



UK Health
Security
Agency

Measuring what matters to people with HIV

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Where are we today?

Infection rates are falling

but not for everyone everywhere

Where are we today?

Deaths from AIDS are falling

but there are still preventable deaths

Where are we today?

**Life expectancy for people with
HIV is rising**

but more people are living and
ageing with HIV

Where are we today?

**Complications of
immunosuppression are fewer**

but NCDs and other
comorbidities are greater

Where are we today?

**Biomedical advance has
been awe-inspiring**

but social and cultural change
has been depressingly slow

Where are we today?

Health systems are in evolution

but potentially leaving HIV behind

Where are we today?

Money is available

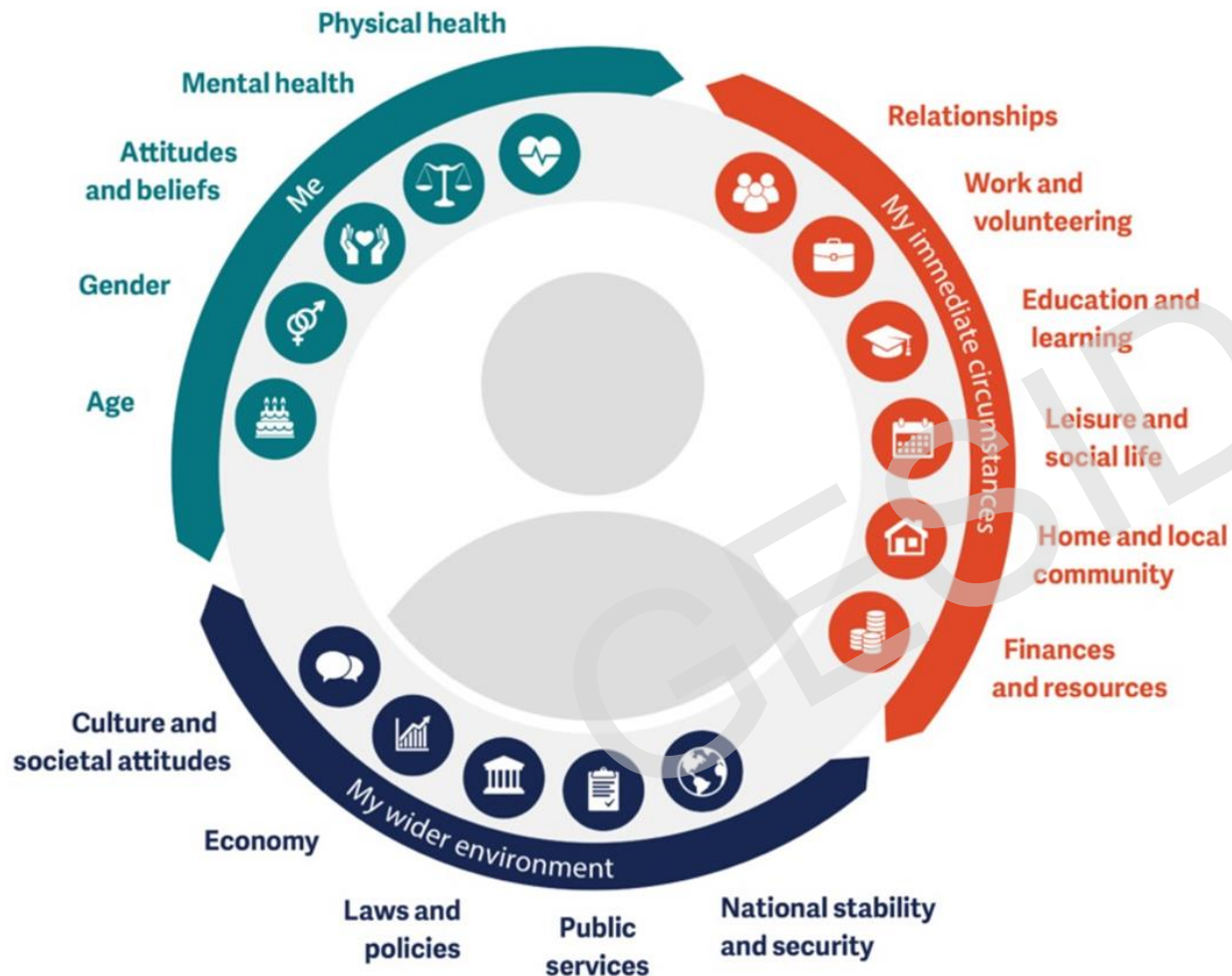
but in lesser amounts and with new constraints

