EHC-ERN-EuroBloodNet Topic on Focus: Ageing well with rare bleeding disorders, for patients and their families

webinar

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Redefining Frailty Together Living Better for Longer

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Living Well, Ageing Well

EHC european haemophilia consortium

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Disclosures

Consultancy	Name of Institutes/Companies
Advisory Commitee member	N/A
Speaking Honoraria	SOBI, Pfizer, Regeneron, Biomarin
Consultancy Fees	CSL-Behring

Key Topics

1. Defining Frailty
2. Defining Frailty Syndromes
3. Fixing Frailty Syndromes

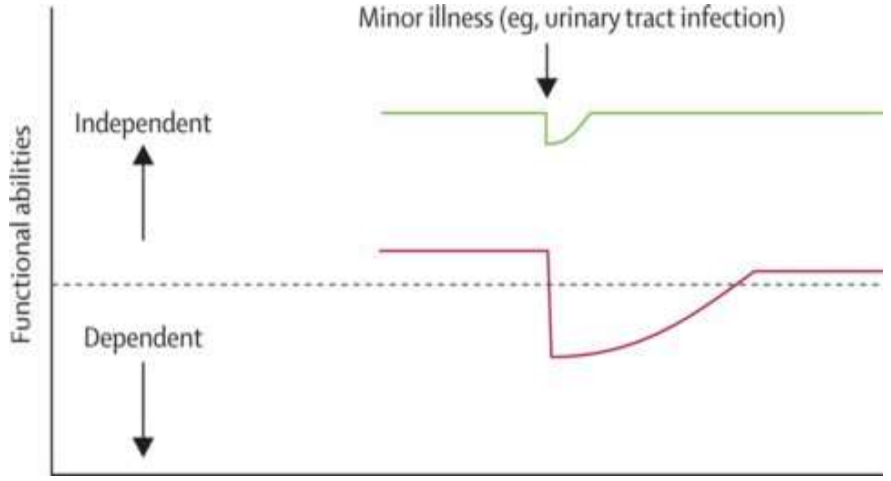
01

Defining Frailty

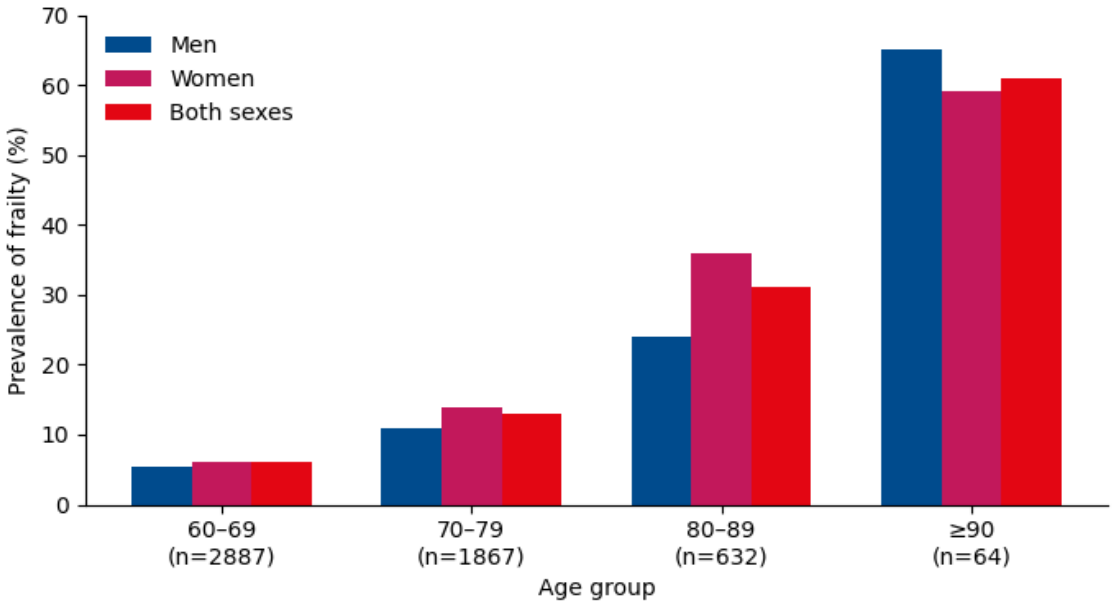
Frailty – A Definition

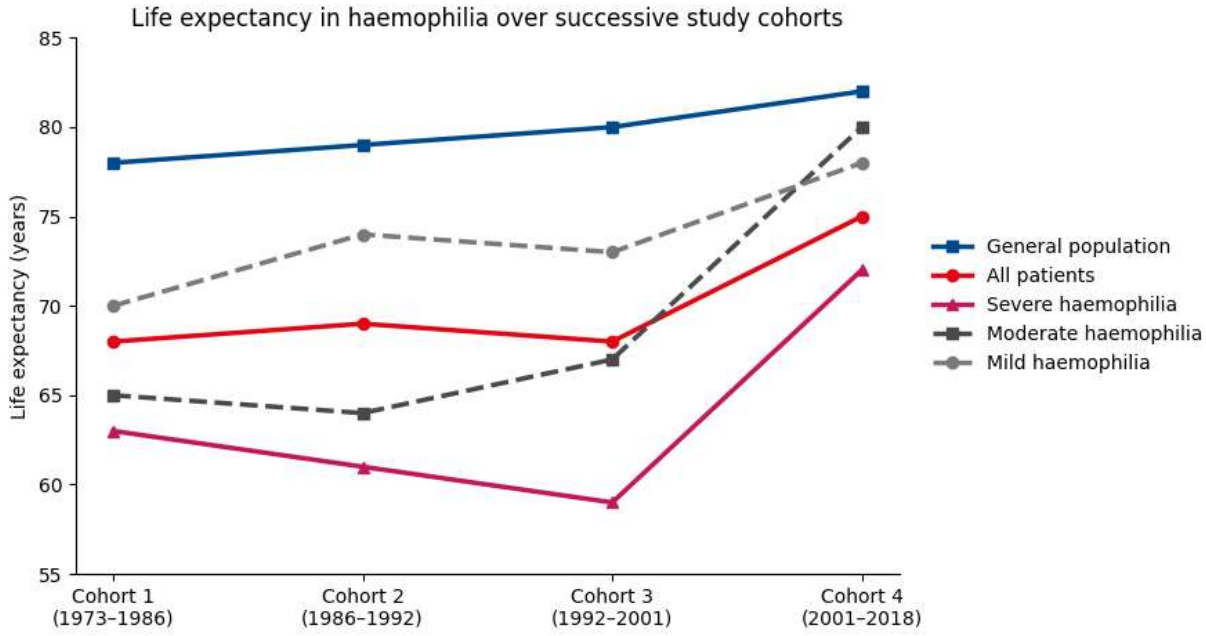
- **Definition:** A state of increased vulnerability due to a cumulation of deficits which leads poor resolution of homoeostasis after a stressor event

