, MHBA
Friedrichson@med.uni-frankfurt.de



TRANSFUSIONSREGISTRY.EU

ENROLLING A NEW PATIENT

01. LOGIN
Username & password

02. INITIAL RECORD
Signed informed consent form and information on data protection

03. BASIC DATA
Enter the patient's personal data and request a pseudonym (PID)

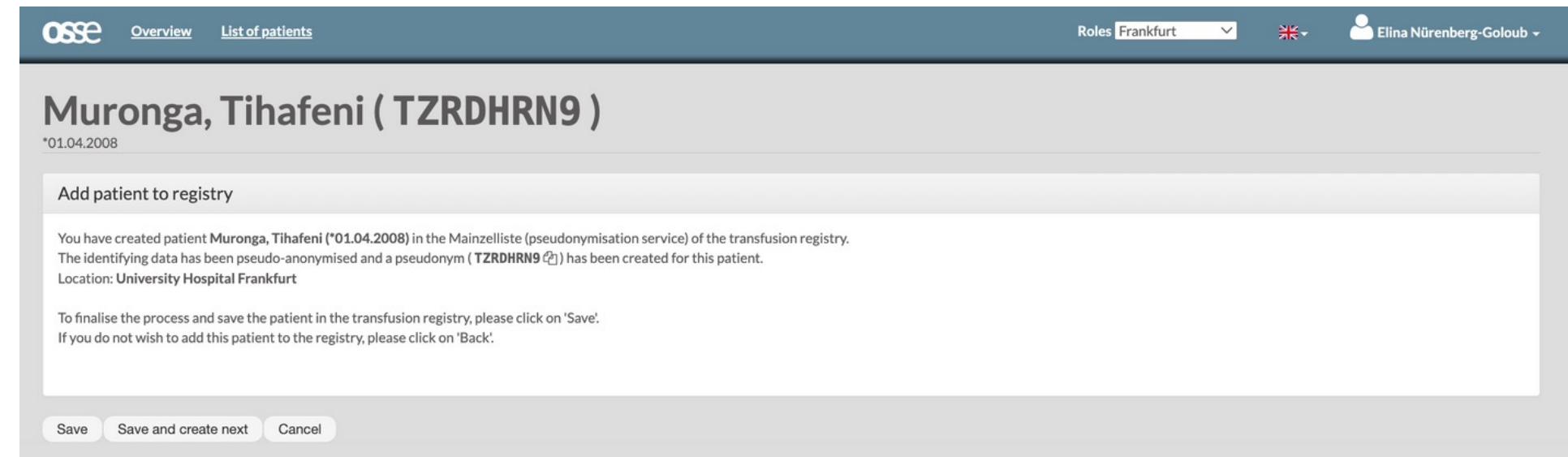


TRANSFUSIONSREGISTRY.EU

