AGEING&HIV

CHAIN UKI

CARE OF HIV AND AGEING IMPLEMENTATION NETWORK

Matters Most to Me:

What do people ageing with HIV want from healthcare services?

Chair:
Dr Howell Jones

Speakers:
Jo Josh
Memory Sachikonye
John Jaquiss
Dr Daniella Chilton

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What matters to me ... female perspectives

Women are individuals

- Mother
- Family member
- Friend
- Social animal
- But ALWAYS aware living with HIV …

Consequences of growing older....

These are not inevitable BUT

- Menopause side effects
- Weight gain and mobility
- Growing financial worries
- Independence

Social contact

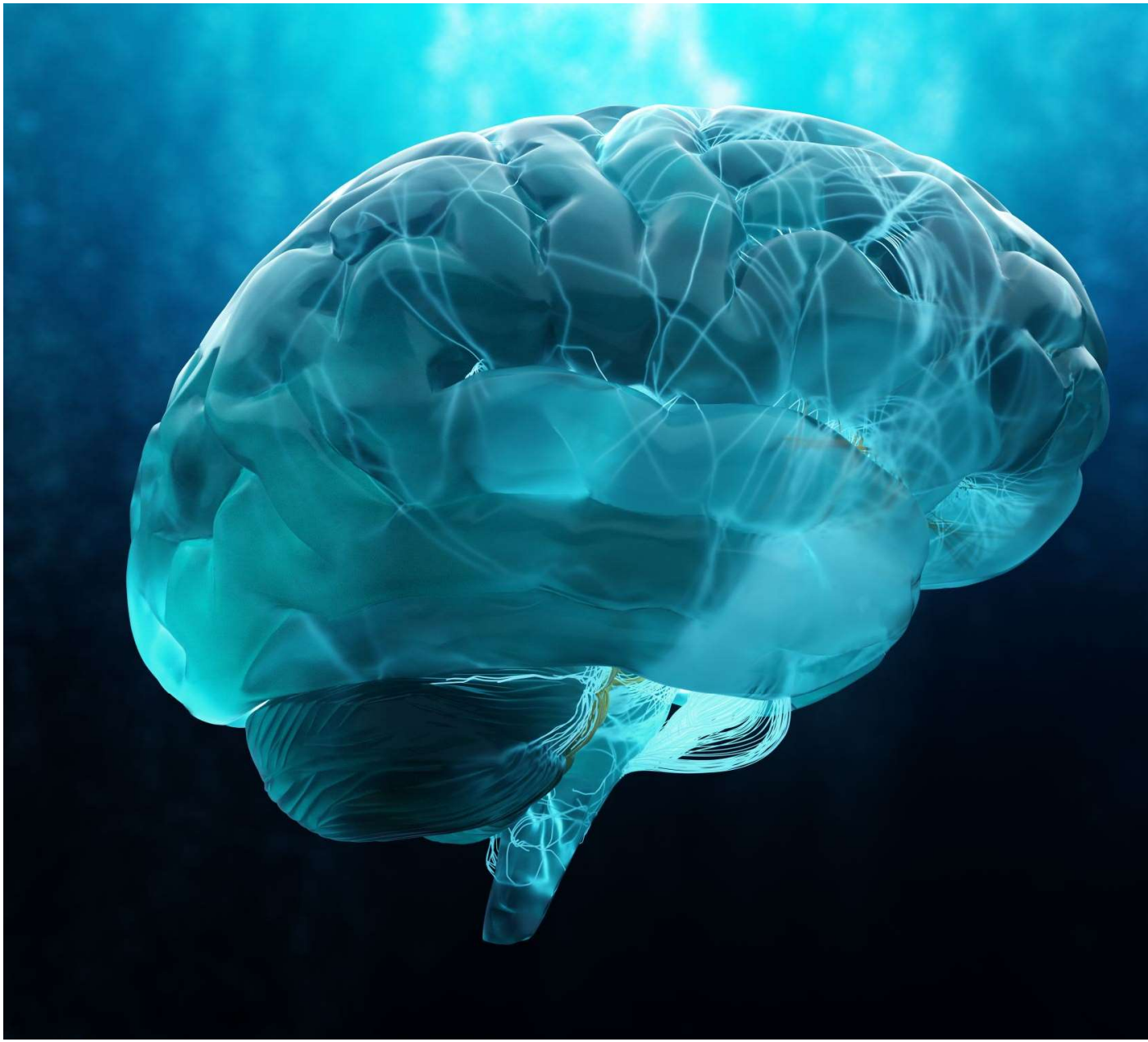
Isolation? Why and where?

Stigma marches on

Friends and lovers

Appearance

Mental health



Fear of Alzheimer’s or dementia

- Lack of information
- Need for the facts
- Need for counselling
- Need for reassurance

What matters most to me?

- Green spaces
- Peace

- And, of course, Family…

What do we really, really want?

