



INTRODUCTION

- The life expectancy of people living with HIV is similar to those of the general population, when appropriate monitoring and effective antiretroviral treatment is provided.
- Health-related quality of life (HRQoL) may be influenced by personal, psychosocial, and behavioural factors as well as health conditions.
- Social support is a protective factor for HRQoL, wellbeing, and mental and physical health.
- Findings from the Positive Voices 2017 survey (PV2017) (age: 18 years+, mean: 48 years; gender: 69% men, 31% women, and 1% trans/gender diverse) demonstrated that people living with HIV had a lower HRQoL compared to the English population (Kelly et al., 2018; PHE, 2020).
- HRQoL scores (EQ-5D-5L utility scores) from Positive Voices 2022 (PV2022) were compared to those from PV2017 and the population of England (2018 data, so pre-COVID-19 pandemic) (HSE, 2018).



METHODS

- PV2022 ran between April 2022 and March 2023, and surveyed 4,540 participants (corresponded to approximately 5% of the country's HIV population) who provided enough demographic data (age: 18 years+; mean: 50 years; gender: 67% men, 31% women, and 2% trans/gender-diverse) to enable weighting to be applied. Proportions of the weighted data were then used to represent all people who were attending HIV care in England, Wales, and Scotland during 2022 (UKHSA, 2024).
- EQ-5D-5L* is a well-established standardised tool for measuring HRQoL, comprised of five domains (5D): mobility (walking), self-care (washing and dressing), usual activities (work, study, homework, family, leisure), pain/discomfort, and anxiety/depression. The five levels (5L) of response were: no problems; or slight; moderate; severe; or extreme problems.
- PV2022 responses were converted into 'utility scores' (range: 0 to 1, 0=as bad as being dead; 1=full health) using a value-set (Van Hout et al, 2012). The utility scores were compared to those from PV2017 and the general English population in 2018 (age: 16 years+; mean: 41 years; gender: 67% men, 31% women, trans/gender-diverse unknown).

RESULTS

- In PV2022, the proportion of people with HIV reporting problems was higher than those in the general population in four domains, and similar for pain and discomfort (Fig. 1).
- The proportion who reported feeling depressed or anxious was particularly high in PV2022 (51% vs 33% in the English population of 2018; $p < 0.0001$). Also the proportion of those feeling severely/extremely anxious or depressed was 9% vs 3% for England in 2018 ($p < 0.0001$).
- Between 2017 and 2022, there was very little change in the proportion of problems experienced by people with HIV, except a slight increase in those feeling pain and discomfort, which rose from 46.1% to 48.8% ($p = 0.033$).

