



**HIV and
Later Life**



UNIVERSITY OF
LEADING
THE WAY
WESTMINSTER



HIV, Later Life & 'end of life' (EOL) care

European AIDS Treatment Group, *Ageing with
HIV Conference*

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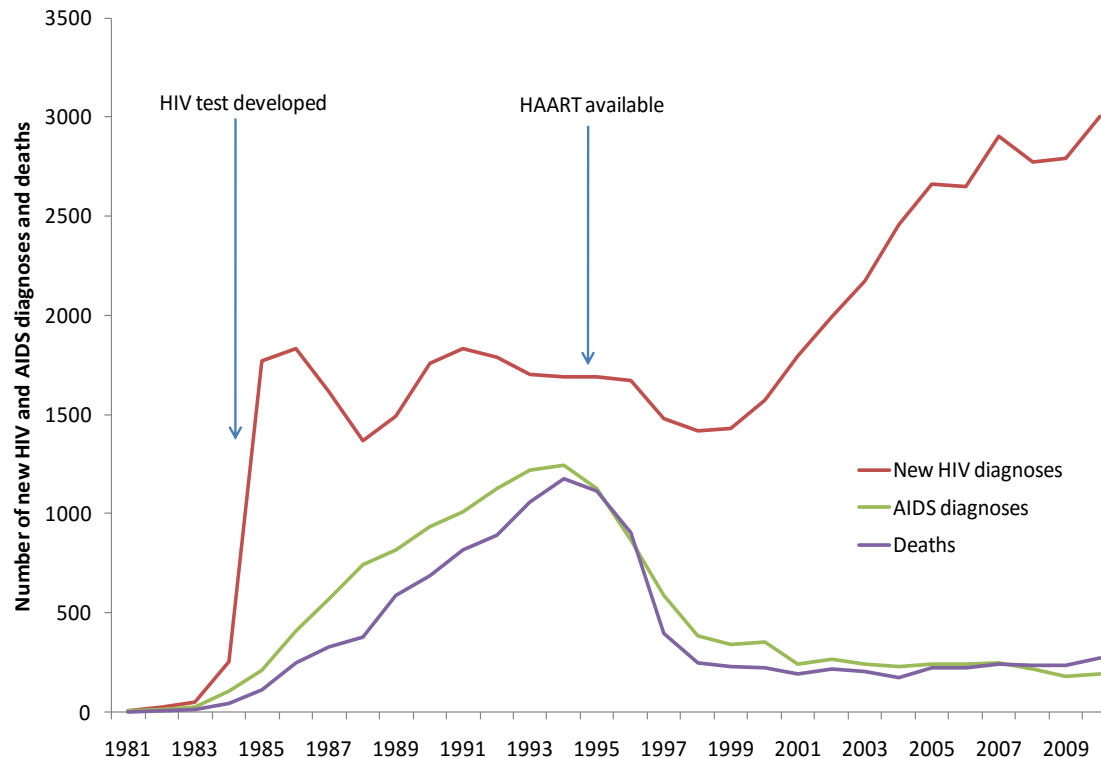


SOME NUMBERS

- ◆ PLWH who present late for Dx have a 10 X risk of death
- ◆ 530 PLWH reported to have died in 2013, mostly late Dx
- ◆ People aged 50+ are the **fastest-growing group** with HIV in the UK
 - ◆ Longer life for people with HIV due to HAART
 - ◆ Increasing HIV acquisition in later life
- ◆ **Of 81,510 adults in HIV care in 2013, 27%** were aged >50yrs
- ◆ The number of people living with diagnosed HIV infection aged 50+ in the UK has increased **six fold** between 2002–2011
- ◆ Number of people living with HIV aged 65+ ‘has grown **tenfold**’ in a decade (Gebo & Justice, 2009: 246)

SOME NUMBERS

New HIV and AIDS diagnoses and deaths among MSM: United Kingdom, 1981-2010



WHAT WAS 'HIV AND LATER LIFE (HALL)'?

- ◆ A 2-year, multidisciplinary study, quantitative and qualitative methods
- ◆ Exploring experiences, **social support, mental health & quality of life** of people > 50yrs living with HIV in the UK
- ◆ Long-term and recently diagnosed
- ◆ Recruited through 3 clinics, and HIV service organisations, in London
- ◆ Life-history interviews + mental health/QoL survey (76) – 12 BA men/18 BA women; 9 White men/9 White women; 53 MSM



AGEING + HIV: DISTINCTIVE CONCERNS

- ◆ HIV Stigma, esp. of older PLWH
- ◆ Uncertainty (e.g. bio: normal ageing/HIV/meds interact)
- ◆ Difficulties forming relationships
- ◆ Isolation
- ◆ Support and understanding for older PLWH
- ◆ Concerns about independence/HIV stigma in long-term care
- ◆ Disclosure complexities/rejection fears
- ◆ Disruption of envisaged futures
- ◆ Finances in later life