Memory Sachikonye

UK-Community Advisory Board (UK-CAB)

Ageing & HIV: A multidisciplinary meeting on HIV and Ageing
12 September 2025

I will cover

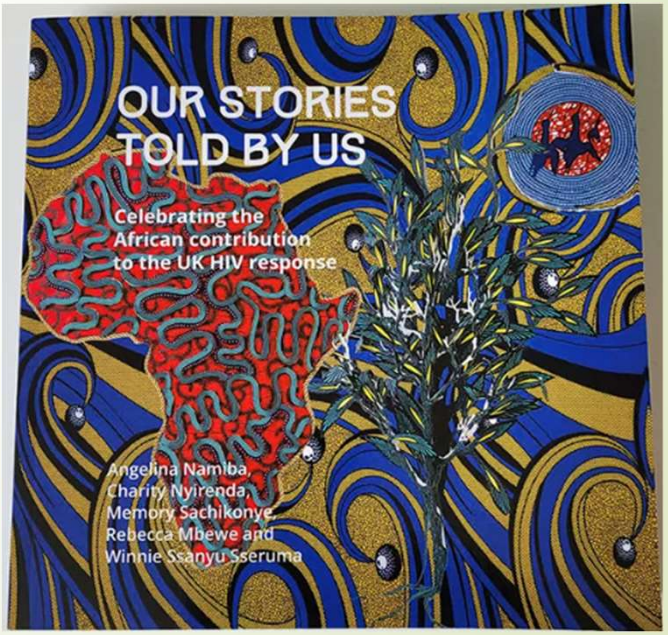
- My story
- Migrant experience
- Women's Health needs and inequalities
- The older woman living with HIV
- Community and family expectations
- Co-morbities
- What do we really want?

About me

- Born in Zimbabwe and diagnosed with HIV 24 years ago on a visit to the UK for a family wedding.
- I had a CD4 of 6 and a very high viral load.
- Currently live with chronic kidney disease and had kidney transplant in 2015; had a breast cancer diagnosis and ongoing treatment from February 2024.
- I am an HV treatment advocate and activist and a peer mentor.

Migrant experience

- Before coming to the UK
- My diagnosis and the role of peer support
- Immigration struggles and volunteering
- My other health issues
- Support network – our book: https://ourstoriestoldbyus.com/



Women's Health needs and inequalities

Findings from Women and HIV – invisible no longer (2018) – still ongoing today

- **Women make up one third of people living with HIV in the UK**, yet are left out of research, decision-making and service design and delivery.
- .**Almost half** (45%) of women living with HIV in the UK **live below the poverty line.**
- **Over half** of women living with HIV in the UK **have experienced violence** because of their HIV status.
- **Nearly one third** (31%) have **avoided or delayed attending healthcare** due to fear of discrimination.
- **Two thirds** (67%) are **not satisfied with their sex lives.**
- Despite this, **half of women** living with HIV (49%) **described their quality of life as 'good' or 'very good'**, while a further 38% called it 'acceptable'.
- **Isolation and loneliness** – services closing down.

The older woman living with HIV

- We often have a huge number of caring responsibilities and frequently neglect self-care.
- We're so busy looking after everyone else we don't seem to have time to look after ourselves.
- There's also a prevalent societal belief that women over 50 shouldn't be sexual beings, so if we are having any trouble in that area, it can be hard to get support.
- Many healthcare professionals don't factor in sexual pleasure as a need for older women with HIV.
- Triple stigma – HIV, ageism, sexism
- Financial burden – care giver responsibilities, no security
- Menopause – cultural stigma and do not access support

Community and family expectations

- We are expected to support aging parents in the family
- Expected to childmind are random times and dates
- Leaned for emotional support within the family
- Source of Wisdom and expected to set examples of maturity
- Expected to manage household responsibilities

Comorbidities

- Some of us are living multiple morbities.
- We need the other barriers to good health in other disease areas addressed as we experience, particularly as we age.
- For many of us HIV is well controlled, but we struggle to get good healthcare in other areas. Particularly in GP care where 10 minutes isn't enough when we have multiple interconnecting health problems.
- Navigating the health system is not easy – multiple clinics to attend and you have to narrate your HIV history and spell the medication names!

What do we really, really want?

- **Universal access to consistent HIV treatment**, care and support for all, regardless of where we live. This will ensure that the virus is suppressed to undetectable levels. This access will improve health outcomes and reduce transmission risks.
- **Community and Peer Support**: strong networks of peer support groups will be available, providing women with a platform to share experiences, seek advice, and build resilience.
- **Zero HIV stigma,** or at least robust interventions to address all levels of stigma. From the self to Societal; it should be integrated into general health care. This will make it easier for women to access comprehensive health services, including sexual and reproductive health, mental health, and chronic disease management.
- **Focus on Quality of Life**: We have a life beyond viral suppression, the focus should on enhancing the overall quality of life for people living with HIV, including aspects such as sexual health, nutrition, and social well-being.
- **Involvement in Decision-Making** - Women living with HIV will have a significant role in shaping policies and programs that affect their lives, ensuring that interventions are responsive to their specific needs

Finally

- **We need to focus on Equity:** Efforts to end AIDS will prioritize equity, ensuring that women, particularly for the racially minoritized communities, benefit equally from advancements in HIV care and prevention.
- By 2030, the vision is not just to reduce the burden of HIV but to create a world where women living with HIV can thrive with dignity, health, and equal opportunities.
- **We still require investment** in the fight against HIV so we are empowered to take on leadership roles, advocating for our rights and the needs of our communities;
- **Ageing –** is the health system robust enough to meet the needs of the first generation of ageing PLWH?
- Are the care homes equipped and informed to care for PLWH?

Thank you

Thank you to my peers from

4MNet

for sharing their lived experiences.

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Understanding what matters most to PLHIV who are ageing

Daniella Chilton

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Learning what matters most?

