

## HIV Outcomes – Roundtable Meeting

### HIV and Health Related Quality of Life in the UK

16 June 2021

The meeting was chaired by Professor Jane Anderson, Chair of HIV Outcomes.

### Session 1 – The Patient Perspective

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#### This session was led by Silvia Petretti, Chief Executive Positively UK

- People living with HIV are a very diverse group; they are young, old, and from across the gender spectrum. No single issue, because we don't have single issue lives. Stigma is a problem, and it fuels a number of other problems such as mental health difficulties, loneliness, being disconnected from loved ones and friends. And all of this is on top of the multiple other discriminations often faced by people who are living with HIV.
- Positively UK believe health-related quality of life (HRQL) can be achieved by focusing on three aspects;
  - Clinical – We meet people where they are, and we focus on increasing their knowledge
  - Connection – We strengthen connections and enable access to networks, which can bring vital improvements to empower people to live well
  - Confidence – We must create space for confidence, and recognise the intrinsic value of people just as they are, to help them not to be defined by their HIV

#### Amanda Ely - Chief Executive, CHIVA

- HIV can be a part of people's lives if they have grown up with it – but that impact evolves as the person grows and changes, and goes through the different stages of growing-up. For example, the social context around schools and friendships, how schools are involved, and how stigma can impact as a child gets more grown up are all major factors. Intersectionality is critical – we cannot separate a child's HIV out from the other difficult experiences that they will come across, and that every child will go through (albeit to different extents). And for some of the children living with HIV, these can be more extreme.
- Young people describe very powerfully the relationship they have with their HIV, and how they grow with it and navigate that relationship. So the challenge is how can we make that a positive relationship, how can we empower them and help them deal with and manage. We want to enable young people to be their own advocates, and to be confident and informed patients who are able to access the services that they need.

#### Mike Podmore – STOPAIDS

- Quality of life (QoL) and HIV can be health related, but it can also be wider, for example in HIV it could be the psycho-social elements, and also there are a lot of non-HIV specific factors, socio-economic concerns, or difficulties around education, migrations status etc.
- In the global policy space – there continues to be important processes with global institutions that we are trying to advance, for example the UNAIDS strategy – the inclusion of the 10,10,10 targets was a big step - but also trying to get a reference to QoL.
- Despite the recent UN high-level meeting and political declaration, there are lots of challenges remaining, but there were important steps forward also and we need to build on that and ensure adequate funding is provided

#### INITIATIVE PARTNERS



#### OBSERVER MEMBERS

- European AIDS Clinical Society (EACS)
- European Centre for Disease Prevention and Control (ECDC)
- Fast Track Cities
- UNAIDS
- UNITE

## Questions and discussion

- Following COVID, there is a growing recognition of community work demonstrating the impact of interventions and how effective they can be.
- More talk of co-production, and looking at health inequalities and lived experience etc, but not clear who is going to be picking up the bill.
- ICS' are so new, it is the perfect time to be taking issues like this to them. QoL is such an individualised issue, is this the way that we can demand person centred care at the heart of everything? Although it will mean different things to different people.
- Social work model, person centred, individual assessments, that people requiring social care are entitled to. It is a model that is sufficiently flexible to be individualised, but also able to be used to measure, and consider socio-economic impacts on people.

## Session 2 – Knowledge, Research, Data and Metrics

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### **This session was led by Valerie Delpach - Head of National HIV surveillance and Monitoring at Public Health England**

- This is a vast issue, and there isn't one single measure that we can use. Talk of the 'fourth 90' can make it seem like we need just one measure, and there is multitude of issues and measures that together make-up HRQoL; and of course, these vary for each individual.
- It would be great to have a map of what we know currently; what studies are going on and where gaps might still exist - would be very keen to be involved in such a piece of work. But we also need to examine that, when we are capturing data, we are clear what purpose it is for. While a single measure of HRQoL might be worthwhile, it could not capture everything.