- In short – **a loss of resiliance**



Demographics of Frailty





Prevalence of Frailty Increases with Age

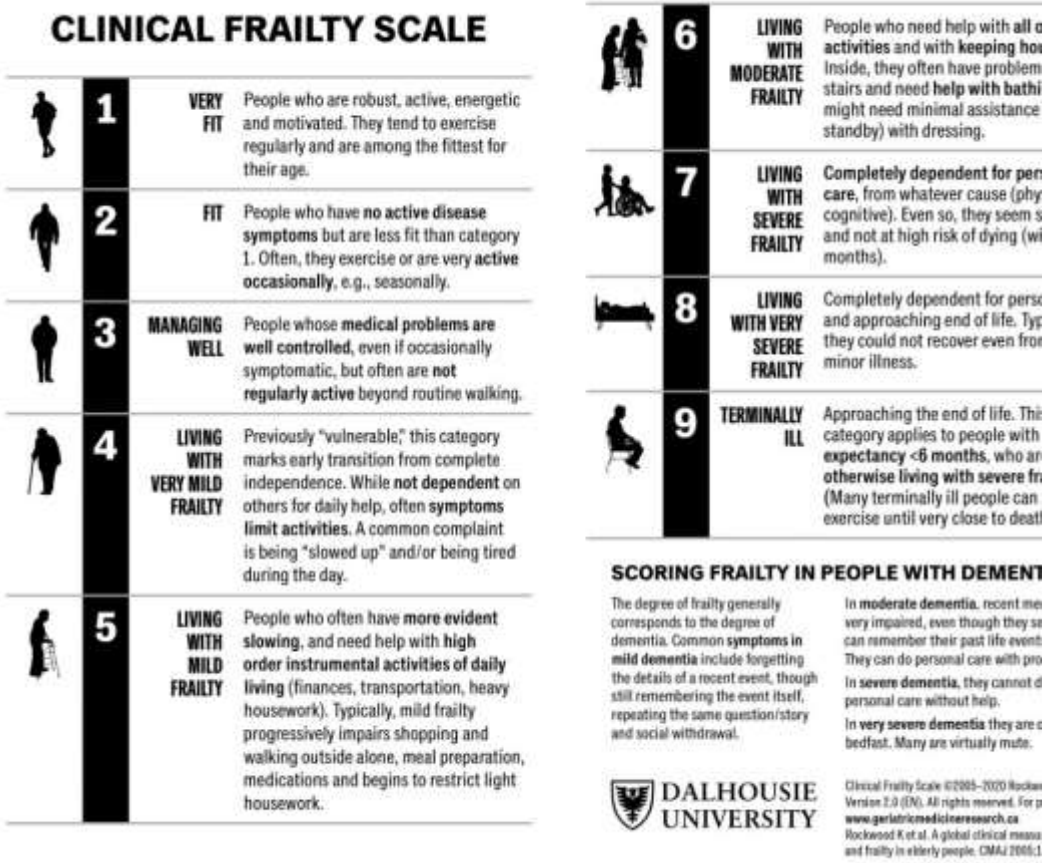
The Haemophilia Population is Ageing

An Inescapable Conclusion

In the future, more people with bleeding disorders will have Frailty

Measuring Frailty

- The Clinical Frailty Score (CFS) is an easy to use, well validated tool to measure frailty
- Uses function as a surrogate marker for frailty
- Validated for those > 65
- There are no specific validated tools to assess frailty in haemophilia



CLINICAL FRAILTY SCALE

1	VERY FIT	People who are robust, active, energetic and motivated. They tend to exercise regularly and are among the fittest for their age.
2	FIT	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**, even if occasionally symptomatic, but often are **not regularly active** beyond routine walking.
4	LIVING WITH VERY MILD FRAILTY	Previously "vulnerable," this category marks early transition from complete independence. 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	LIVING WITH MILD FRAILTY	People who often have **more evident slowing**, and need help with **high order instrumental activities of daily living** (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework.
6	LIVING WITH MODERATE FRAILTY	People who need help with **all o activities** and with **keeping hou** Inside, they often have problem stairs and need **help with bathi** might need minimal assistance standby) with dressing.
7	LIVING WITH SEVERE FRAILTY	**Completely dependent for per care**, from whatever cause (phy cognitive). Even so, they seem s and not at high risk of dying (wi months).
8	LIVING WITH VERY SEVERE FRAILTY	Completely dependent for pers and approaching end of life. Typ they could not recover even fro minor illness.
9	TERMINALLY ILL	Approaching the end of life. This category applies to people with **expectancy <6 months**, who ar **otherwise living with severe fr** (Many terminally ill people can exercise until very close to deat

SCORING FRAILTY IN PEOPLE WITH DEMENT

The degree of frailty generally corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent me very impaired, even though they s can remember their past life event They can do personal care with pro

In **severe dementia**, they cannot d personal care without help.

In **very severe dementia** they are bedfast. Many are virtually mute.

DALHOUSIE UNIVERSITY

Clinical Frailty Scale ©2005–2020 Rockw Version 2.0 (EN). All rights reserved. For p www.geriatricmedicineresearch.ca

Rockwood K et al. A global clinical measu and frailty in elderly people. CMAJ 2005;1

02

Defining Frailty Syndromes

REVIEW ARTICLE · Volume 23, Issue 11, P3409-3423, November 2025 · *Open Access*

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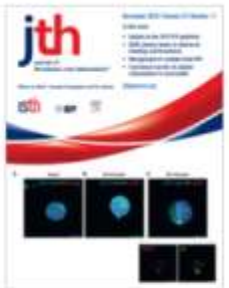
Frailty and frailty syndromes in persons with hemophilia: a review

William McKeown [1,2] · Stephanie Taylor [3] · Susan Shapiro [3,4]

Affiliations & Notes · Article Info



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The Frailty Syndromes – AKA 'Geriatric Giants'

- **Immobility** (Reduced mobility/walking speed)
- **Instability** (Falls)
- **Incontinence** (Urinary/faecal)
- **Impaired Cognition** (Dementia/delirium)
- **Iatrogenesis** (Vulnerable to side effects)

Holistic Multidisciplinary Assessment (Comprehensive Geriatric Assessment) keeps older people alive and in their own homes

All frailty and frailty syndromes have multifactorial causes – therefore there are lots of opportunities to make things better

03

Fixing Frailty Syndromes

Immobility and Falls

- Incidence:
  - 40% of > 85-year-olds fall/year
- Key risk factors:
  - Arthropathy, sarcopenia, chronic pain, depression, **postural hypotension**, polypharmacy, reduced confidence, **environment**
- Complications
  - Fractures/bleeding

Falls almost always have multiple causes

Drop in blood pressure of **20 mmHg systolic or 10 mmHg diastolic** within 3 minutes of standing up from sitting or lying down

Immobility and Falls

- Medical
  - **Screen for osteoporosis (FRAX)**
  - Review Medication
  - Review Comorbidities
  - Review Pain
- Nursing
  - **Assess lying standing blood pressures**
  - Assess vision
- Physiotherapy
  - Strength and balance training
  - Appropriate walking aid
  - Falls prevention
  - Second stair- rail
  - **Environmental Assessment**

Impact of a Multifactorial Falls Assessment

Multifactorial falls interventions reduce falls risk by **34%** (Lee and Yu 2020)

Take Home Message on Falls:

Always ask “Why did the fall happen?”