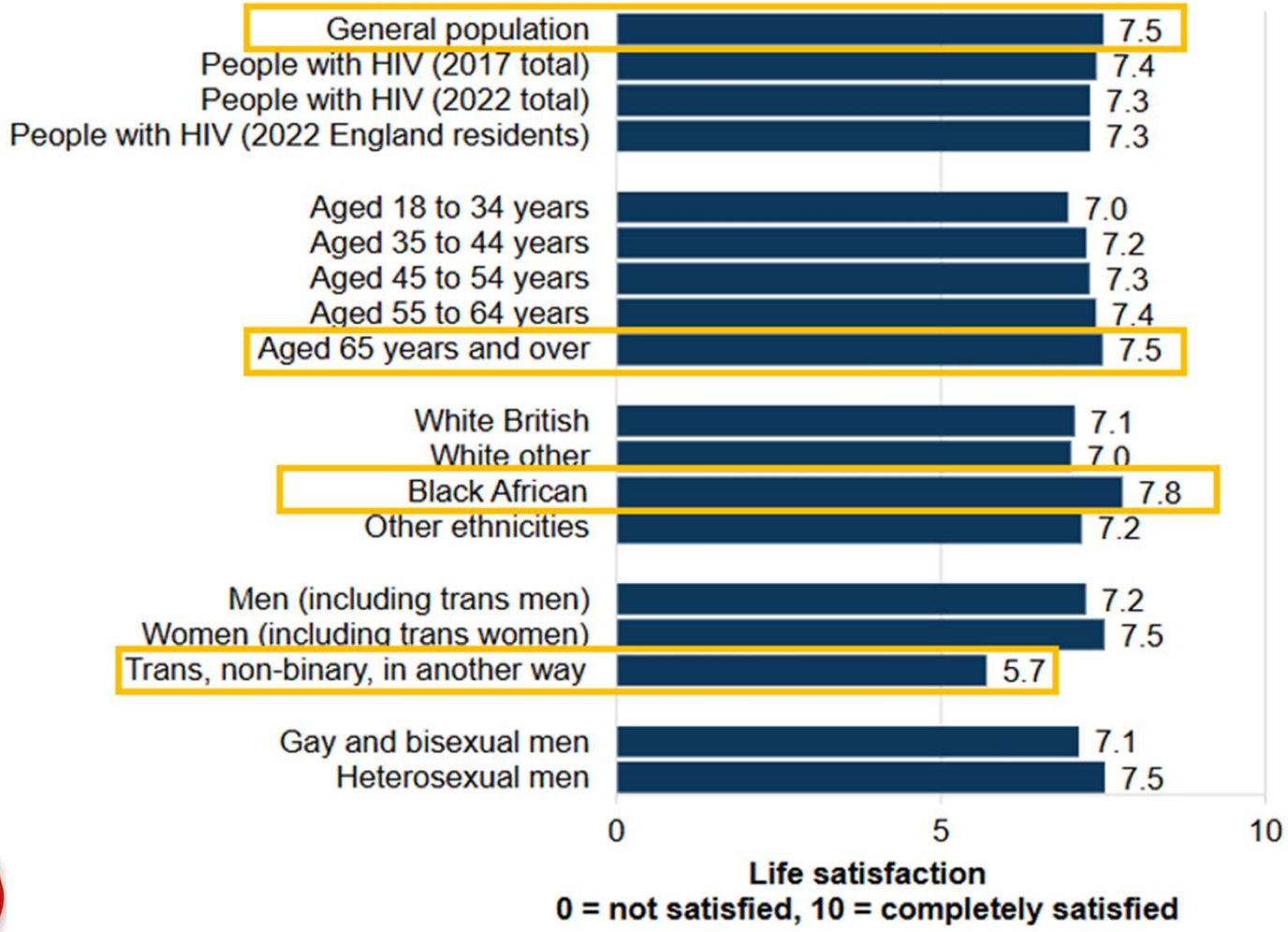
- Positive voices
- Discovering unmet need
- Use of PROMs
- Developing a new ‘Ageing well’ service

What is important to our patients?

- Mental health
- Loneliness and isolation – 15% unmet need
- Managing long term conditions – 64% have at least 1 co-morbidity in addition to HIV
  - LTC support identified as unmet need in 14%
  - Health seeking behaviour altered by stigma:
    - 14% afraid of being treated differently;
    - 6% report being treated differently
- Welfare needs – housing, employment, benefits applications

1. Positive Voices 2022: survey report - GOV.UK accessed Sept 2025
2. M Kall, C Kelly, M Auzenbergs, and V Delpech. Positive Voices: The National Survey of People Living with HIV - findings from the 2017 survey. January 2020. Public Health England: London.
3. Bailin SS, Gabriel CL, Wanjalla CN, Koethe JR. Obesity and Weight Gain in Persons with HIV. Curr HIV/AIDS Rep. 2020 Apr;17(2):138-150. doi: 10.1007/s11904-020-00483-5. PMID: 32072466; PMCID: PMC7719267.

Life satisfaction rating in PLHIV



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Positive Voices
the national survey of people living with HIV