### **Adamma Aghaizu – National Infection Service, Public Health England**

- What is QoL, and how do we measure it? It is subjective and needs to be assessed from an individual perspective. It includes social, community and spiritual aspects, as well as physical and mental health. And there are a lot of other individual factors, such as age, beliefs, etc and then a whole set of community level factors – relationships, finances, social etc. And lastly, there are wider environmental aspects, such as the economy, employment, the level of community, etc
- There is no consensus definition of what is 'good' HRQoL, but there are a wide range of tools that are used, both generic and specific to HIV. The generic ones are useful for comparing with wider population.
- Positive Voices survey is the largest of its kind, it is nationally representative, and it's about measuring HRQoL. It includes 100 data items, and it asks questions around diagnosis, mental health, reproductive health, met and unmet needs on housing, careers, childcare, general wellbeing, lifestyle and a range of other issues.
- Its key findings are life satisfaction for people with HIV was worse than general population, with mental health issues being particularly prevalent, including anxiety and depression. Comorbidities are prevalent, and around 1 in 6 people with HIV are worried about being treated differently, and 1 in 10 didn't seek health support when they required it (for several reasons).

### **Amanda Williams – Consultant Paediatrician and Chair of Trustees, CHIVA**

- Children growing up with HIV can have worse outcomes and increased comorbidities, increased mortality and less viral suppression. Most children with a long-term condition will see worse outcomes in adolescence, so this is not exclusive to HIV, although HIV presents additional layers of difficulty and challenges.

- In the UK, there is the national surveillance collaborative paediatric HIV study finished in 2021. This was a national survey that looked at pregnant women and babies/children allowing long term collection of data and linking it to adult data. Around 2,000 children and young people are included, 80% are over 15 years, many are black and/or born abroad. Outcomes have improved with increased and improved treatment, and of the cohort 62% have now transitioned to adult care.
- However, the outcomes after transition are not as good, with raised mortality (10 times greater than for young people without HIV, and there are also higher rates of mental health and cancer) and increases in new AIDS events. Poverty, migration issues and number of other socio-economic issue can also be big challenges. The complexity of the issues for young people in transition from child to adult care is huge, and if we don't do it properly, we will fail to understand the outcomes and needs of the small population of people who were born with HIV, as distinct for the much larger adult population with HIV.

### **Questions and discussion**

- There are opportunities to work within the changing commissioning landscape in England, for example there is the clinical dashboard in HIV, and adding agreed QoL measures to such a dashboard would be welcome. The whole dashboard of clinical indicators is under review at the moment.
- The Positive Voices survey from PHE is quantitative, but PHE have also worked on a project with Positive Voices to look at data from the perspective of people living with HIV, which was very valuable. There was an interest among attendees as to where more information can be found on Positive Voices.

## **Session 3 – Next Steps Towards Greater Health-Related Quality of Life**

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**This session was led by Angelina Namiba, Co-Founder and Director of the 4M Network**

### **Deborah Gold - Chief Executive, National AIDS Trust**

- From the discussion so far, there seems to be some consensus on what needs to happen, so what comes next? HRQoL as the '4<sup>th</sup> 90' but it relates to the whole continuum, and is relevant to everyone at all stages of the HIV spectrum. Wellbeing obviously covers a huge gamut of factors than can impact upon someone's life; stigma, discrimination etc all play into the wider issue. Understand that it is too broad to measure, but as a community, we need to reach a consensus because if we want to progress, we need to be able to measure it in order to improve it.
- Lots of frameworks of measurement do exist, how much are they used and what level of consensus is there on where to focus? We need a simple, individualised measure, led by people with HIV.

### **Richard Angell – Campaigns Director, Terrence Higgins Trust (THT)**

- THT are working as part of HIV Action Plan, hoping to encourage a more holistic view. This is a unique opportunity.
- As HIV epidemic evolves and the focus widens, people need to see themselves as part of HIV work, and that is how to break through the stigma.
- Linking with mental health is important, and to make the point of elevating the support in this area. There is not enough psychological support as part of MDTs.
- There are important areas that will not be covered by the HIV Action Plan (HIV criminalisation, needle exchanges, ban on serving in the army etc.) as they are not covered by DHSC.