Conceptual approach to health

“Health is a state of complete physical mental and social well-being and not merely the absence of disease or infirmity”

- WHO 1948

Quality of life: What do we mean?



“I think, living with HIV is a bit hard and tricky. Sometimes, you just feel down, you feel lethargic, tired. The aches and pains in your body, physical... Yes, so it's all physical, mental... Especially with lethargy and tiredness, low mood...Yes, I know everyone gets stressed and depressed, but if you are on the medication, it's a different feeling that you're feeling in your body...Sometimes, If you take them late you have the hangover effect.... Sometimes, for me, I get foggy and forgetful, muddled. I stopped going to college because I could hear the teacher talking, but I couldn't process what she was saying or what was going on. It was just useless for me to keep going to college.”

- Black African woman in her 40s living with HIV

Patient-reported outcomes

- Any report of the status of a patient's health condition or experience that comes **directly from the patient, without interpretation by a clinician or anyone else.**
- Measure patients' perceptions of their own health that either cannot be directly observed (e.g, depression, quality of life, fatigue, pain) or are not easy to directly observe (e.g, adherence, drug use, ability to perform daily activities).
- Subtle distinction
 - Patient reported **OUTCOME** measures (PROMs)
 - vs
 - Patient reported **EXPERIENCE** measures (PREMs)



Patient-reported outcomes within HIV: a brief history

- Pre-ART:
 - Focused on understanding risk and transmission patterns, and supporting opioid use and substitution therapies
- Mid-1990s:
 - Shift to monitoring clinical treatment outcomes, such as ART adherence, symptom burden, & HRQoL
- 2000s:
 - Greater importance in informing therapeutic choices in the presence of ART with similar efficacy
 - PROMs assessing QoL, fatigue, depression & anxiety
 - Became a prerequisite as secondary outcome in ART clinical trials
- Greater focus on long-term health (the 4th 90):
 - How people living with HIV cope with their HIV as a life-long condition, including issues with ART, long-term follow-up and the social and personal repercussions of living with HIV¹, as well as how HIV affects the ageing process