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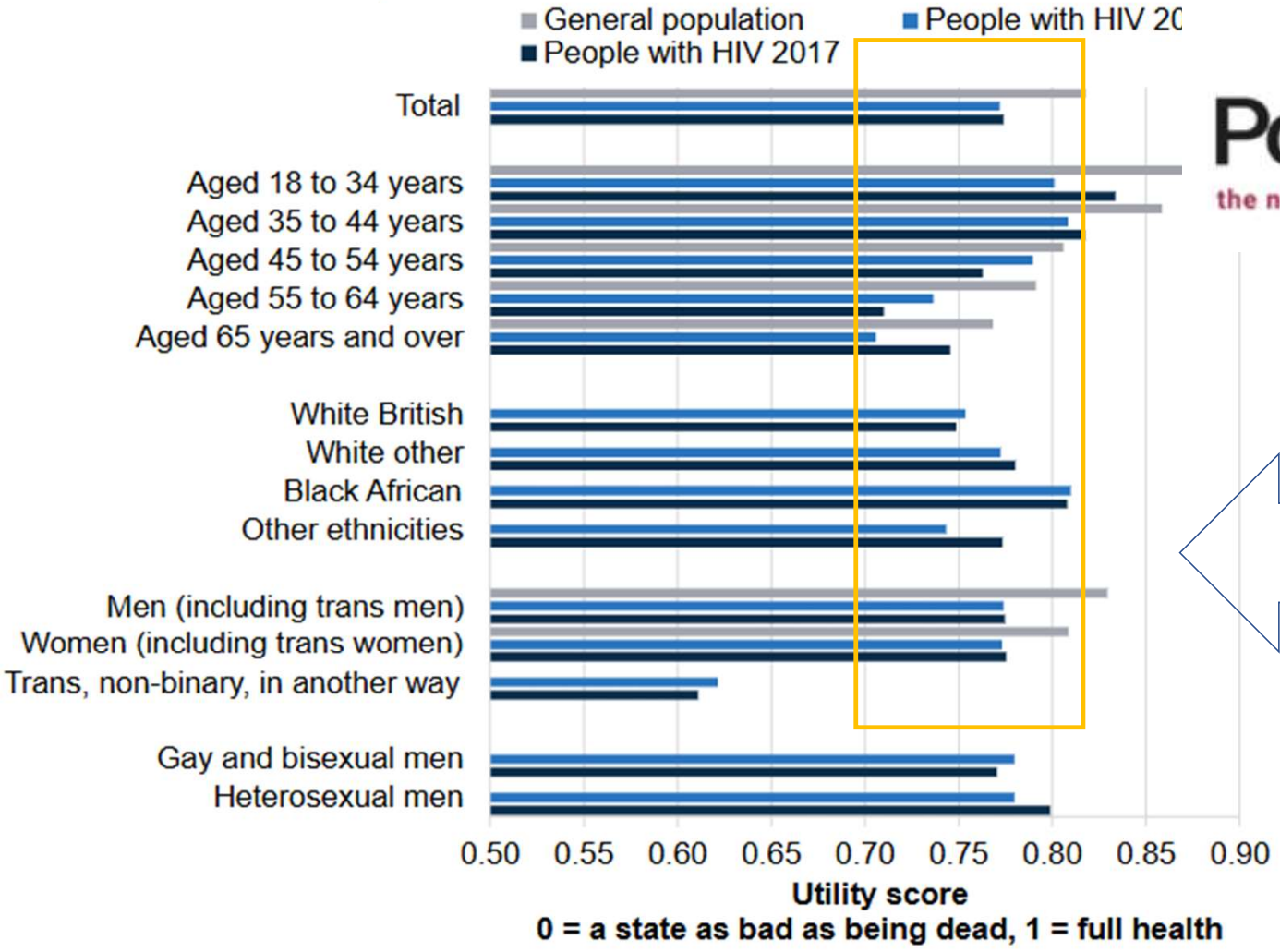
Health related QOL



The grey lines are longer: HRQOL is better in the general population than it is in PLHIV

What are patient's priorities?

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Health may not be a top priority

Safety in relationships, STIGMA

Having a safe place to stay

Having enough to eat / money to survive

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Why Use PROMs?

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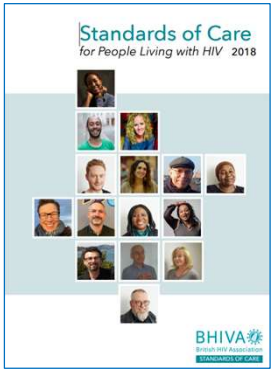
- Widely accepted as beneficial to making care more personalised and holistic
- Can improve doctor-patient communication on more complex issues such as mental and sexual health
- Can increase commitment to self care and satisfaction in the service – pt feel 'heard'
- Places pt at the centre of therapeutic decisions – personalises healthcare and helps us define unmet needs
- May even speed up an appt, if we have pre-populated information

EACS European AIDS Clinical Society



- Utility is 3-fold:
  1. Essential data for pt evaluation in clinic
  2. Clinical decision making re pathways – stratifying care
  3. At service level assess quality of care provided

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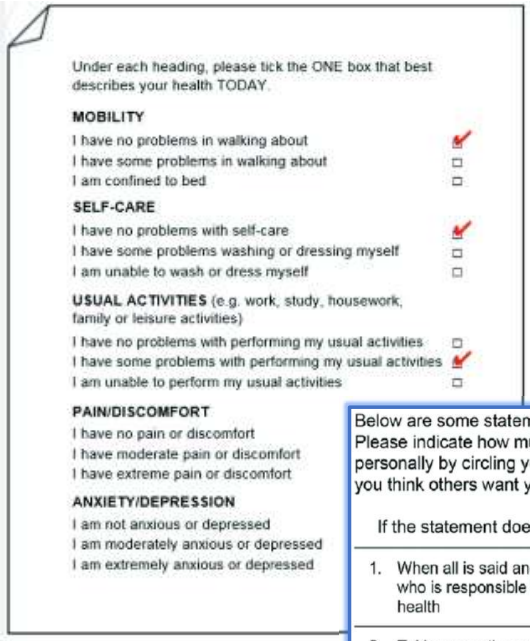
Generic PROMs

- Allow us to compare with other LTC
- EQ5D simple, quick, free – scored to enable look at changes over time in person and potentially across services
- PHQ / GAD depression and anxiety

- Patient activation measure
- Stratifying care according to empowerment
- Improving empowerment through intervention



Under each heading, please tick the ONE box that best describes your health TODAY.