Incontinence

- Incidence:

	Urinary	Faecal
Community	10%	5%
Residential/Nursing Home	50%	50%

- Key risk factors:
  - Cognitive impairment, prostate issues, diabetes, obesity, **immobility**, medication, **lifestyle**
- Complications
  - Discomfort, dignity, social isolation, skin breakdown

Incontinence

- Medical/Pharmacy
  - Review medication (e.g. diuretics)
  - Review prostate issues
- Nursing
  - **Review and advise on lifestyle**
  - Pads and sanitary products
- Physiotherapy
  - Strength and balance training
  - **Pelvic floor exercises**
  - **Adapt Toilet (e.g. grab rails, raised seat)**

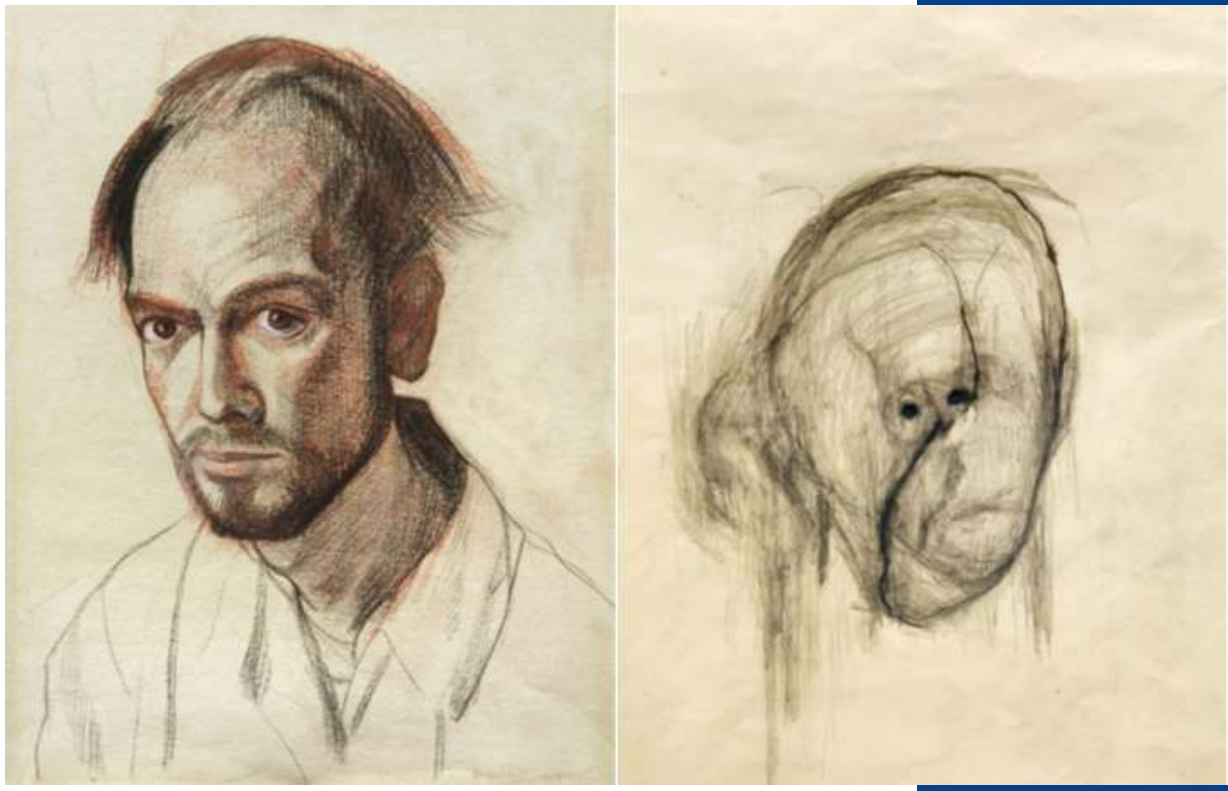
78% of men with weekly urinary incontinence do not seek medical help (Shamliyan 2009)

Take Home Message on Incontinence:

ASK about it!

Cognitive Impairment

- Incidence:
  - 20% of general older population
- Key risk factors:
  - Depression, hypertension, intracranial bleeding, **poor hearing**
- Complications
  - **Loss of independence**, loss of self, malnutrition, incontinence, sleep disruption, legal and ethical issues



Cognitive Impairment

- Medical
  - Assess cognition
  - Review medication
    - For bleeding disorder
    - Others
  - Is treatment appropriate?
- Nursing
  - Train carers and family
  - **Hearing screen**
- Occupational Therapist
  - Is home environment safe?

8% of all dementia is attributable to poor hearing (Ellingjord-Dale, Strand et al. 2025)

Take Home Message on Cognitive Impairment:

Never ignore a hearing problem

Side Effects of Medication/Polypharmacy

- Incidence:
  - 58% of PWH/VWD on 4+ medications
- Key risk factors:
  - Chronic pain, multi-morbidity
- Complications
  - Endless!!!
  - Adverse drug reactions, drug–drug interactions, increased risk of falls, cognitive impairment and delirium, functional decline and frailty, medication non-adherence, hospital admissions and readmissions, higher mortality risk, renal and hepatic strain, orthostatic hypotension, gastrointestinal side effects such as nausea, constipation and bleeding, and increased healthcare costs and overall treatment burden.

Side Effects of Medication/polypharmacy

- Definitions
  - Polypharmacy – 4/5 + medications
  - Superpolypharmacy – 10+ medications
- Medical/Pharmacy
  - Structured medication review
  - Review patient understanding
  - **Calculate anti-cholinergic burden**
- Nursing
  - Review pain and non-pharmacological options