ENROLLING A NEW PATIENT

04. CONFIRM

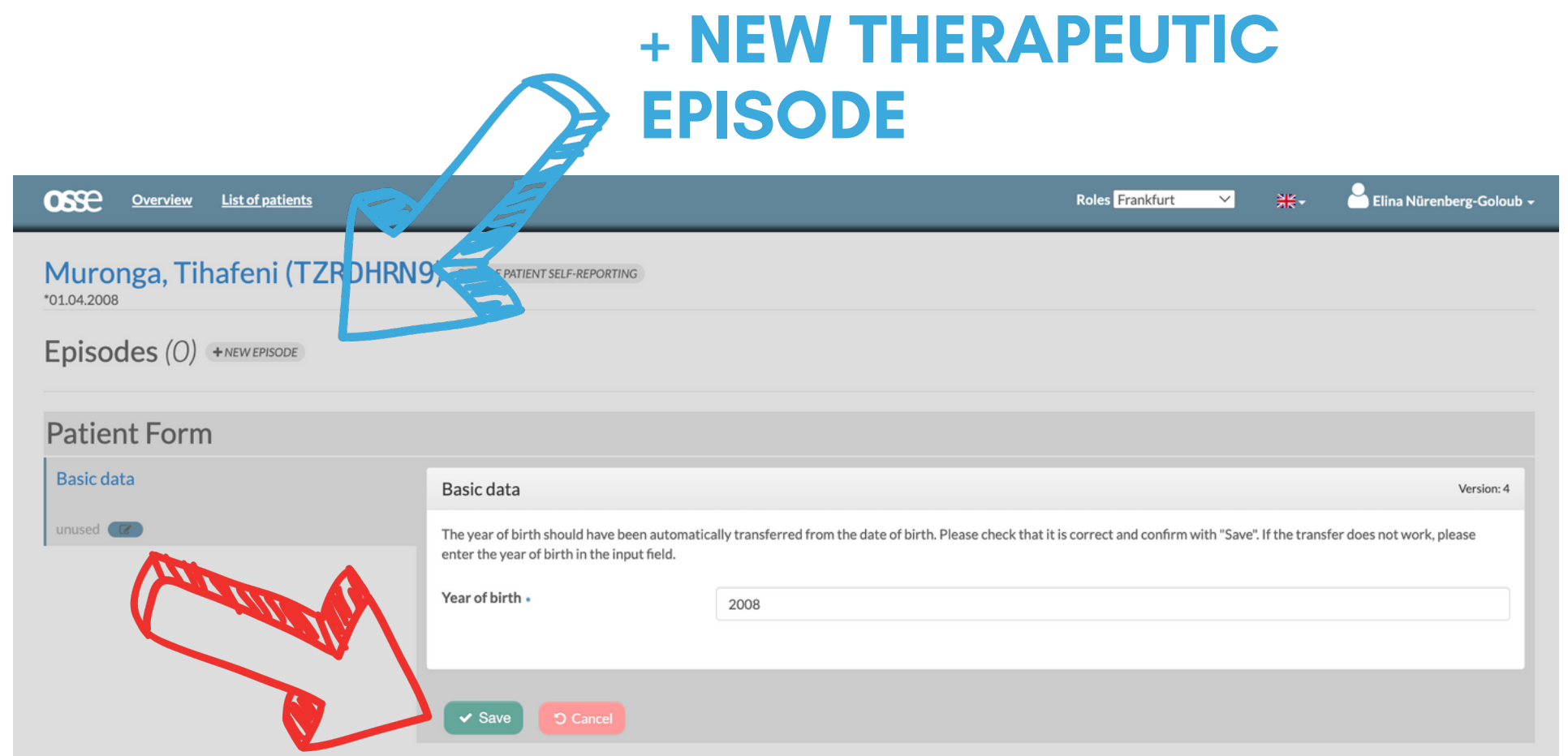
Save, correct, or create additional patients



05. SAVE MASTER DATA

The year of birth must be confirmed once again so that it can be safely entered in the register.

+ NEW THERAPEUTIC EPISODE



06. ADD NEW THERAPY

Create a new therapy episode and begin long-term follow-up.

SAVE!