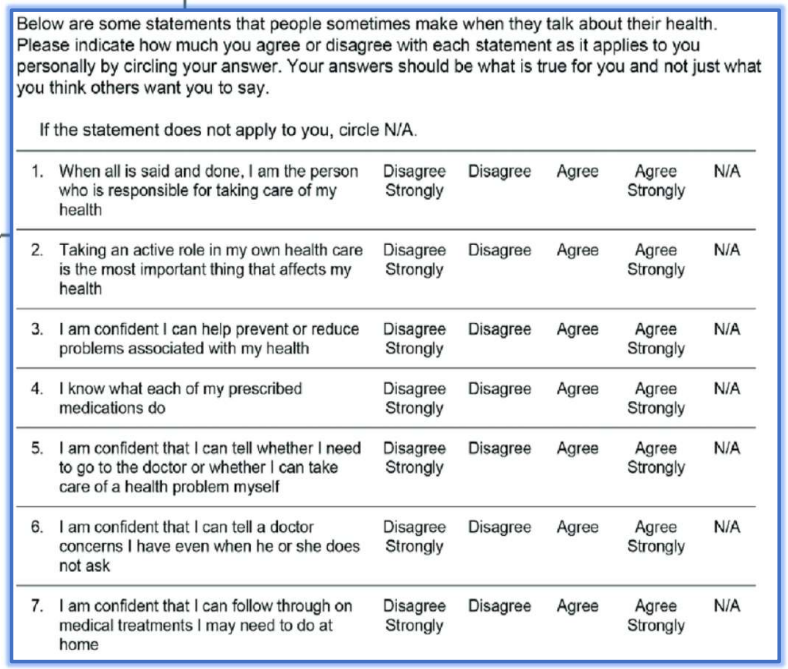
MOBILITY
- I have no problems in walking about ☑
- I have some problems in walking about ☐
- I am confined to bed ☐

SELF-CARE
- I have no problems with self-care ☑
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☑
- I am unable to perform my usual activities ☐

PAIN/DISCOMFORT
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

ANXIETY/DEPRESSION
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed



Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

1.	When all is said and done, I am the person who is responsible for taking care of my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
2.	Taking an active role in my own health care is the most important thing that affects my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
3.	I am confident I can help prevent or reduce problems associated with my health	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
4.	I know what each of my prescribed medications do	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
5.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
6.	I am confident that I can tell a doctor concerns I have even when he or she does not ask	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
7.	I am confident that I can follow through on medical treatments I may need to do at home	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A