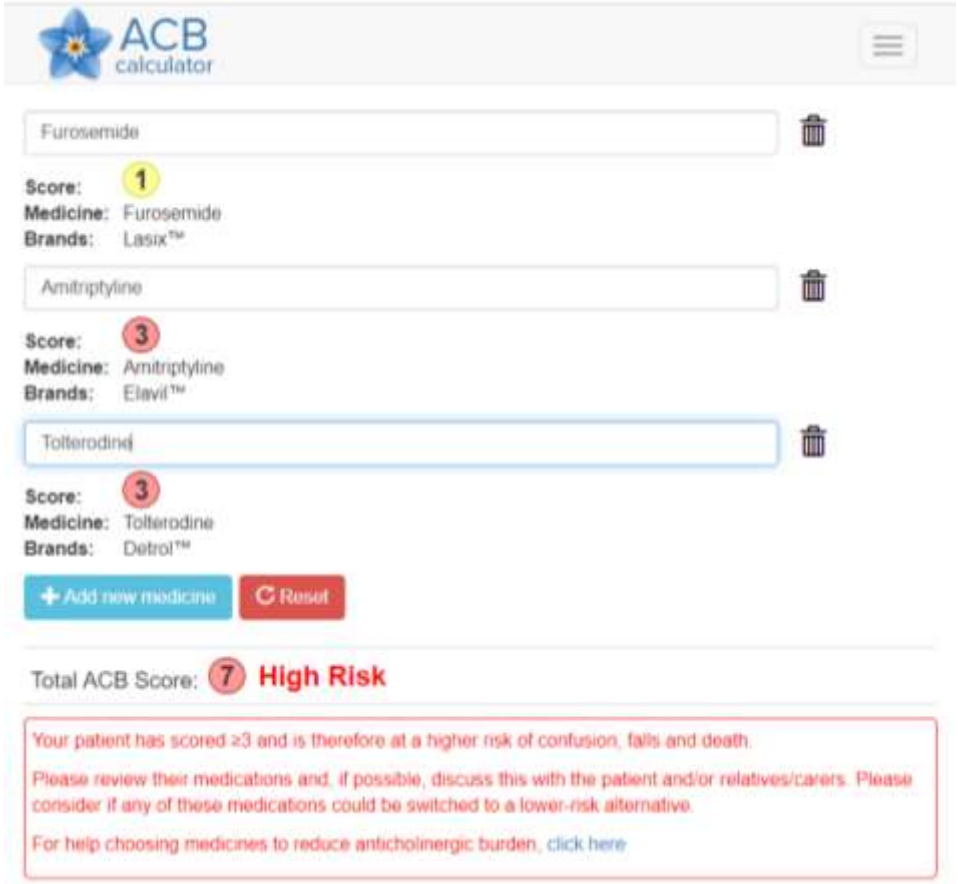
Impact of Superpolypharmacy

Double mortality

Triple Falls Risk

Anti-Cholinergic Burden

- Google *Anticholinergic Burden Calculator* and calculate your ACB score
- If possible, wean to a stop medications with a high ACB score that are not benefiting patient
- Common Offenders Include:
  - Amitriptyline
  - Solifenacin
  - Tolterodine
  - Prochlorperazine



Take Home Message on Polypharmacy

Regularly review medications (every year)

Conclusion

There is so much that can be done for frailty and improve older peoples' lives.

Think Frailty – Think Frailty Syndromes

Immobility/Falls
Incontinence
Imapired Cognitions
Iatrogenesis (side effects of medication)

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Strong at any age – Redefining frailty together

Haemophilia and other bleeding disorders

Susie Shapiro
Associate Professor and Consultant Haematologist, Oxford, UK

22 January 2026

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Disclosures

- Conference support
  - Chugai/Roche, Octopharma, Takeda, Sobi, CSL Behring
- Speaker/honoraria
  - Chugai/Roche, Takeda, Sobi, CSL Behring
- Consultancy
  - E-therapeutics
- Research grants
  - BMS, Sobi

Classic ‘systems’ approach

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Clinical management in older age – systems approach

- Preventing and treating bleeds
  - Joint bleeds / traumatic bleeds
  - Intracranial haemorrhage
  - Gastrointestinal bleeding - angiodysplasia
  - Easier bruising

- Chronic joint damage, pain and functional restrictions

- HIV
- Hepatitis C

Shapiro and Makris, BJHaem 2019

Clinical management in older age – systems approach

- Bone and muscle health
  - Osteoarthritis
  - Osteoporosis
  - Mobility, balance and increasing tendency to falls
- Heart disease and stroke
- Cancer
- Decreasing visual acuity
- Depression
- Loss of social network
- Cognitive impairment and dementia
- Loss of independence

Shapiro and Makris, BJHaem 2019

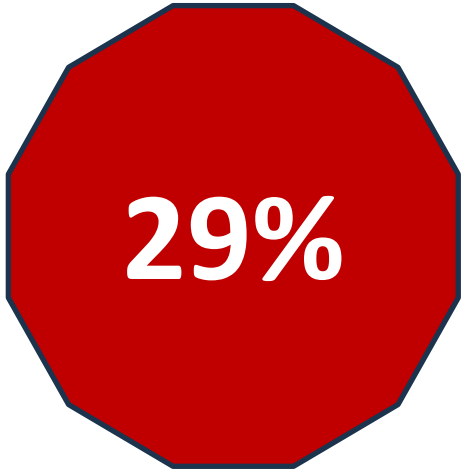
A different approach – global approach

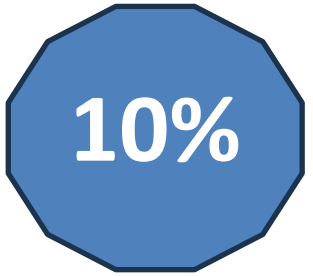
Frailty

Frailty syndromes

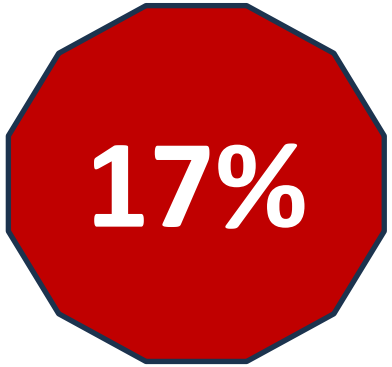
Frailty in people with haemophilia vs general population – estimated retrospectively from 87 medical records

>65 years





50 - 65 years



Sangha G….McKeown W, Shapiro S. Haemophilia. 2023

Frailty in people with haemophilia

- Large UK Haemophilia Centre
- Initiated recording CFS at routine outpatient clinics in all PWH ≥50 years
- Established new guidance for referrals if frailty identified:
  - Highlight frailty (CFS ≥4) to GP
  - Refer to hospital geriatrics clinic if CFS ≥6 or new frailty syndrome

- 116 PWH registered ≥50 years

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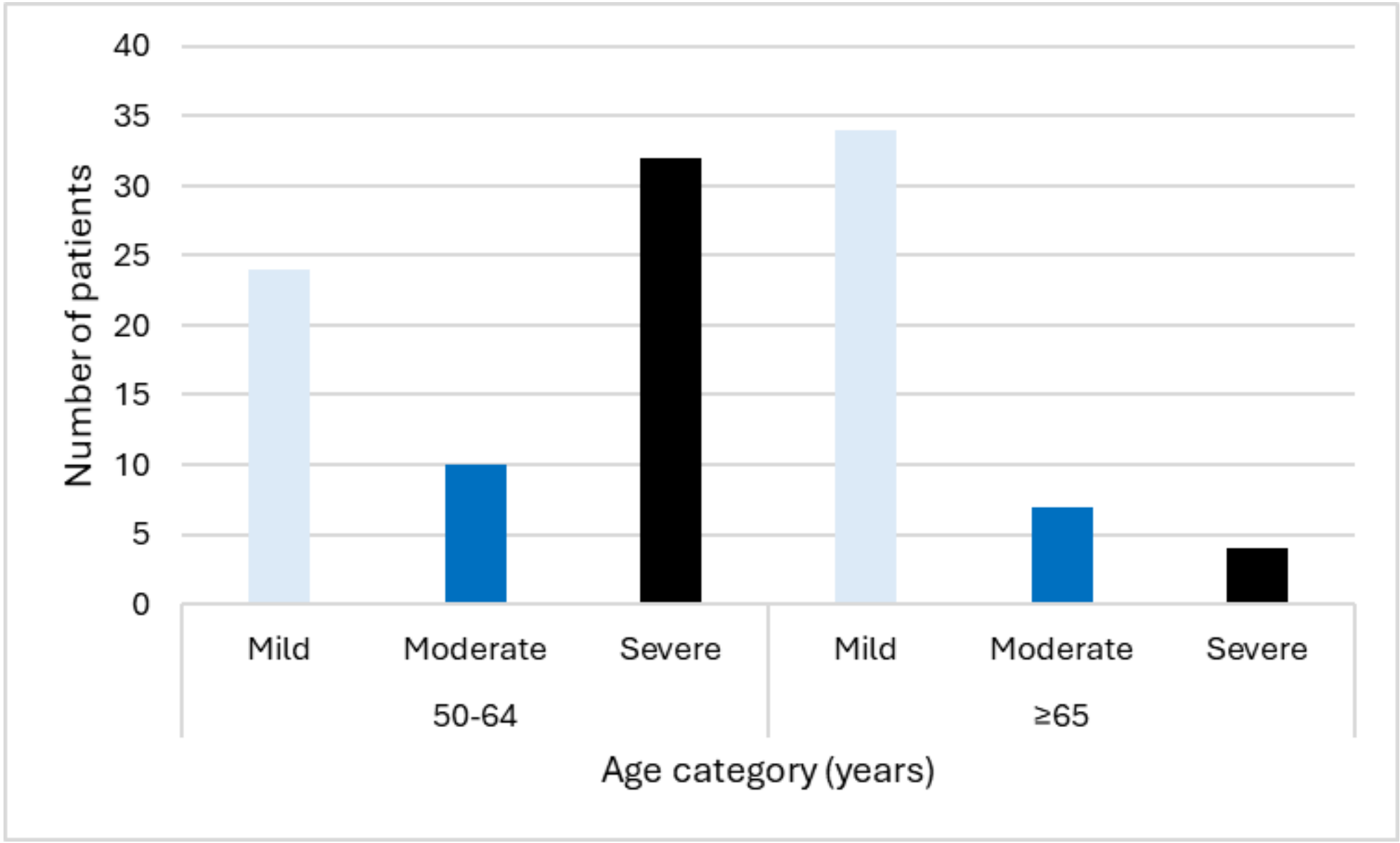
Haemophilia severity