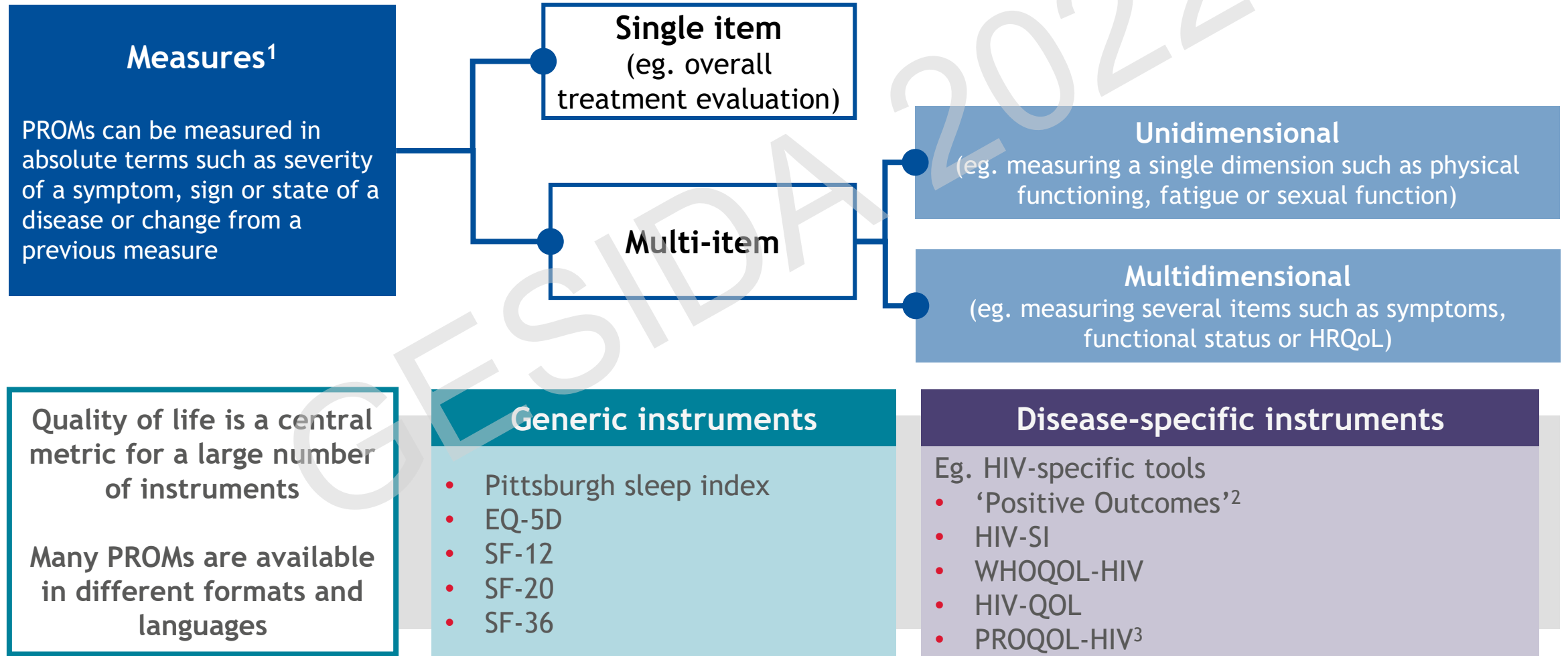
Simple, valid, reliable

Validated - measure what matters to the target population comprehensively, accurately. Generic HRQoL tools should be pre-validated in HIV populations

Reliable - show change over time

Comparison - allow comparisons within or between HIV populations / general population

Patient-reported outcome measures



Patient-reported outcomes

A 2017 review identified 117 different HIV-specific PROMs

	Generic or developed in other diseases (number of items)	HIV specific (number of items)
Core patient-reported outcomes		
HRQoL	EuroQol (EQ-5D) and EQ-5D-Y (Y)* (5 + Visual Analogue Scale); HUI2 and HUI3 (15-16); MQOL (16); MOS SF-36 (36); MOS SF-20 (20); MOS SF-12 (12); WHOQOL-BREF (26); PedsQL* (15 core + 30 supplementary)	ACTG-21 (21); MOS-HIV (36); PROQOL-HIV (43); WHOQOL-HIV BREF (31); FAHI (47); PozQoL (13); Positive Outcomes (23); QOL-CHA1* (47)
Self-rated health	SF-36 (first question)	..
Patient empowerment	CD-RISC (25); CD-RISC-10 (10) and CD-RISC2 (2); BRS (6); PAM-13 and PAM-22; HCEI (8)	..
Life satisfaction	PWB (4); FLZM (28)	..
More patient-reported outcomes		
Stigma and discrimination	..	People Living with HIV Stigma Index† (10 areas [can be adapted to local context]); HSS (40) and derived versions; HSSC (10 and 12)*
Antiretroviral therapy adherence, treatment side-effects	SMAQ (6); MASRI (12)	ACTG Adherence Questionnaires and derived versions (5-20); HIV Symptom Index and ACTG; Symptom Distress Module (20)
Fatigue or sleep disorders	FIS (40) and derived versions; ESS (8); GSQS (15); PSQI (19)	HRFS (30)
Mental health (anxiety, depression, stress, etc)	CES-D (20, 10 [short version]); HAD (14); BDI-II (21); DASS-21 (21); GHQ (12, 28, 30 and 60); PHQ (9 and 15); GAD-7	..
HIV status disclosure	..	HIV Disclosure Scale (14); Adolescent HIV Disclosure Cognition and Affect Scale* (18)
Weight management	IWLS (9); BIS (10)	..
Pain and function	Visual Analogue Scale; McGill Pain Questionnaire (20); BPI (9 [short form]); BCPQ (2)	HDQ (69)
Use of alcohol, tobacco, and drugs	AUDIT (10); AUDIT-C (3); Fagerstrom (6); CAST (6); DUDIT (11)	..