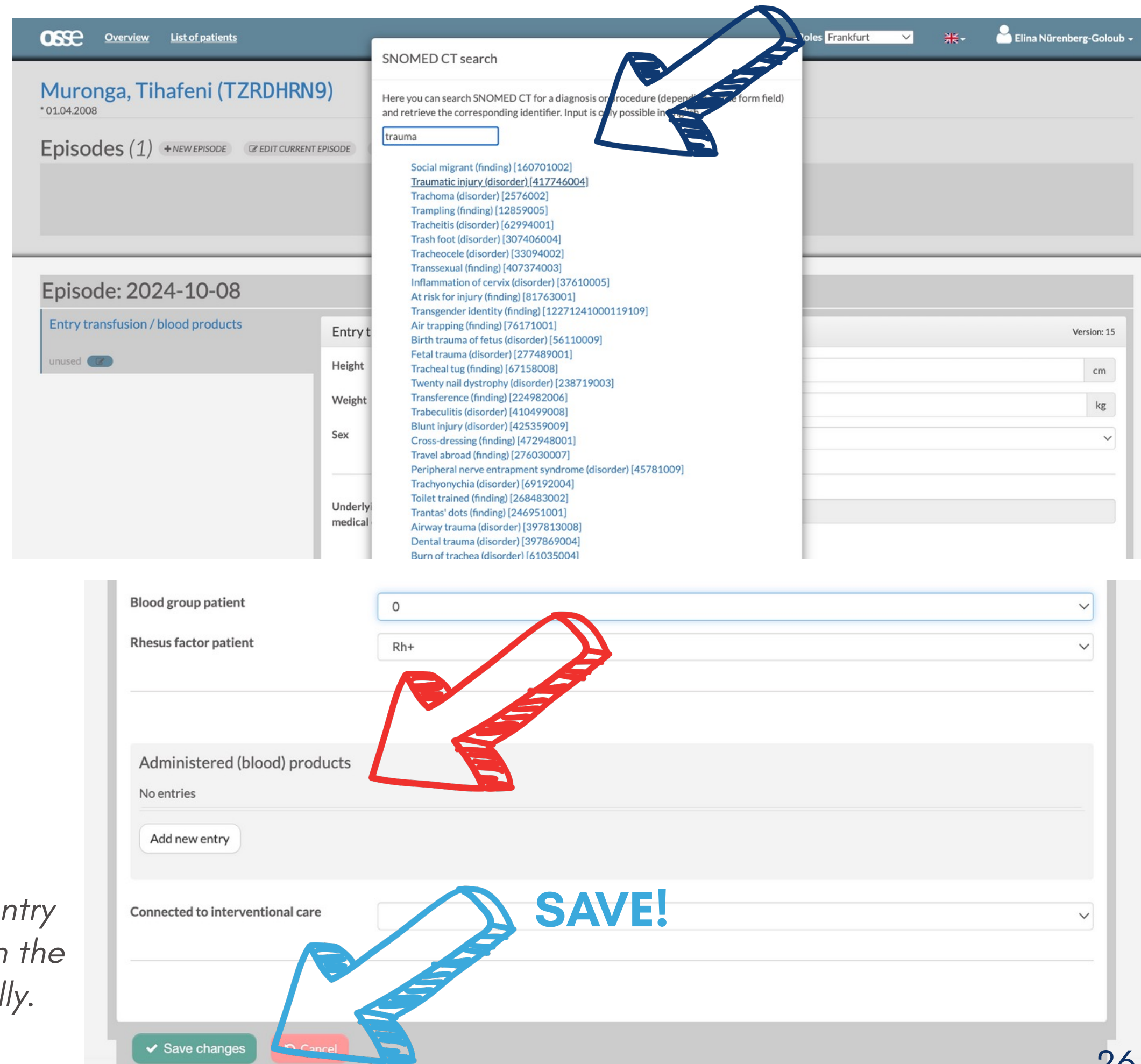
TRANSFUSIONSREGISTRY.EU

ENROLLING A NEW PATIENT

07. MEDICAL HISTORY
*Diagnosis(s) are recorded in SNOMED – in **English**, some patience required when loading.*

09. ENTER BLOOD PRODUCTS
***New entry** with date, indication, dose, result for each product type (RBC, plasma, intravenous iron, etc.)*

 **FOLLOW-UP ACTIVATED!**
Automatically when saving a blood product entry with date. Patients receive the first email with the questionnaire after 3 months and then annually.



The screenshot displays the TRANSFUSIONSREGISTRY.EU interface. At the top, the header includes the logo, navigation links (Overview, List of patients), and user information (Frankfurt, Elina Nürenberg-Goloub). The main content area shows the patient profile for Muronga, Tihafeni (TZRDHRN9), born 01.04.2008. The 'Episodes (1)' section is active, showing an episode from 2024-10-08 with the entry 'Entry transfusion / blood products'. A modal window titled 'SNOMED CT search' is open, displaying a list of search results for the term 'trauma', including 'Traumatic injury (disorder)' [417746004]. A blue checkmark is drawn over the search results. Below the episode entry, there are fields for 'Blood group patient' (0) and 'Rhesus factor patient' (Rh+), both with dropdown menus. A red checkmark is drawn over these fields. The 'Administered (blood) products' section shows 'No entries' and an 'Add new entry' button. At the bottom, there is a 'Connected to interventional care' dropdown menu and a large blue 'SAVE!' button. A blue checkmark is drawn over the 'SAVE!' button. At the very bottom, there are 'Save changes' and 'Cancel' buttons.