N=111
Age range 50-88 yrs
Median 62 years



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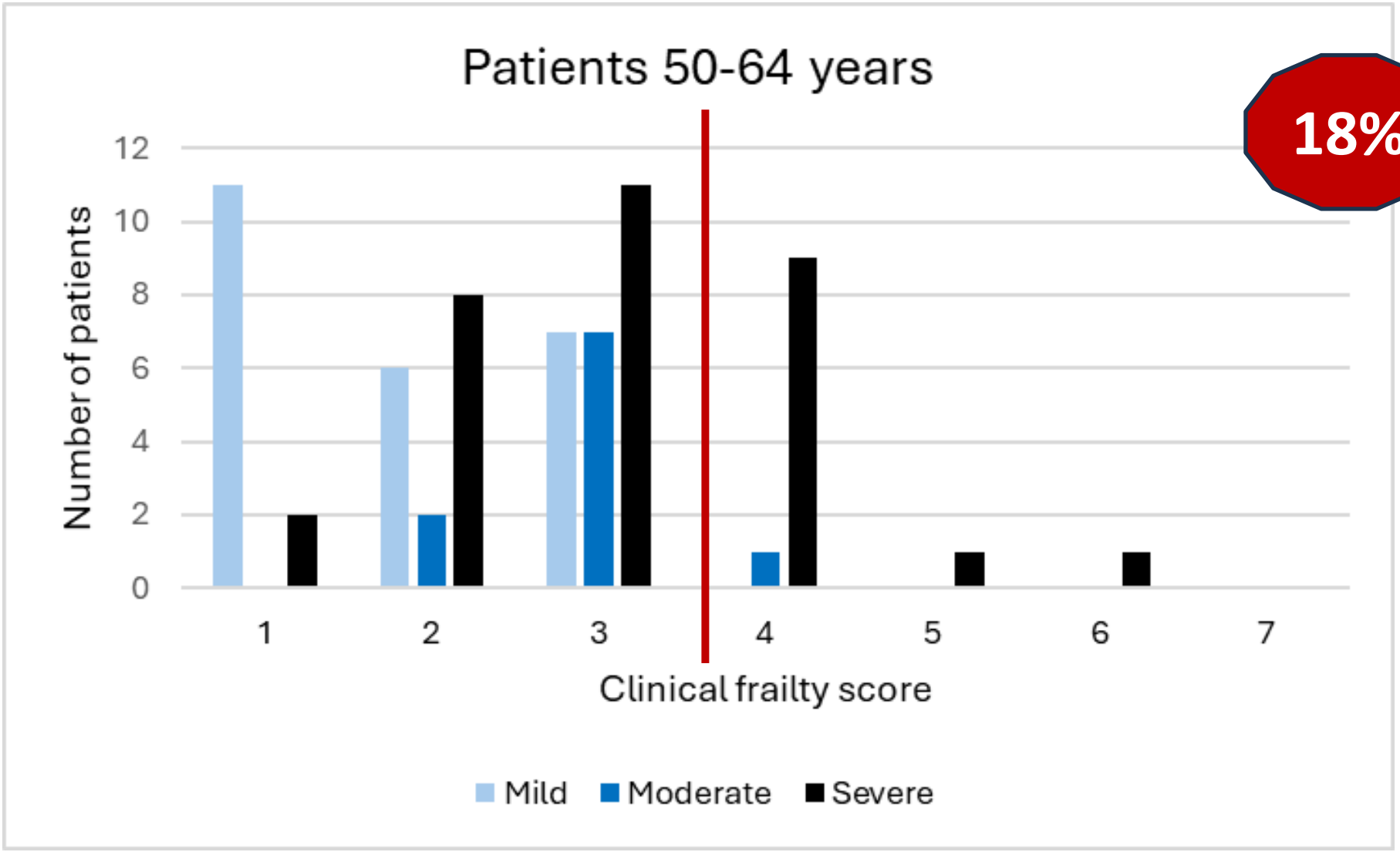
CFS by haemophilia severity and age



