HIV and Ageing: Responding to an Emerging Public Health and Social Challenge

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HIV and ageing in the UK

- One in five (21%) of all new HIV diagnoses are aged 50 and over ¹
- Late diagnosis in 50+ remains high ¹
- The UK cohort of people living with HIV is ageing
  - 40% of people living with HIV are aged 50+ ¹
  - Predicted to rise to 54% by 2028 ²
- Diverse group with different needs and experiences ³

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¹ PHE (2019). National HIV surveillance data tables
² Yin et al (2015). Over half of people in HIV care in the United Kingdom by 2028 will be aged 50 years or above
³ THT (2017). Uncharted Territory. A report into the first generation growing older with HIV
Health

- Have more long term health conditions than general population
  - Those diagnosed pre 1996 have more additional conditions
- Concern over how they will manage multiple health conditions
- Worried about the uncertainty of the impact of living with HIV long term
- Worried about the impact of taking medication long term
- Have experienced mental health issues

‘I also fear what illnesses lie ahead… you’re getting older and there’s no way round that... but wondering how HIV plays out.’ (Male, 58, white British, gay, diagnosed in 1988)
Health and social care

- Coordinating health care has become more difficult
  - Communication between health professionals often problematic
- Concern that GPs are not always knowledgeable about HIV
- Fear of discrimination from social care workers
- Concern about being able to access adequate social care in future
- Most have no provision to pay for future social care

‘The big worry for the future is this social care thing. What is needed?... Do I as someone living with HIV need something different? I don’t have any kids of my own.. I don’t have that [safety net]’

(Male, 59, white British, gay, diagnosed in 1982)
Employment

- 45% of 50-64 economically active (72% general population)
- 36% of the respondents solely reliant on welfare benefits
  - Further 5% relied on benefits as major part of their income.
  - More likely to be diagnosed pre 1996
- Individuals who were receiving benefits had
  - Lowest levels of wellbeing
  - Highest levels of HIV self-stigma

‘There is a definite attitude that if your life is dependent on Government money, then your life is less valued than those people who are working …and I get very resentful about that.’

(Male, 58, white British, gay, diagnosed in 1988)
Poverty

Over half of over 50s are living in poverty

- Double that of general population
- Increased from 48% in 2010
- But over 65s more likely to rate themselves as having enough money

‘Finances ...well I don’t have any, well nowhere near what I need to be healthy, to be secure… for the medication to work properly, you need to eat well - but eating well, eating enough, costs money, money I don’t have.’

(Male, 52, white British, gay, diagnosed in 2001)
Loneliness and Social Isolation

High levels of loneliness and social isolation experienced

- 3x more likely to experience high levels of loneliness than the general population
- A third were socially isolated
- Social isolation increases with decreasing income

Loneliness poses a risk to health and wellbeing

‘I worry about the future – about being alone. A place to go and socialise is important, but with all the cuts I don’t think there will be many groups to go to, there just isn’t the money’

(Male, 59, white British gay, diagnosed in 1982)

Women

- Lowest reported ratings of wellbeing
  - 28% rated wellbeing as ‘very good’ or ‘good’
- On lower incomes than men (on average)
- More concerned about all aspects of growing older with HIV
- Wanted information and support, particularly regarding the menopause

‘I just worry about providing for my children, that I can’t earn enough money, that I will get too sick to work. I worry about my health and money a lot.’
(Female, 52, black African, heterosexual, diagnosed in 2016)
Final Thoughts

- Increasing numbers of people living with HIV aged 50 and over
- Living with multiple conditions may bring complexity around coordination of care
- A well equipped and informed primary health and social care sector, supported by third sector organisations, will be vital.
- Many are living on limited means and have no provision for the future
- Stigma and discrimination still problematic, leading to loneliness and mental health issues
- Must ensure that this first generation are not forgotten and that their voices are heard