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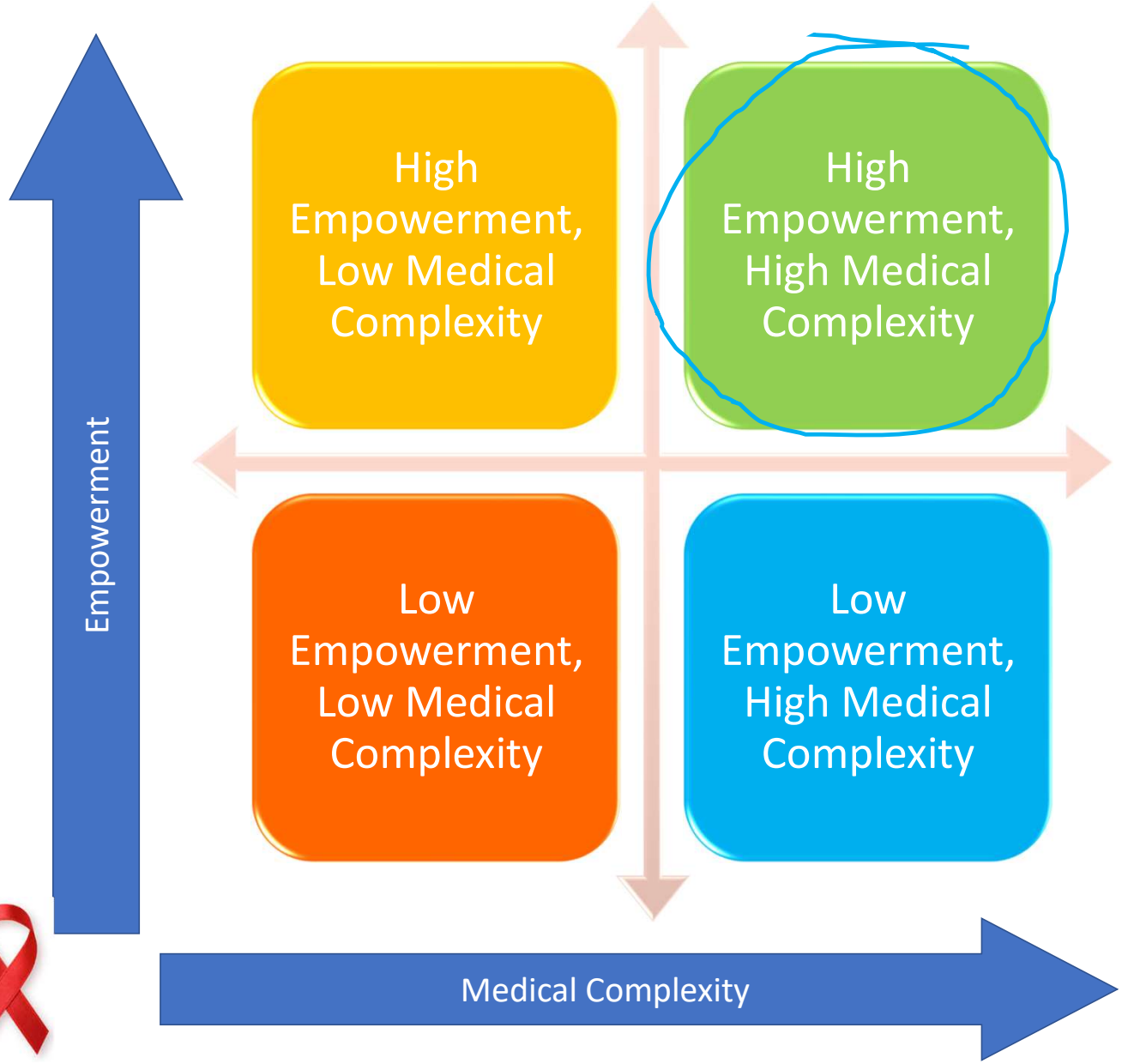
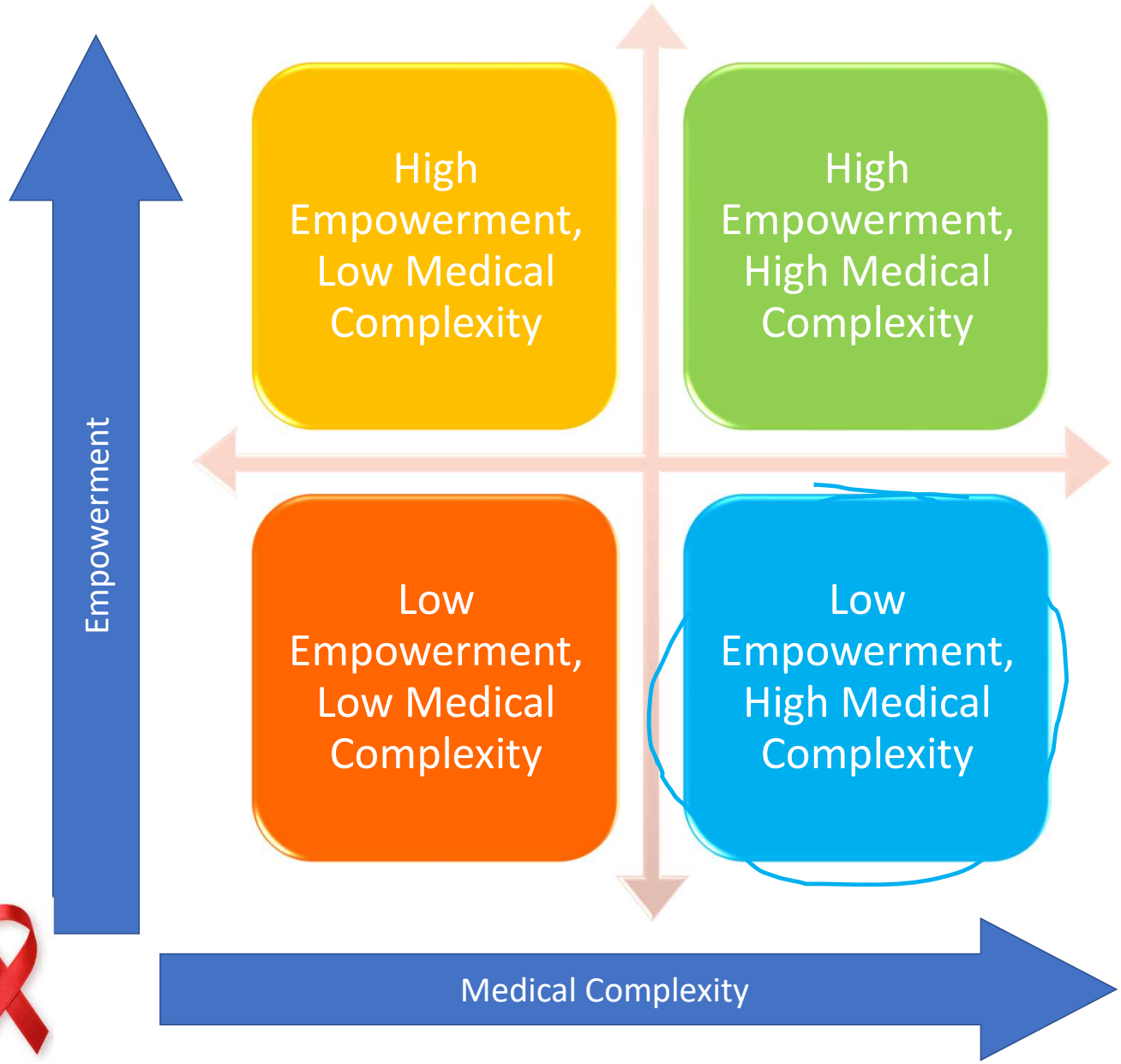


- 1 to 1 coaching
- Group work?
- Higher intensity FU
- Lifestyle interventions
- Bigger goals



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- L2FU / DNA case work
- 3rd sector organisations
- Peer support
- 1 to 1 coaching
- Case management
- Group work
- Smaller goals

