

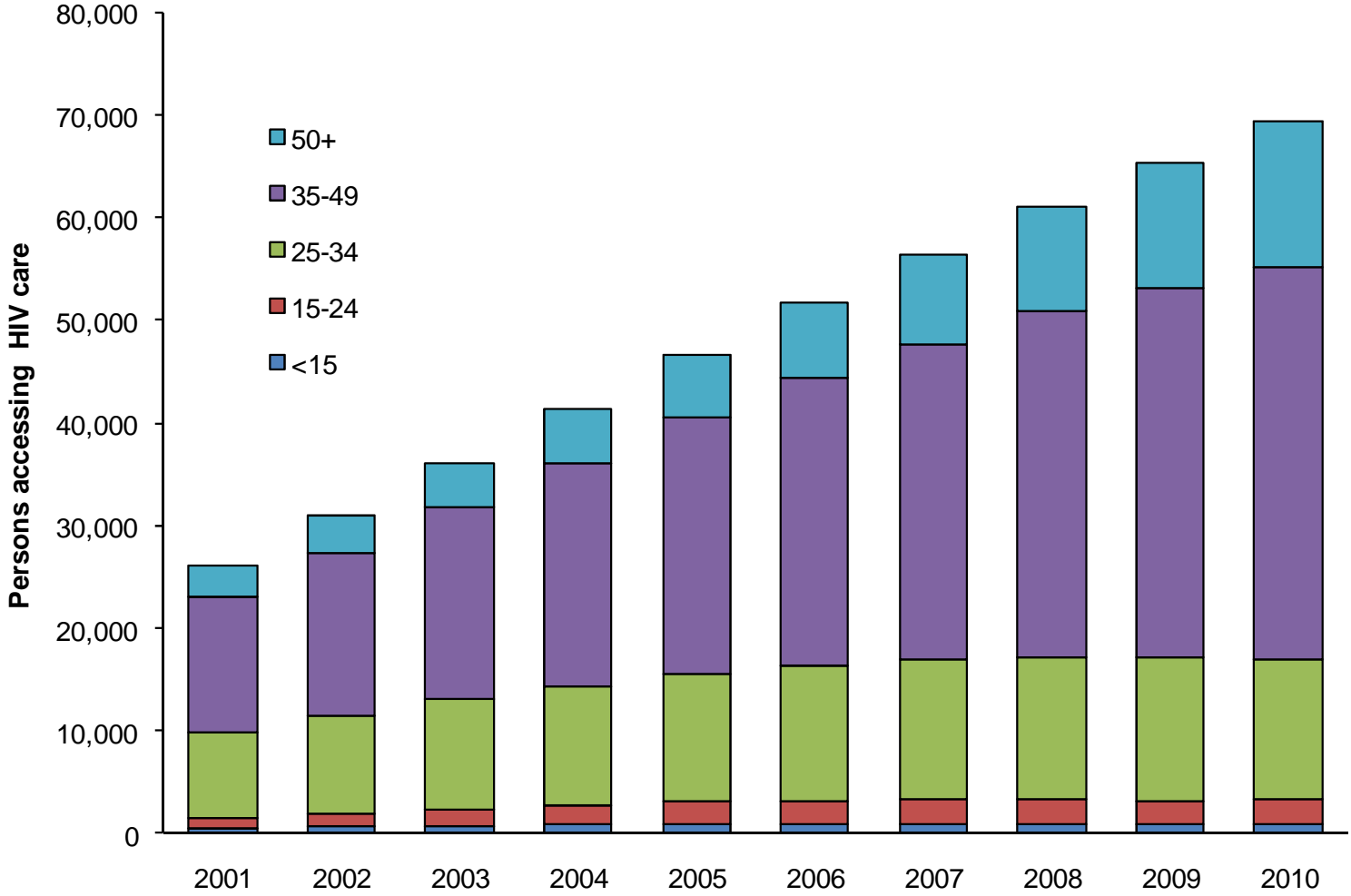


50 Plus – the THT/Age UK research

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HIV diagnosed persons seen for HIV care by age group*, UK



*Excludes persons with age not reported, 3 in 2001 and 0 in 2010.