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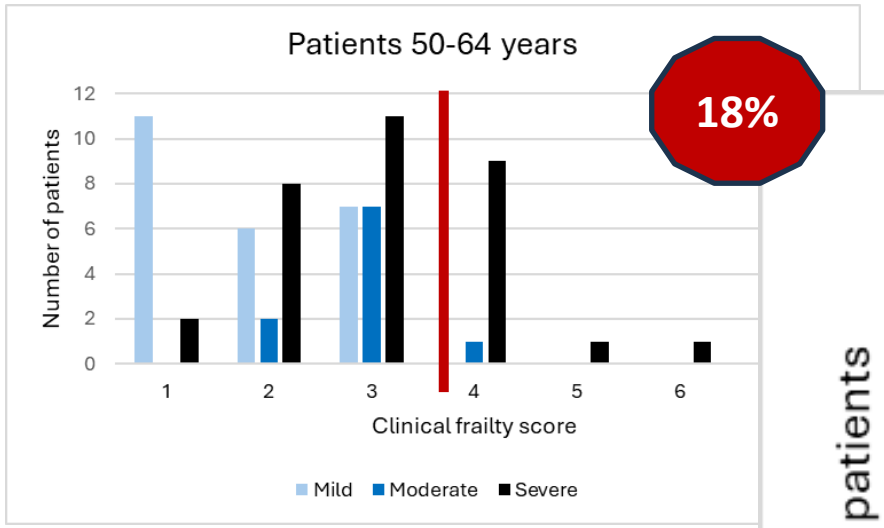
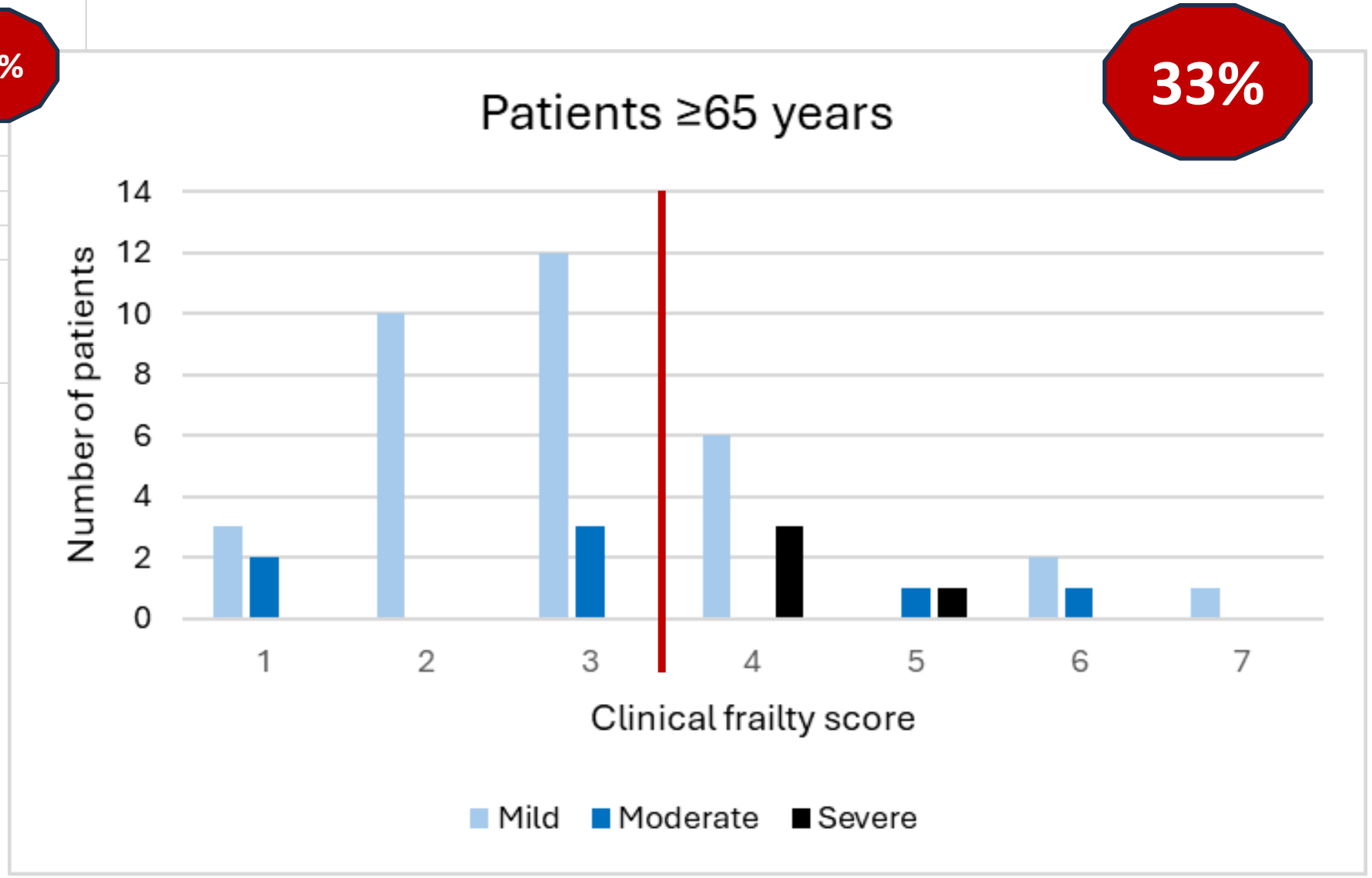
CFS by haemophilia severity and age





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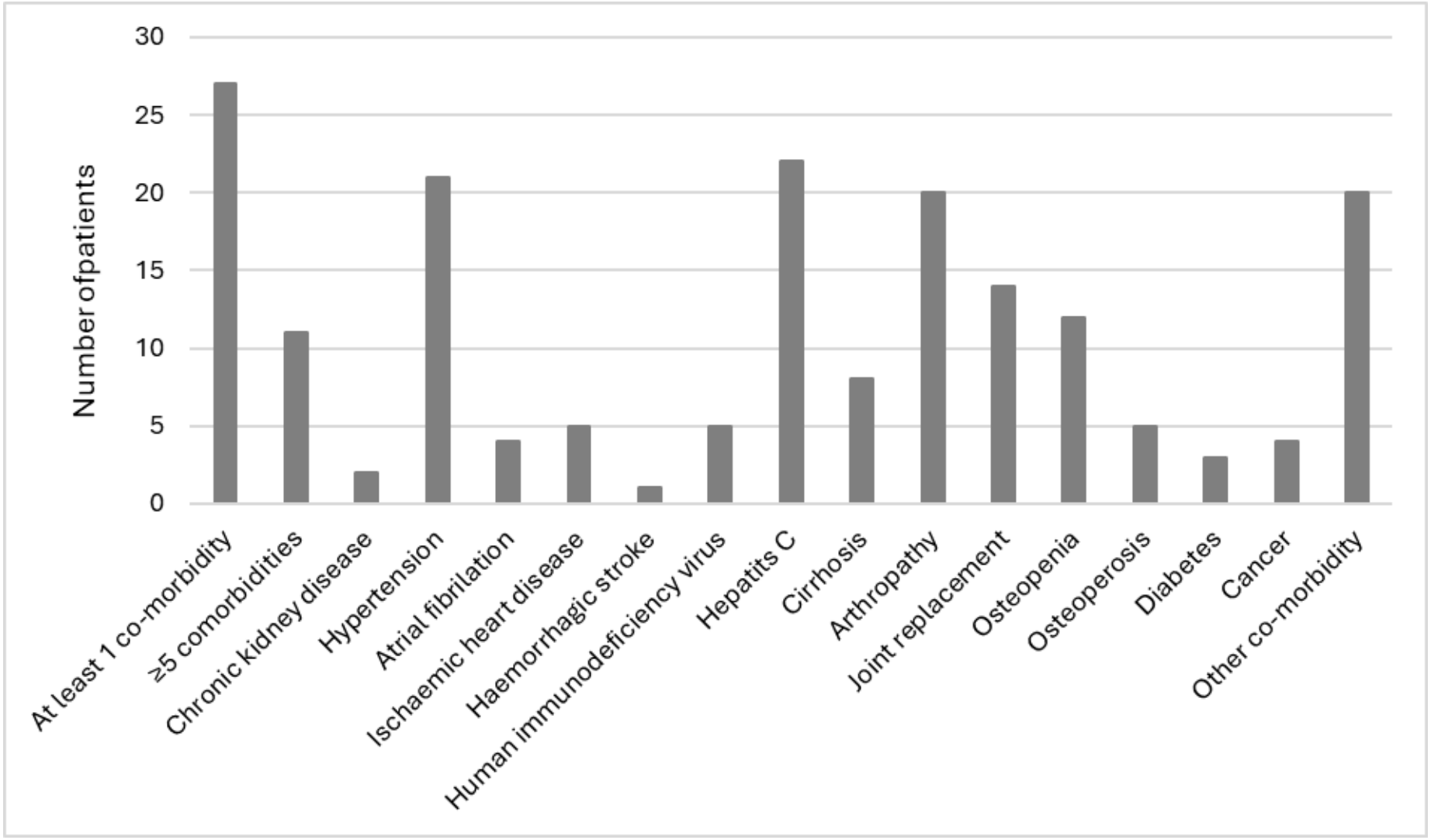
Frequency of comorbidities in those with CFS ≥4