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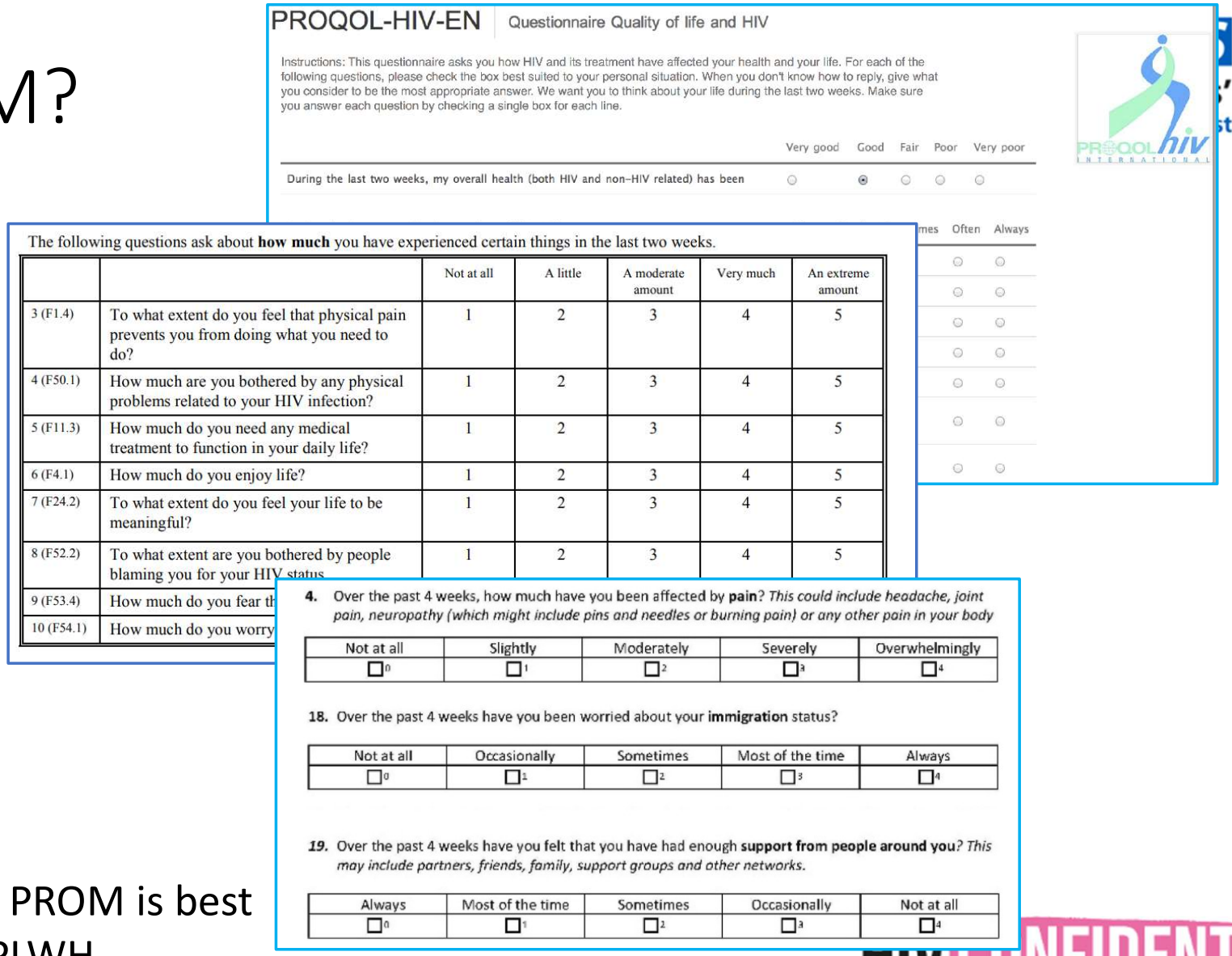
Which HIV PROM?

- MOS-HIV
- WHOQOL-HIV
- PROQOL-HIV
- MQOL-HIV
- POZQOL
- CEAT-HIV
- Positive outcomes HIV PROM



PROQOL-HIV-EN Questionnaire Quality of life and HIV

Instructions: This questionnaire asks you how HIV and its treatment have affected your health and your life. For each of the following questions, please check the box best suited to your personal situation. When you don't know how to reply, give what you consider to be the most appropriate answer. We want you to think about your life during the last two weeks. Make sure you answer each question by checking a single box for each line.

	Very good	Good	Fair	Poor	Very poor
During the last two weeks, my overall health (both HIV and non-HIV related) has been	○	◉	○	○	○

	Often	Always
	○	○
	○	○
	○	○
	○	○
	○	○
	○	○
	○	○

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5
5 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
6 (F4.1)	How much do you enjoy life?	1	2	3	4	5
7 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
8 (F52.2)	To what extent are you bothered by people blaming you for your HIV status	1	2	3	4	5
9 (F53.4)	How much do you fear th					
10 (F54.1)	How much do you worry					

4. Over the past 4 weeks, how much have you been affected by **pain**? *This could include headache, joint pain, neuropathy (which might include pins and needles or burning pain) or any other pain in your body*

Not at all	Slightly	Moderately	Severely	Overwhelmingly
☐0	☐1	☐2	☐3	☐4

18. Over the past 4 weeks have you been worried about your **immigration** status?

Not at all	Occasionally	Sometimes	Most of the time	Always
☐0	☐1	☐2	☐3	☐4

19. Over the past 4 weeks have you felt that you have had enough **support from people around you**? *This may include partners, friends, family, support groups and other networks.*