Context



- People with HIV over 50 fastest growing group of people with HIV
- Better treatment means newly diagnosed life expectancy rising into 70s
- Frailty and diseases of ageing occurring earlier and more often in people with HIV
- Complex treatments and side effects now interacting with diseases of ageing to create major uncertainties for treatment and care
- Social care cuts will impact hard on people with HIV

50 Plus – the research

- 50Plus research funded by Joseph Rowntree Foundation, done in conjunction with MBARC
- Surveyed 410 people with HIV over 50 (one in 25) and 40 in depth interviews
- Mix of long term survivors and newly diagnosed
- Oldest respondent aged 78 (some UK PWHIV in 80s)
- Qualitative and quantitative surveys plus literature and research review
- Investigative trip to US, who are ahead of us on this

Comparisons with US

- Similar disease progression and complexities
- Lack of communication and collaboration between clinicians in differing specialities
- Lack of understanding of older LGBT people in particular
- Fears of stigma in mainstream older people's services
- Strong need for closer working between older people's support organisations and those for HIV



Research process

- Collaboration with expert panel including older people with HIV
- Paper & online questionnaire devised with panel, based on THT & US experience
- Piloted with older people with HIV
- Demographics of responses checked part way through and extra outreach done to Africans
- Closed & open questions
- 40 in depth interviews, weighted towards African respondents

Research areas

- Demographics
- Living conditions
- Money
- Health (mental & physical)
- Lifestyle
- Relationships & disclosure
- Experiences of stigma & discrimination
- Service preferences
- Future fears

50 Plus Results

Top-rated concerns for the future

- Financial Difficulties (79%)
- Difficulties with self-care (76.3%)
- Mental Health Issues or Depression (72.9%)
- Inability To Access Proper Healthcare (69.5%)
- Social Stigma & Discrimination (66.3%)

Financial Difficulties

Less financial security, less housing security, more reliance on state benefits

“Somehow the category ‘financial difficulty’ doesn’t begin to address the unending stress of permanent financial anxiety”

“Lack of funds for my old age - since I was diagnosed in 1985 I regarded this as a death warrant and ceased to make any pension provisions”

Difficulties with self-care

Half have mobility and self care problems that are likely to worsen

*“My main concern is for how long I can continue with my medication....
As I get older will the problems get worse?”*

*“I am getting medical conditions that I thought would come much later
in life. I wonder what is going to ‘go broke’ next.”*



Inability To Access Proper Healthcare

Twice the level of other long term conditions as peers; high levels of need for GPs but many experiences of poor treatment in primary care

“Whenever I have a problem not directly related to my CD4 or VL... my GP and other specialists generally ignore my concerns and refer me back to the HIV clinic as they tend to see all problems in the context of my HIV. I end up being piggy in the middle”

Mental Health & Depression



Long term uncertain prognosis; high levels of isolation and stigma; loss of peers

“I am particularly concerned about mental impairment, and early onset of dementia”

“HIV has severe emotional links, causing me sleeplessness, worry and the feeling of utter destruction”

Social Stigma & Discrimination

One in five experienced discrimination due to HIV or age in last year;
many had fears about future care, especially gay men, and
reluctance to engage with organisations for older people

“I also fear that in case I need to be cared for, the carer would be as ill-informed and prejudiced about HIV as the rest of the general public”

“Would residential homes or places for the long term sick have the expertise to be able to look after an older person with HIV”

Other key issues

- High levels of positive outcomes of disclosure of status (versus)
- Ongoing discrimination experiences
- Preference for HIV specialist services over others
- Despair about money
- General perception of good health

What people wanted

- Information about HIV & health issues for older people
- Social care (and decreased stigma within it)
- Social support & networking
- Counselling/emotional support

Some of the unknowns

- Differences between long term and recently diagnosed (analysis to be done from existing research)
- Disconnect between high level of financial worries and apparent belief little can be done to change situation
- Practical implications for social care in era of austerity
- Issues for older African men
- Positive ways to impact social isolation
- Mental health – needed further investigation
- Involvement mechanisms for older people with HIV; ways of evolving activism and self-help

How do we further this agenda?

- Collaborative work between Ageing & HIV support organisations to improve social care and reduce stigma
- Engagement with clinical and primary care services to ensure health needs are met and referral pathways clear
- Focus on self-management strategies and what PWHIV can do to help themselves (exercise, nutrition, accessing support to improve physical & mental health outcomes)

Help and information for people who have HIV and are 50 or over



50+ & HIV+

Written for people with HIV, by people with HIV



Further Information

- 50Plus Project – full report at www.tht.org.uk/50plus
- ROAH Project (US) – www.acria.org/center/introduction
- Email for further info – lisa.power@tht.org.uk

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