Select the tool fit for the purpose

PATIENT-LEVEL: improve communication, routinise person-centred assessment, rapidly identify and focus on what matters: acknowledge, act, refer

SERVICE-LEVEL: quality improvement, audit, local contracting & referral pathways

NATIONAL-LEVEL: national surveillance, inform HIV policy, health system evaluation, integration of health & social care, advocacy

	Considerations
Population-level prevalence or surveillance	Ability to compare with general population surveys, use of probability sampling to ensure representativeness, and extra resources, long-term investment, or incentives that might be required due to population size and frequency of collection
Cohort research (including nested interventions)	Causal pathway to clinical outcomes and other measures and focused research question
Clinical use (patient level)	Measurement of symptoms and side-effects, short-forms that can be easily collected and scored, and developmental age for child respondents
Clinical trial research	Cost-effectiveness studies to derive utility (QALY, DALY) and measures responsive over a relatively short period of time, given the limited duration of HIV clinical trials
Multicountry monitoring	Brief, multidimensional tools that can be easily collected in routine monitoring and cross-cultural validation and adaptation

Considerations include sampling, length, mode, format, generic versus HIV-specific outcome measures. QALY=quality-adjusted life-year. DALY=disability-adjusted life-year.

Methods to collect patient-reported data

Mode of collection	Advantages	Disadvantages
Interviewer-administered	<ul style="list-style-type: none"> • Support short questionnaires in clinical practice • Cost of interviewer time 	<ul style="list-style-type: none"> • High volume limits amount & quality of data • Social desirability bias (sexual behaviour, drug use, or domestic violence may be systemically misreported) • Fear of repercussions • Over report to access care / induce response
Self-administered paper questionnaires	<ul style="list-style-type: none"> • Minimal participant burden • Ease and speed of administration, • Flexibility in terms of mode of administration and timing of assessment. 	<ul style="list-style-type: none"> • Data entry, cleaning & reconciliation are labour intensive leading to time lags
Self-administered electronic questionnaires	<ul style="list-style-type: none"> • ↓ Human resource burden, minimises errors, and enables sophisticated survey administration • Provide automated, user-friendly reports which score multidimensional tools and interpret results in real-time 	<ul style="list-style-type: none"> • Challenges where cultural mistrust in technology or government exist • Individual concerns about how their data will be stored and used

Involve people with HIV in every step of the process!

- ✓ Meaningfully involve people living with HIV in designing and selecting PROMs and person centred services which focus on their needs
- ✓ Ensure people living with HIV know about PROMs, and understand their value and importance to them & their healthcare
- ✓ Ensure inclusion & accessibility in terms of language, literacy, and disability (including vision impaired) and support access for all
- ✓ Collaborate with organisations that champion peer support.

UK experience

- 2010 – Beyond Viral Suppression
- 2011 – first consultation with people with HIV
- 2012 – pilot of Positive Voices HIV survey
- 2016 – National HIV Stigma Survey
- 2017 – Kings Fund report
- 2017 – first national Positive Voices survey
- 2018 – Included in BHIVA Standards of Care
- 2022 – WHO acknowledges HRQoL

STILL NO CONSENSUS ON WHAT TOOL TO USE!