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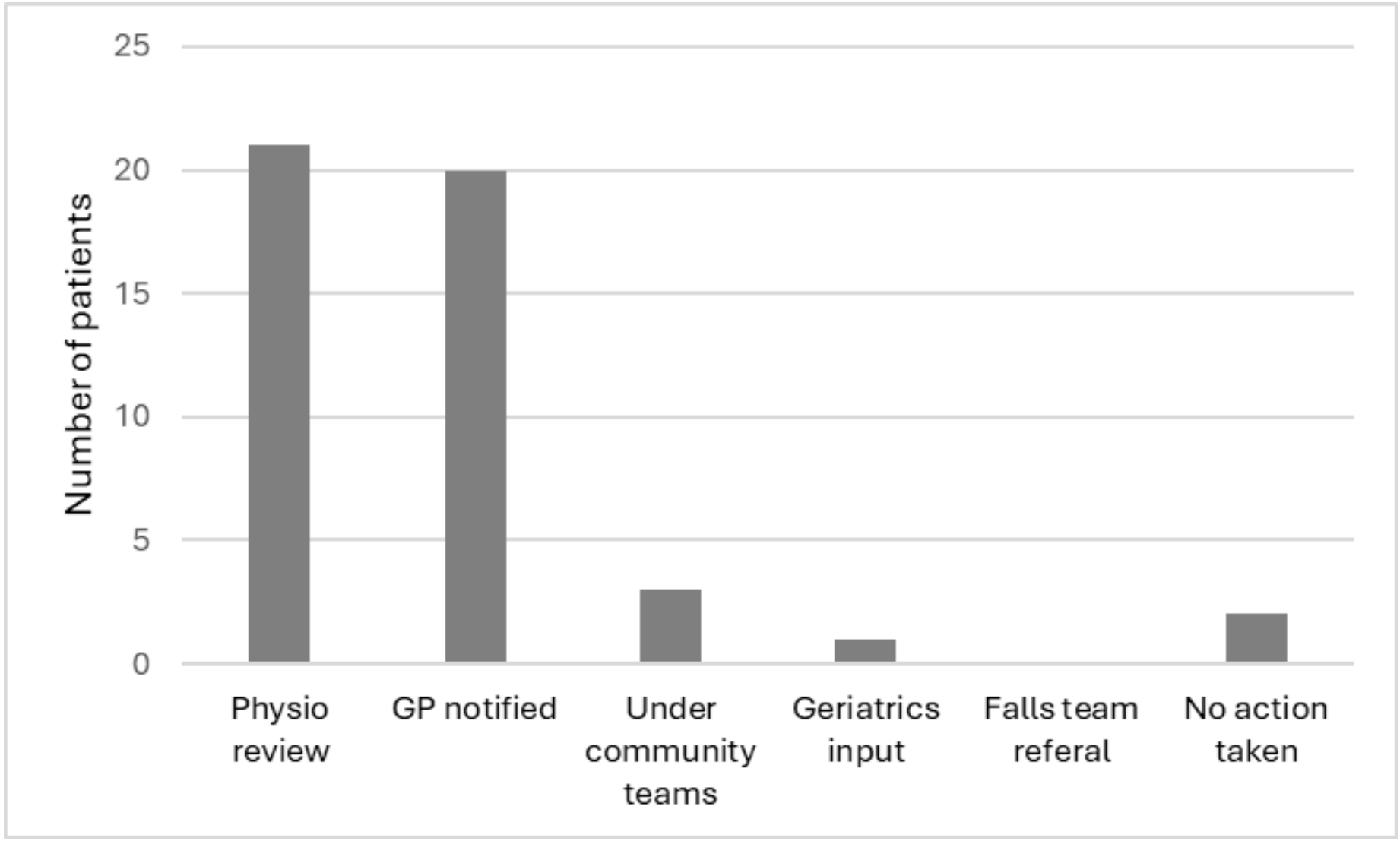
Actions taken by haemophilia MDT when CFS ≥4



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Patients with CFS ≥5

Severity	Age (yrs)	CFS	HJHS	≥5 co-morbidities	Key drivers of frailty
Severe	54	5	33	N	Haemophilic arthropathy
Severe	62	6	42	Y	Haemophilic arthropathy Psoriatic arthropathy
Severe	68	5	57	N	Haemophilic arthropathy Spinal stenosis
Moderate	66	6	35	Y	Haemophilic arthropathy
Moderate	79	5	-	N	Haemophilic arthropathy Sciatica
Mild	71	6	-	Y	Ankylosing spondylitis THR
Mild	85	6	-	Y	CVD, PVD
Mild	88	7	-	Y	Stroke

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Patients with CFS ≥5

Severity	Age (yrs)	CFS	HJHS	≥5 co-morbidities	Key drivers of frailty	Impact
Severe	54	5	33	N	Haemophilic arthropathy	Physio, ortho, GP
Severe	62	6	42	Y	Haemophilic arthropathy Psoriatic arthropathy	Physio, ortho, GP
Severe	68	5	57	N	Haemophilic arthropathy Spinal stenosis	Physio, ortho, GP
Moderate	66	6	35	Y	Haemophilic arthropathy	Physio, ortho, GP
Moderate	79	5	-	N	Haemophilic arthropathy Sciatica	Declined physio
Mild	71	6	-	Y	Ankylosing spondylitis THR	GP, mobility aids, social care package
Mild	85	6	-	Y	CVD, PVD	GP
Mild	88	7	-	Y	Stroke	GP, social care package