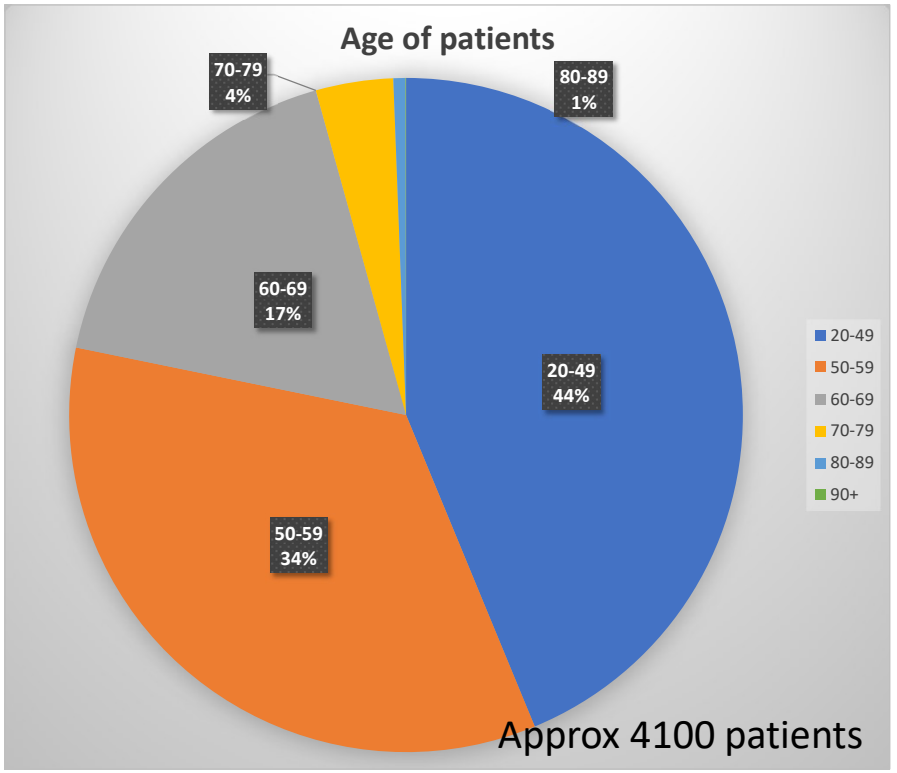
Always	Most of the time	Sometimes	Occasionally	Not at all
☐0	☐1	☐2	☐3	☐4

No clear steer on which PROM is best
Good if its validated in PLWH

Developing a new Ageing well service

Guy's and St Thomas' NHS Foundation Trust

- Established 'Living well' clinic – aimed at supporting pt to manage co-morbidities
- Ageing cohort, but younger than some
- Age 50-59 is the largest Age bracket
- 56% of cohort now >50 years old
- Developing a frailty service
- Staffing:
  - ANP
  - Consultant pharmacist
  - Physio
  - Dietitian
  - HIV consultant support
- Working closely with older persons team at GSTT



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Developing a new Ageing well service

Guy's and St Thomas' NHS Foundation Trust

- Service co-design with patients
- Focus group – everyone over 50 invited!
- Digital and F2F options
- 35 pt: 24 male, 11 female
- Themes:
  - Problems associated with older age eg osteoporosis, falls, poor vision
  - Co-morbidities, particularly pre-diabetes, obesity
  - Concern that GPs / other specialists don't understand or are not confident around ART and DDI, or complexity around HIV
  - Pill burden, lack of oversight of all meds
  - Longer to recover from illnesses
  - What is HIV-related, what is ageing?
  - A feeling that as we get older we are not listened to as much
  - Benefits, mental health, financial issues, housing
  - Agreed the name of the clinic 'Ageing well'

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Developing a new Ageing well service

Guy's and St Thomas' NHS Foundation Trust

- Active case finding
- Sending out FRAIL questionnaire to all pt over the age of 50: return rate 10%
- Rockwood for others
- Active case finding
- Holisitic CGA with ANP, input from the rest of the MDT
- Case presentation later…

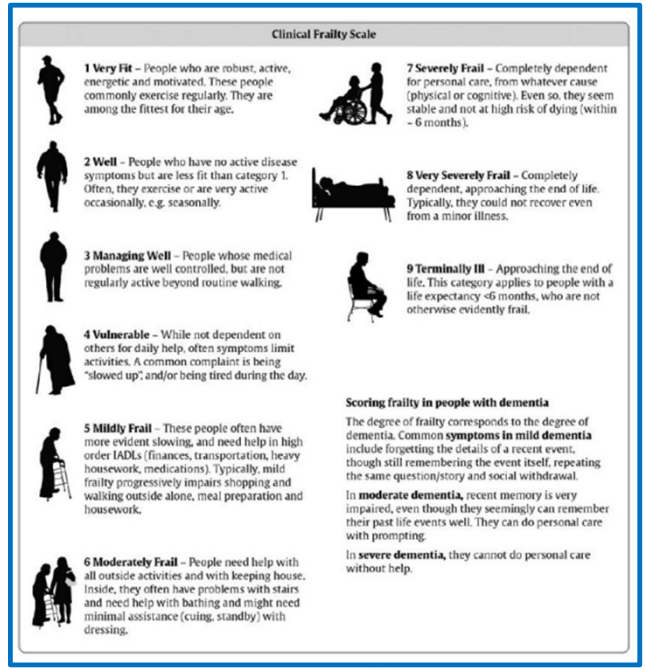
The Simple "FRAIL" Questionnaire Screening Tool

Fatigue: Are you fatigued?
Resistance: Cannot walk up one flight of stairs?
Aerobic: Cannot walk one block?
Illnesses: Do you have more than 5 illnesses?
Loss of weight: Have you lost more than 5% of your weight in the last 6 months?

Scoring: 3 or greater = frailty; 1 or 2 = prefrail

FRAIL:Pt self scores

Rockwood: Clinician scores



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Summing up

- We are well placed to support our patients to age well
- Our patients continue to have poorer HRQOL
- Varied and complex needs, medical and non-medical
- PROMs can help us identify unmet need, monitor progress and evaluate our services
- Stratify patients into the best services
- Screening for frailty, interventions to support ageing well
- Co-designing new services with patients for best results