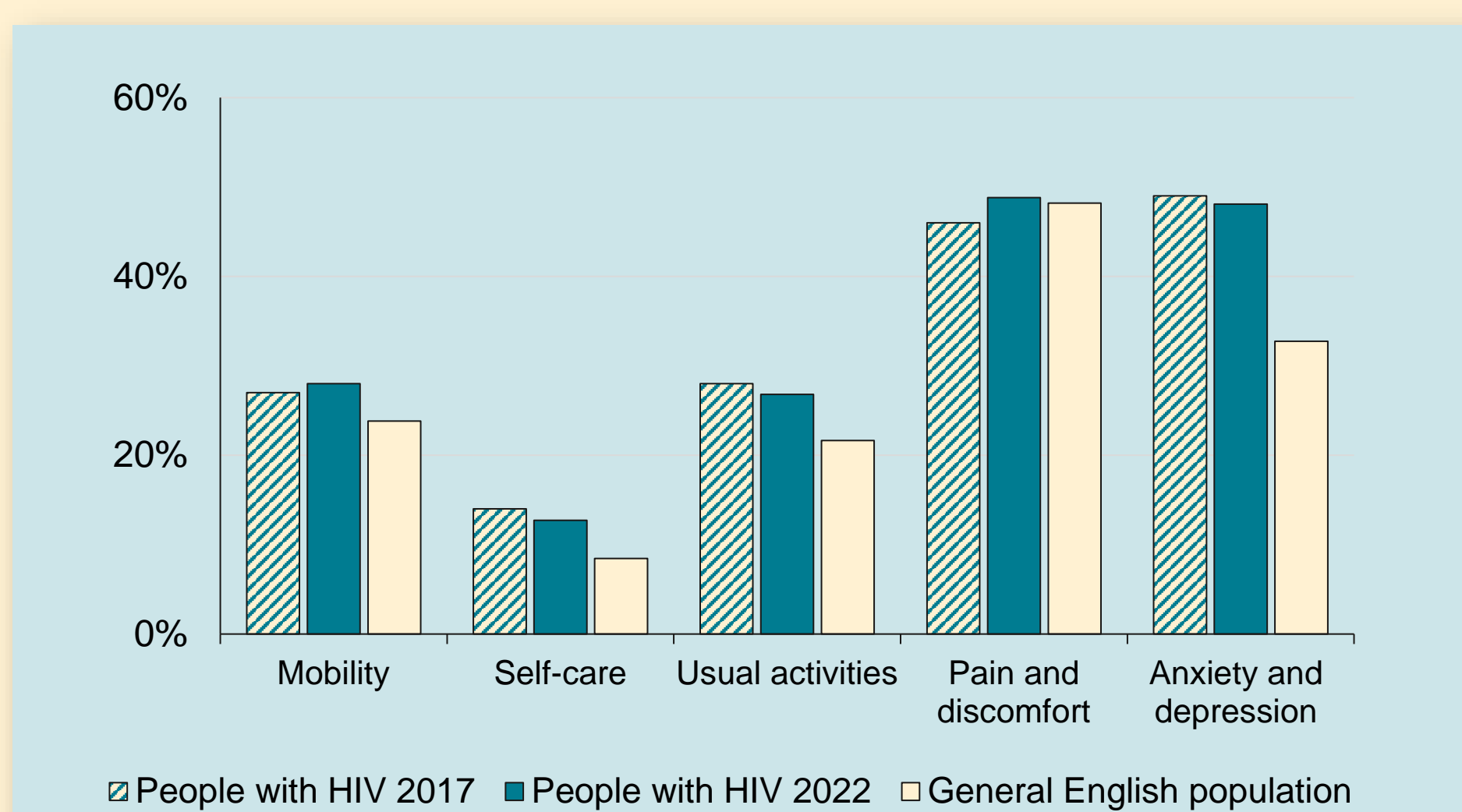


Figure 1 Percentage of people with HIV who reported having had problems in each of the five EQ-5D-5L domains in PV2022 and PV2017 compared to the general English population of 2018

- The overall, mean, weighted utility score of 0.77 in both PV2022 and PV2017 was lower than the score of 0.82 in the general population (Fig. 2).
- In both PV2022 and PV2017, black African people living with HIV had higher HRQoL than those from other ethnicities (0.81).