## **Professor Caroline Sabin - Professor of Medical Statistics and Epidemiology, University College London**

- We know a fair amount about HRQoL; we know the predictors of HRQoL, such as socio-economic factors, gender, etc all coalesce in people with HIV. As do many of the clinical factors which play a role. However, there are also many gaps in knowledge, around for example the factors we can't influence (age, gender, ethnicity) and if/how they correlate with the factors that we can influence?
- With all of these factors, it is difficult to know if they would exist independent of HIV? Is the impact of ageing on HRQoL worse if a person has HIV? When questions like these are raised, would it be more accurate if we compared people with HIV to other people living with a similar chronic condition? It is worth noting that this is not easy to do; associations are not necessarily causal, and we can't always know if changing specific factors will improve HRQoL. Such trials are difficult to get going, as it is not easy to convince funders of the value of such work.
- We need better co-production between the clinical and social science disciplines, and we need more longitudinal studies. Positive Voices is a great tool but is it practical for routine use? QoL is highly subjective, and difficult to detect small (but important) changes, the causes of which are important in identifying the correct interventions. It is easier to argue for something that can be measured, and HRQoL cannot be measured so easily; in a financially stressed system, this is a big problem to overcome.

### **Questions and discussion**

- In terms of the policy opportunities that need to be explored to have an impact, we need to have a clear ask of what we want to change, then identify what needs to change to make it happen. The Action Plan, ICSs, and the Clinical Dashboard Review all present great opportunities. Also, the forthcoming Health Bill could be an opportunity to try and get the law changed to make HIV testing automatically opt-out.
- There are also political and organisational challenges across the UK, and relationships are often strained. But there is competition between the separate systems, playing Wales, Scotland and England against one another has been fruitful.
- With regards research work, the next milestone we can realistically aim for could be to get to a HRQoL that is as good as someone who doesn't have HIV but is in similar socio-economic circumstances i.e. zero negative impact on a person's life as a result of HIV.

## **Discussion on Potential Next Steps**

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- QoL is a spectrum of measurements, what does it look like, how can we measure it? Public health has to be driven by what is available, and what is possible and practical, and so we must look to improve existing measures and tools, for example the DHSC Clinical Dashboard. The DHSC is also committed to publishing (and in the process of working on) a national sexual health strategy this year (as well as the HIV Action Plan) and HIV will be a priority within that too. It is vital that we use this opportunity to influence these strategies while they are open – the opportunity is unlikely to arise again for some years, so we need to create a consensus to feed in.

Potential next steps included:

- undertake a stocktake on HRQoL work in the UK, including a stakeholder map
- develop an evaluation framework which could support the assessment of third sector organisation contributions
- develop consensus on what HRQoL means (and how it can be measured) and how the HRQoL agenda can be taken forward, using the current policy opportunities
- develop an action plan for the mainstreaming of HRQoL in UK HIV policy and practice

## Attendees

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Adamma Aghaizu	Public Health England
Alan Winston	Imperial College London
Amanda Ely	CHIVA
Dr Amanda Williams	CHIVA
Andrew Murungi	Viiv Healthcare
Angelina Namiba	4M network
Prof Caroline Sabin	University College London, NIHR Health Protection Research Unit
Cheryl Gowar	National AIDS Trust (NAT)
Claire Albano	Gilead Sciences
Deborah Gold	National AIDS Trust (NAT)
Duncan Short	Viiv Healthcare
Dr Jaime Vera Rojas	Brighton and Sussex University Hospital
Jane Anderson	Chair, HIV Outcomes
Dr Jenny Whetham	Brighton and Sussex University Hospital
Katie Neate	Public Health England
Dr Laura Waters	BHIVA / University College London Hospitals
Leena Sathia	Gilead Sciences
Lorraine Sherr	St Mary's Hospital, London
Luis Guerra	Gilead Sciences
Maureen Ndawana	One Voice Network
Mike Podmore	STOPAIDS
Muktai Panchal	Dept Health & Social Care
Rhon Reynolds	Viiv Healthcare
Richard Angell	Terrence Higgins Trust
Shaun Watson	National HIV Nurses Association (NHIVNA)
Silvia Petretti	Positively UK
Sylvia Nicholson	Viiv Healthcare
Sydney Joyce	Dept Health & Social Care
Valerie Delpech	Public Health England
Dr Yvonne Gilleece	BHIVA / Brighton & Sussex University Hospitals NHS Trust / Chair, SWIFT and Vice Chair, WAVE