TheKingsFund Ideas that change health care

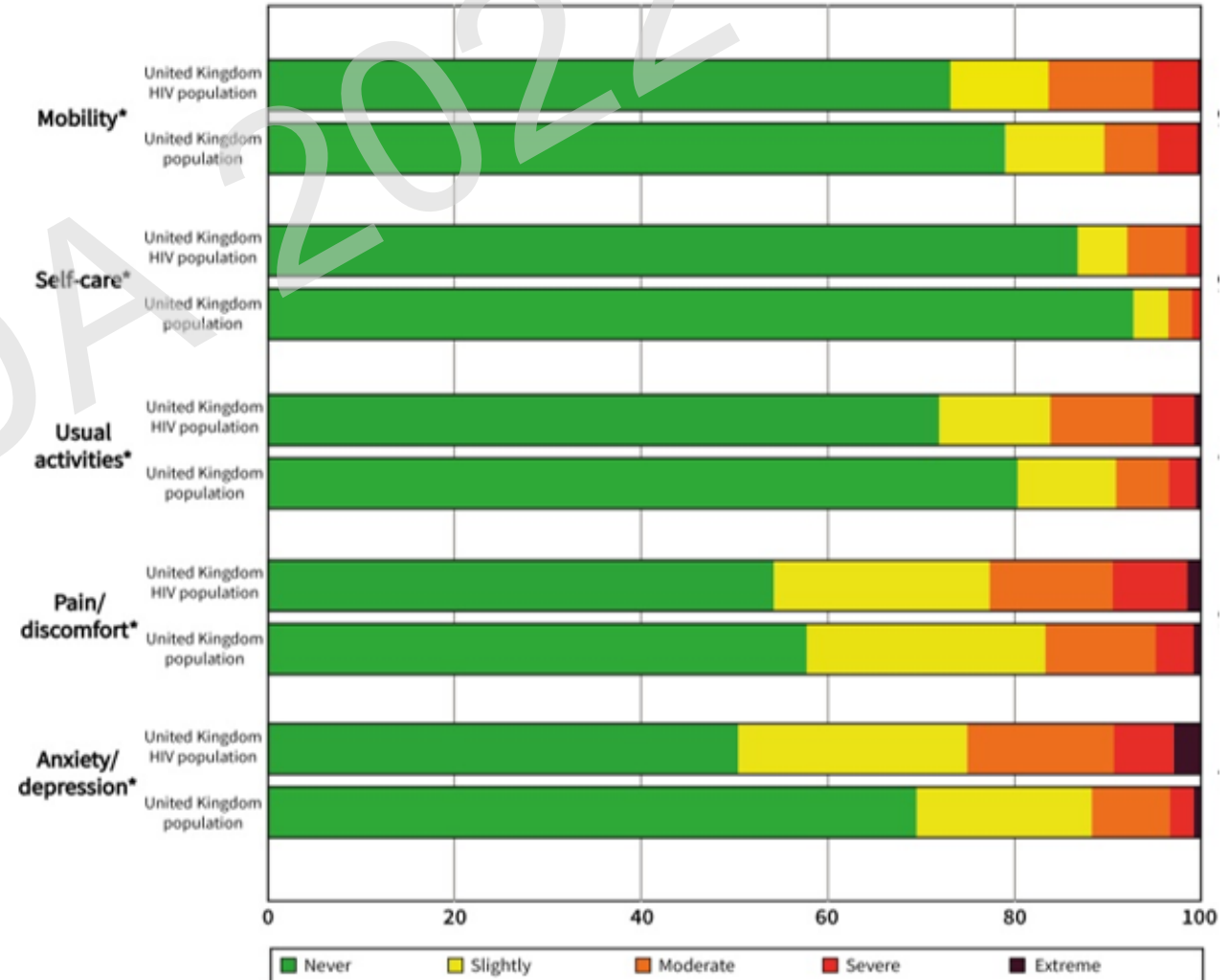
The future of HIV services in England

Shaping the response to changing needs

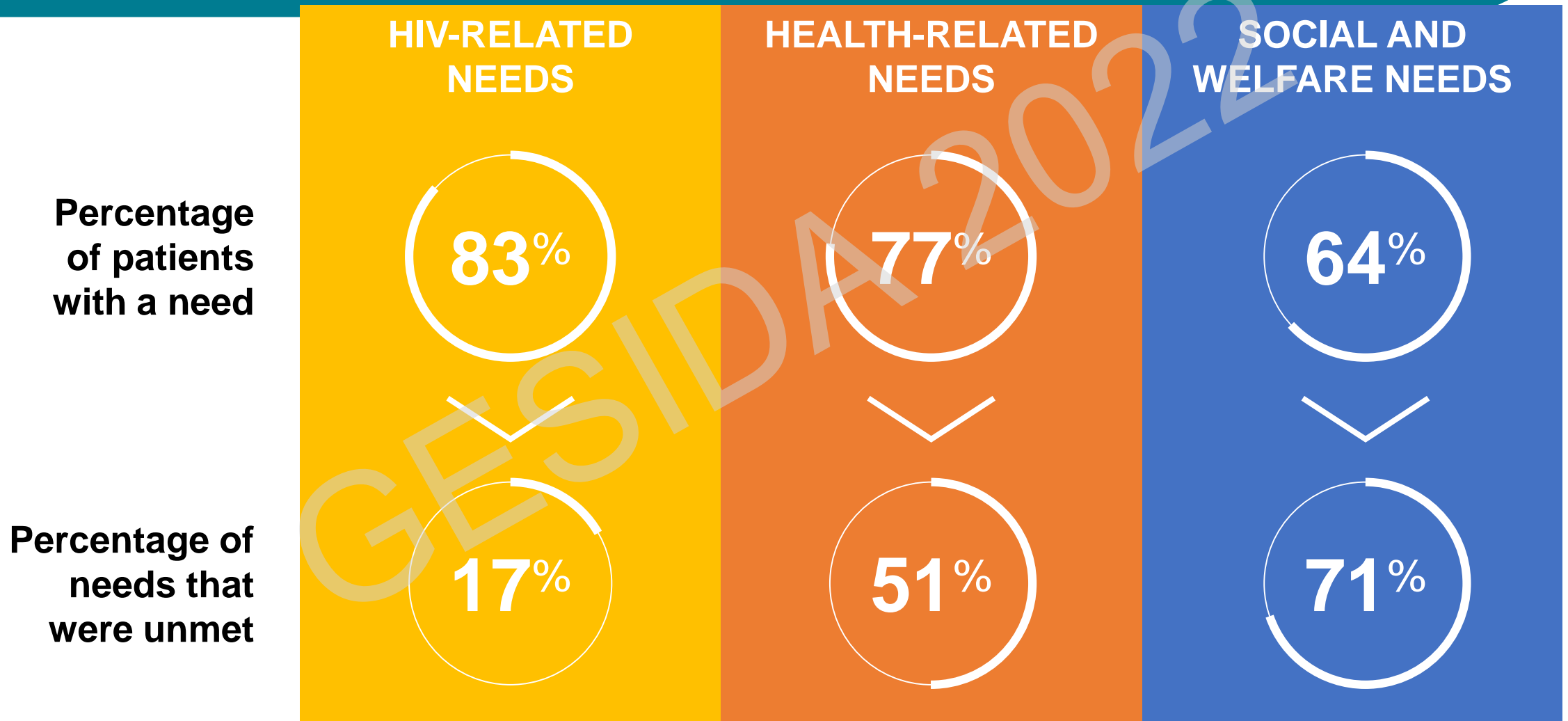


Research: HIV

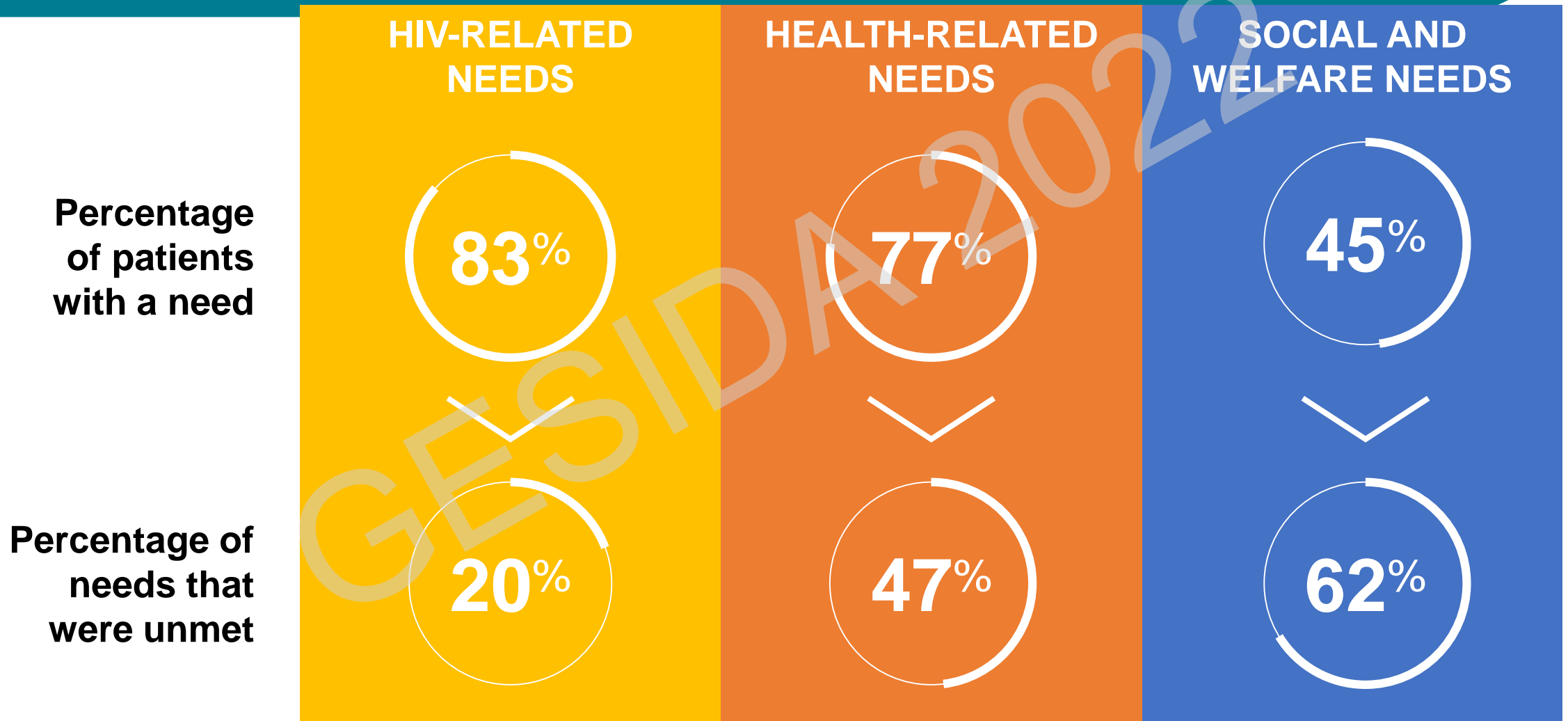
- Started with national surveillance datasets to conduct population-level descriptive and inferential stats
- Started “Positive Voices” survey to collect better data on:
 - Quality of life for people with HIV
 - Stigma and discrimination
 - Met and unmet needs
 - Healthcare usage
 - Lifestyle & risk behaviours



Met and Unmet Need: Positive voices 2017 (UK)



Met and Unmet Need: Positive voices 2017 (UK)



Conclusions

- Measuring patient-reported information like quality of life, stigma, co-morbidities, unmet needs critical in ensuring holistic needs of people with HIV are met
- General principles of “good practice” for measurement, depending on purpose, resources, question
- Involve people with HIV in each step of the process – they will tell you what matters to them!
- Keep talking about it – it takes time to win hearts and minds, and get PROMs on the national/international agenda
- Don't let perfect be the enemy of the good. Measuring something is better than measuring nothing...