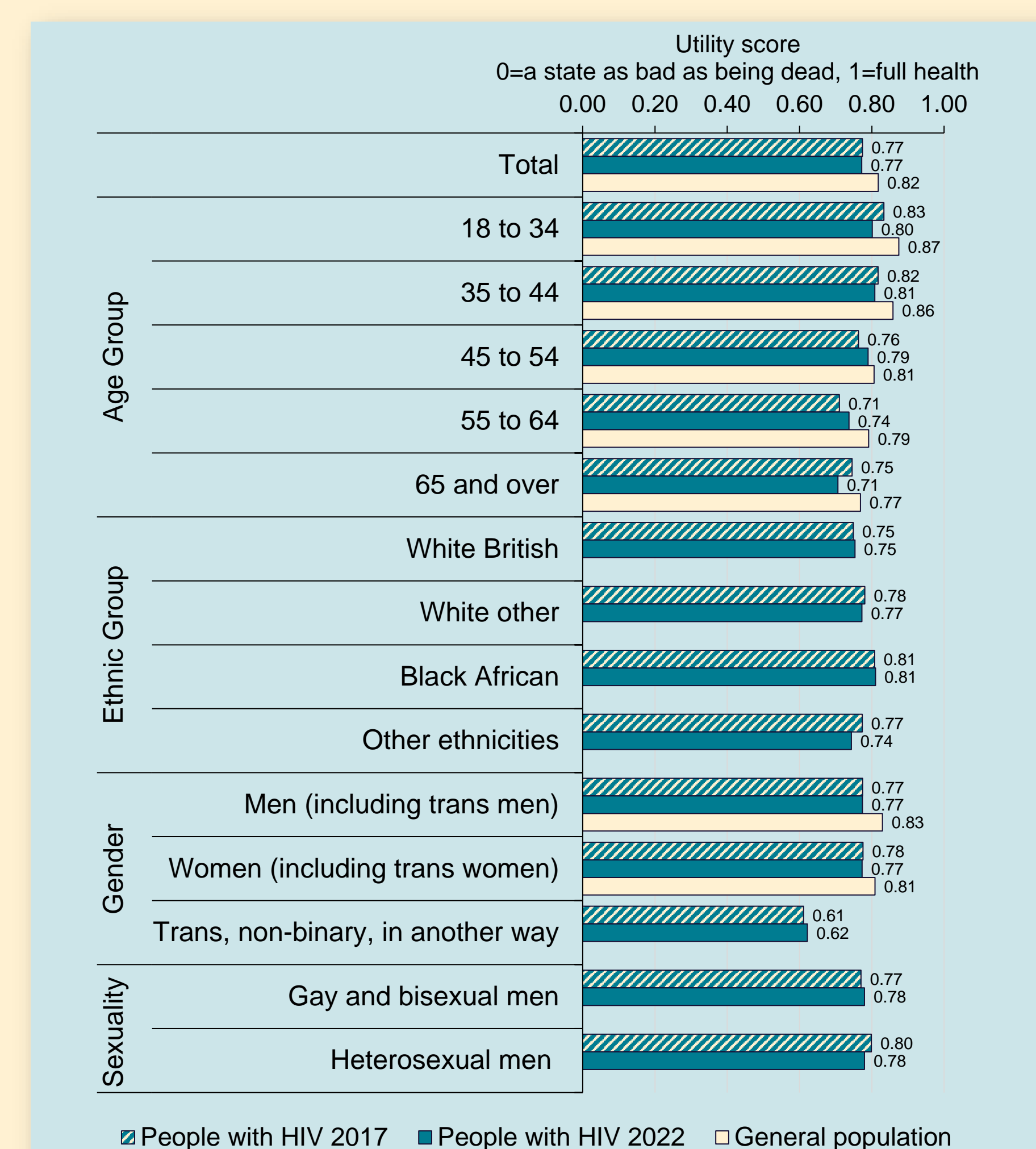


Figure 2 Mean HRQoL utility scores for people living with HIV, by age group, gender, ethnic group, and sexuality in PV2022 and PV2017, compared to the general English population of 2018

- The lowest score was observed in people with HIV claiming disability benefit (Fig. 3).
- Low scores were also seen in those who experienced other challenging issues, such as financial problems, medication issues, depression, or poor self-esteem.