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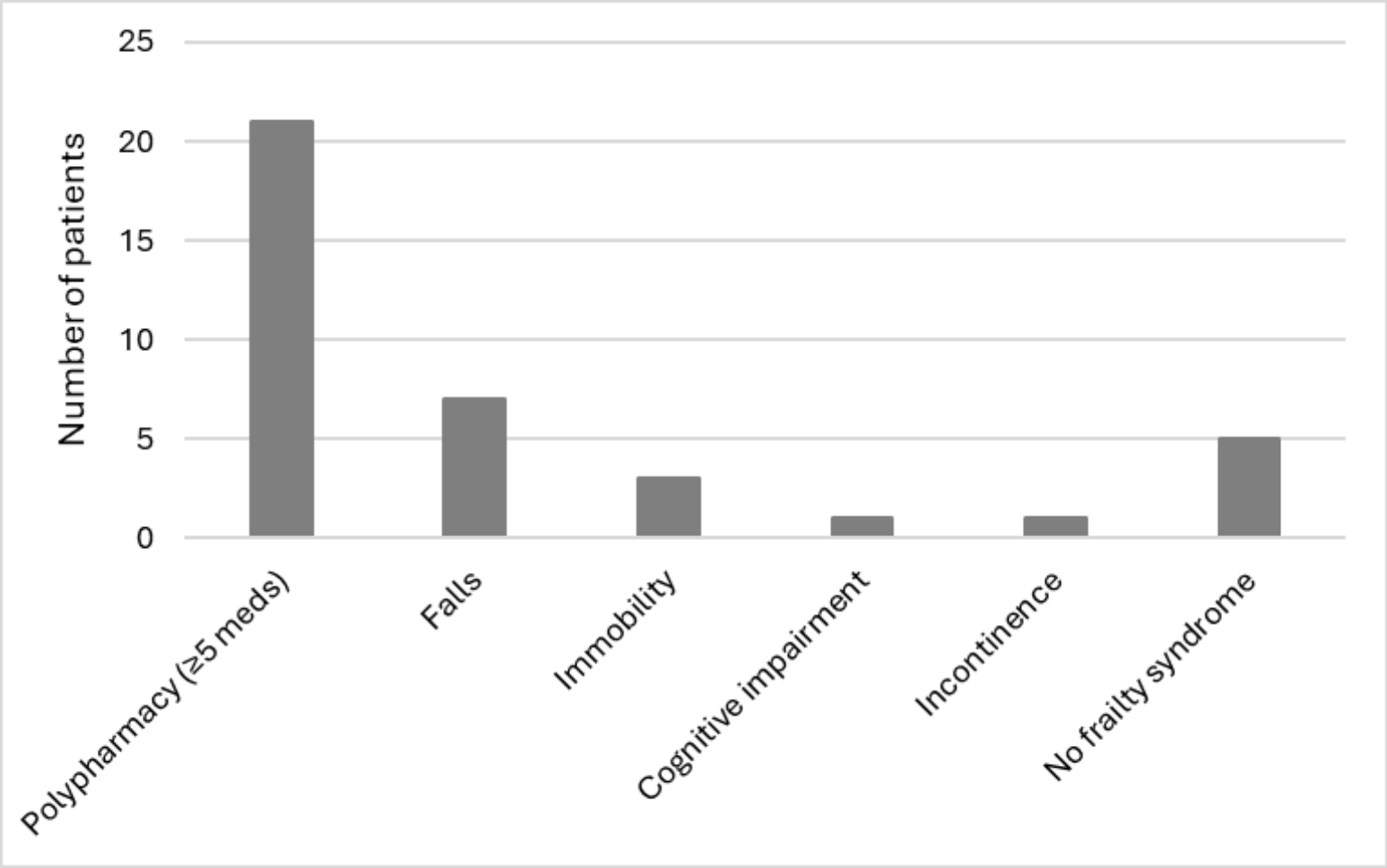
Frailty Syndromes – prevalence

Frailty Syndrome	General population	People with haemophilia
Falls	9% (55-64 yrs) 24% (75-84 yrs)	30% (mean age 40yrs)
Incontinence	21-32%	14%* (mean age 54 yrs)
Cognitive impairment	19%	?
Polypharmacy	45%	58%

* 1 study, very limited data

McKeown W, Taylor S, Shapiro S. Review. *JTH* 2025

Frailty syndromes in patients with a CFS 4 or more



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Severe	62	6	42	Y	Haemophilic arthropathy Psoriatic arthropathy	Y	N
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Moderate	66	6	35	Y	Haemophilic arthropathy	Y	Y
Moderate	79	5	-	N	Haemophilic arthropathy Sciatica	N	N
Mild	71	6	-	Y	Ankylosing spondylitis THR	Y	Y
Mild	85	6	-	Y	CVD, PVD	Y	N
Mild	88	7	-	Y	Stroke	Y	N

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HCP

Ageing well, together

- Use both systems-approach and global approach
- Data/research
- Primary prevention
  - Cardiovascular disease, bone health, nutrition, muscles/balance
- Upskill MDT
  - including on frailty syndromes, dementia friendly environment
  - Prescribing reviews eg liquid rather than tablet, subcutaneous rather than intravenous
- Adapt/expand MDT
  - eg social workers, occupational therapists
  - Loss of independence – education & support of carers/home visits/nursing home visits
- Link with other specialists – Geriatric Medicine, cardiology, oncology

Ageing well, together

- Move from systems-approach to global approach
- Data/research
- Primary
  - Ca… , nutrition
- Upsk…
  - inclu…
  - Prescribing re… intravenous
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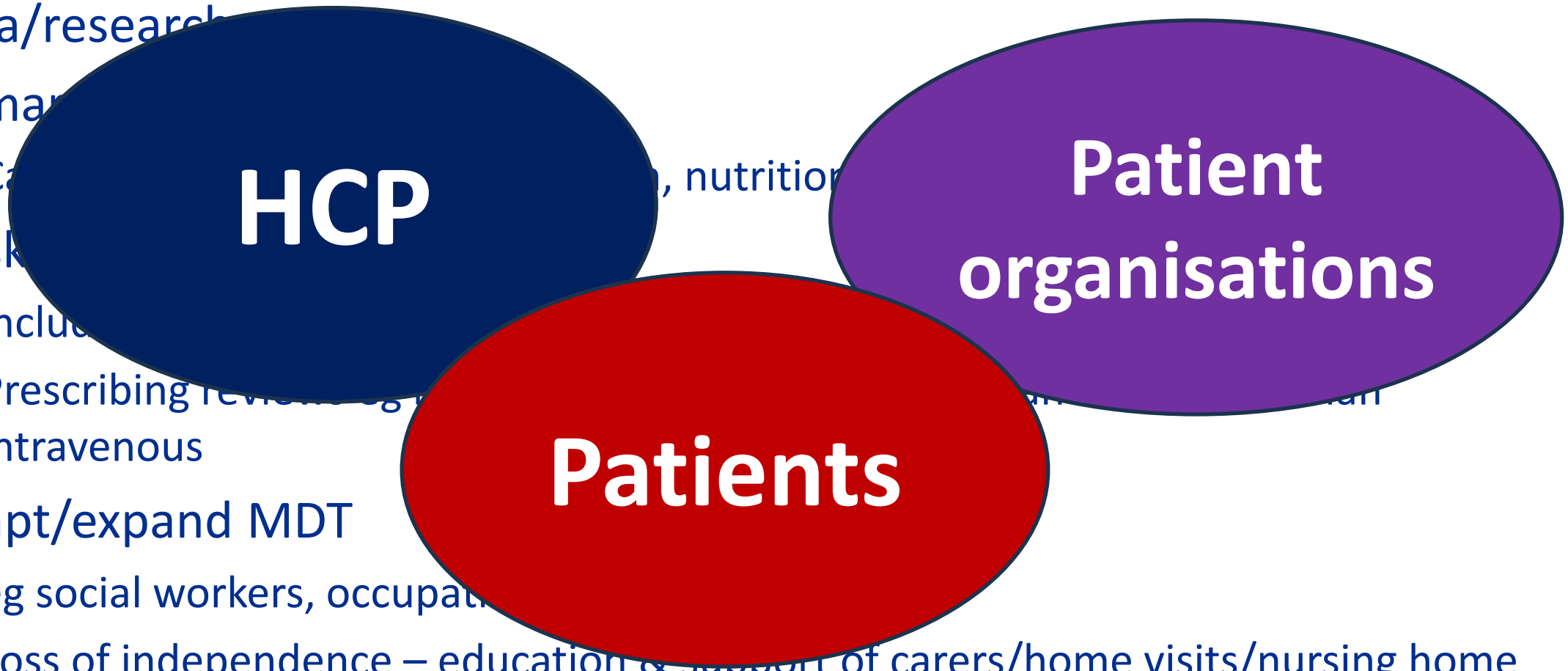

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