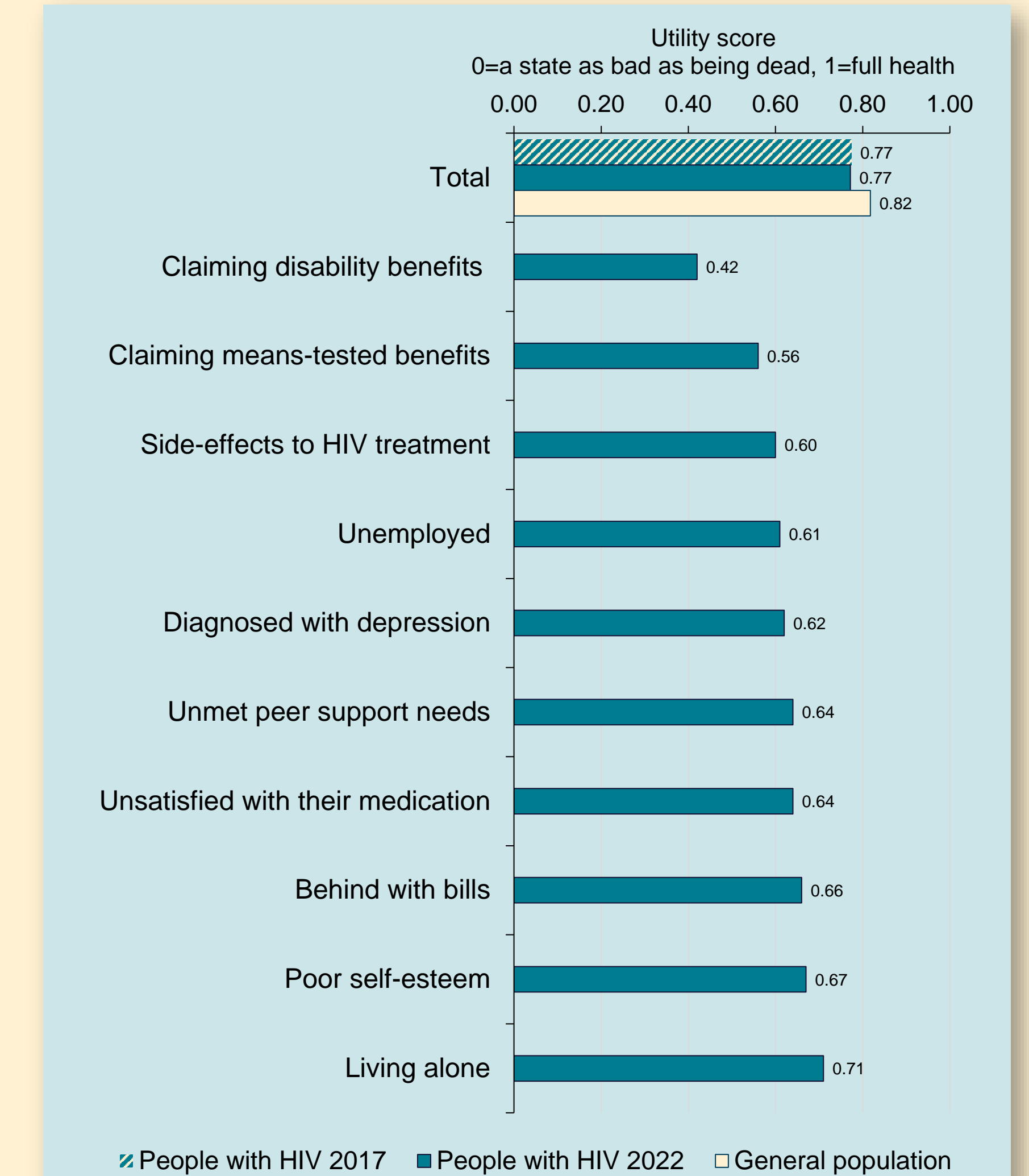


Figure 3 Mean HRQoL utility scores for people living with HIV that had other challenging issues, such as financial problems, medication issues, depression, or poor self-esteem

CONCLUSIONS

- PV2022 showed that, despite near-normal life expectancy and excellent HIV treatment outcomes, HRQoL utility scores were lower in people with HIV compared to the general population, although EQ-5D-5L only measures five HRQoL domains of HRQoL. Further age- and gender-standardised analyses will be undertaken to explore the impact of the differing demographic profiles seen in PV2022, PV2017, and the general English population in 2018.
- Over half of the PV2022 participants felt depressed or anxious, so the provision of good mental health services should be an important consideration for ensuring good HRQoL for this population (Miners, et al., 2014; Popping, et al., 2021). Utility scores for those claiming disability and means-tested benefits were also low.
- Health inequalities remain, so a holistic approach to health and social care should be adopted to improve HRQoL for those with HIV.

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* EQ-5D™ is a trademark of the EuroQoL Research Foundation, UK (English) v2.1

REFERENCES

- Kelly, C., Kall, M., Auzenbergs, M., and Delpech, V. (2018). *Health-related quality of life of adults living with HIV in England and Wales: a utility analysis of EQ-5D-5L compared to the general population*. In: Fourth Joint BHIVA & BASHH Conference.
- Public Health England (2017). *Positive Voices: The national survey of people living with HIV*.
- NHS Digital (2018). *Health Survey for England 2018: Adult health-related behaviours and risks*.
- UKHSA (2024). *HIV: annual data tables*.
- Van Hout, B., Janssen, M. F., Feng, Y. S., Kohlmann, T., Busschbach, J., Golicki, D., Lloyd, A., Scalone, L., Kind, P. and Pickard, A. S. (2012). Interim scoring for the EQ-5D-5L: mapping the EQ-5D-5L to EQ-5D-3L value sets. *Value in Health*, 15 (5), 708-715.
- Miners, A., Phillips, A., Kreif, N., Rodger, A., Speakman, A., Fisher, M., Anderson, J., Collins, S., Hart, G., Sherr, L. and Lampe, F. C. (2014). Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population. *Lancet HIV* 2014; 1: e32-40.
- Popping, S., Kall, M., Nichols, B. E., Stempfer, E., Versteegh, L., van de Vijver, D. A., van Sighem, A., Versteegh, M., Boucher, C., Delpech, V. and Verbon, A. (2021). Quality of life among people living with HIV in England and the Netherlands: a population-based study. *Lancet Regional Health—Europe*, 8.