THE GENERAL MENTAL HEALTH PICTURE

- ◆ Many thriving – 2 out of 3 had good/moderately good mental health
- ◆ 2/3 rated QoL ‘good/moderately good’, 1/5 rated QoL poor
- ◆ Shock of diagnosis and risk of death – important for EOL care
- ◆ Fear, rejection, abandonment and isolation
- ◆ Strain of disclosure, discovery, information control (including medications)
- ◆ Anxiety and depression main focus of narratives here
- ◆ Also much ‘suicide talk’ in narratives
- ◆ Different narratives between groups e.g. MSM LT and Recent Dx, WHF

THE GENERAL QUALITY OF LIFE PICTURE

Better MH and QoL associated with (Quant):

- ◆ Having a partner*
- ◆ Not receiving benefits*
- ◆ Being male
- ◆ Being in paid employment
- ◆ Higher level of income (> £10,000)
- ◆ Being MSM (to a lesser degree)
- ◆ Dx after age 40
- ◆ Attending support groups (helps psychological domain)



ANXIETY & DEPRESSION

*'The crises are coming faster, and they're lasting longer'.
[White Female Heterosexual, 60s]*

*'Everybody's got a whole raft of other anxieties, neuroses,
mental health issues, so I couldn't say that HIV was the
cause of me having a massive depression, but for me it
was one added factor'. [White MSM, 50s, Recent Dx]*

*'I couldn't live like this for another 10 years. The thought
of living in this mental state ... I would just go and find a
lamppost'. [White MSM, 50s, Recent Dx]*



STIGMA AND LIFE COURSE...

Stigma + ageism = new stigma re: ageing with HIV

‘I think with age the stigma gets worse because as an older person you are expected to set good morals. And to say you are HIV positive, people start thinking. “This lady, what was she up to?”’ [BA focus group]

‘And because of my age, I feel that people would look at me and think, God, look at you, how old you are, and you’re HIV positive, look at you, like, some disgusting piece of...’ [50s, WHF]



STIGMA AND LIFE COURSE...

- ◆ *'The big burden I carry is not a health burden, it's the stigma'* (WHM, 50s, LT Dx]
- ◆ Sense of invisibility
 - ◆ as older people living with HIV
 - ◆ as 'atypical cases'
- ◆ Recently Diagnosed MSM can be especially adaptive to HIV
- ◆ Sense among MSM LT Dx their stories are being erased
- ◆ Stigma especially severe for BA men and women



STIGMA AND LIFE COURSE...

'I felt ashamed. I just felt awful. I said to this lady doctor, 'Fancy an old man like me getting that at this age'. (MSM, 60s, recent Dx)

'If I didn't have HIV, I'd feel I'd still have optimism. I'd feel like I'd still got a reasonable amount to offer, I'd feel there's a good chance there'd be somebody out there I could meet.. (WHM, 50s, living with HIV for 9 years).

'I'm in a minority, because HIV is a minority in itself, I'm heterosexual, and, being white ... I'm not sure what the statistics are. But it feels like a minority within a minority within a minority...' (WHF, LT Dx, 60s)



MIGRATION ISSUES

'I have been here and separated from my family for 10 years. They have to come here. It's expensive and I am not working. And some of my family are poor. Sometimes you are OK and sometimes you think if the migration problem was sorted ... That you are a migrant and have to wait for indefinite leave, that alone depresses you. Sometimes I wake up and feel as if I am on Roben Island in South Africa. As I progress in life and age, the thing that worries me most is when will the government give me a hearing? That has been worrying me more than my HIV'. [BA Focus Group]



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UNCERTAINTY: ILLNESS & MORTALITY

'With HIV, when you get older, the problem is with aches and pains; we don't know whether these aches and pains are HIV or it's normal, just because you've never been old. You've never been 50 before you have got HIV.' [BA Female, 50s, Recent Dx]

'I'm 61 this year.... I do feel that a lot more as I become older. It's like it's hanging over you. It's like something that you don't know where it's going to go ... So I think it's the fear of how much longer have I got? Because it's been hanging over for quite a long time, and I do have these troughs and peaks, and I'm thinking, well, will I get one more peak?' [MSM, White, 50s, LT Dx]



SOCIAL AND FAMILY CONTEXTS

*‘I’m thinking, well, how long now am I going to live?
And then looking at the children we are bringing up,
how will the children cope, and how are we going to
leave the children? What support is there for them?’
[BA Female, 50s, LT Dx]*



VARYING TALK ABOUT DEATH

“When I came out 22 years ago HIV was a death sentence, so you would die a fairly horrible death... you brought it on yourself... just desserts for being homosexual and being promiscuous or whatever it was – so a toxic cocktail.” [White MSM, 50s, Recent Dx]

“...it’s made me probably more accepting of death, and having been very near to being dead... I am very clear that you are going to die anyway and I’m quite accepting of it.” [White Heterosexual Male, 60s, LT Dx]

“I’m very scared of death... Death is a big thing. I worry about death.” [White, MSM, 50s, Recent Dx]

END OF LIFE

(e.g. Broom, 2015)

- ◆ Modern institutions tend to shield us from death
- ◆ Focus is on sustaining health, not supporting dying, or the needs of unruly bodies
- ◆ Cultural taboos around death/dying ongoing
- ◆ But 'heroic' deaths get media attention
- ◆ Recently, dying has increased in visibility
- ◆ Some re-enchantment of dying e.g. David Bowie

END OF LIFE

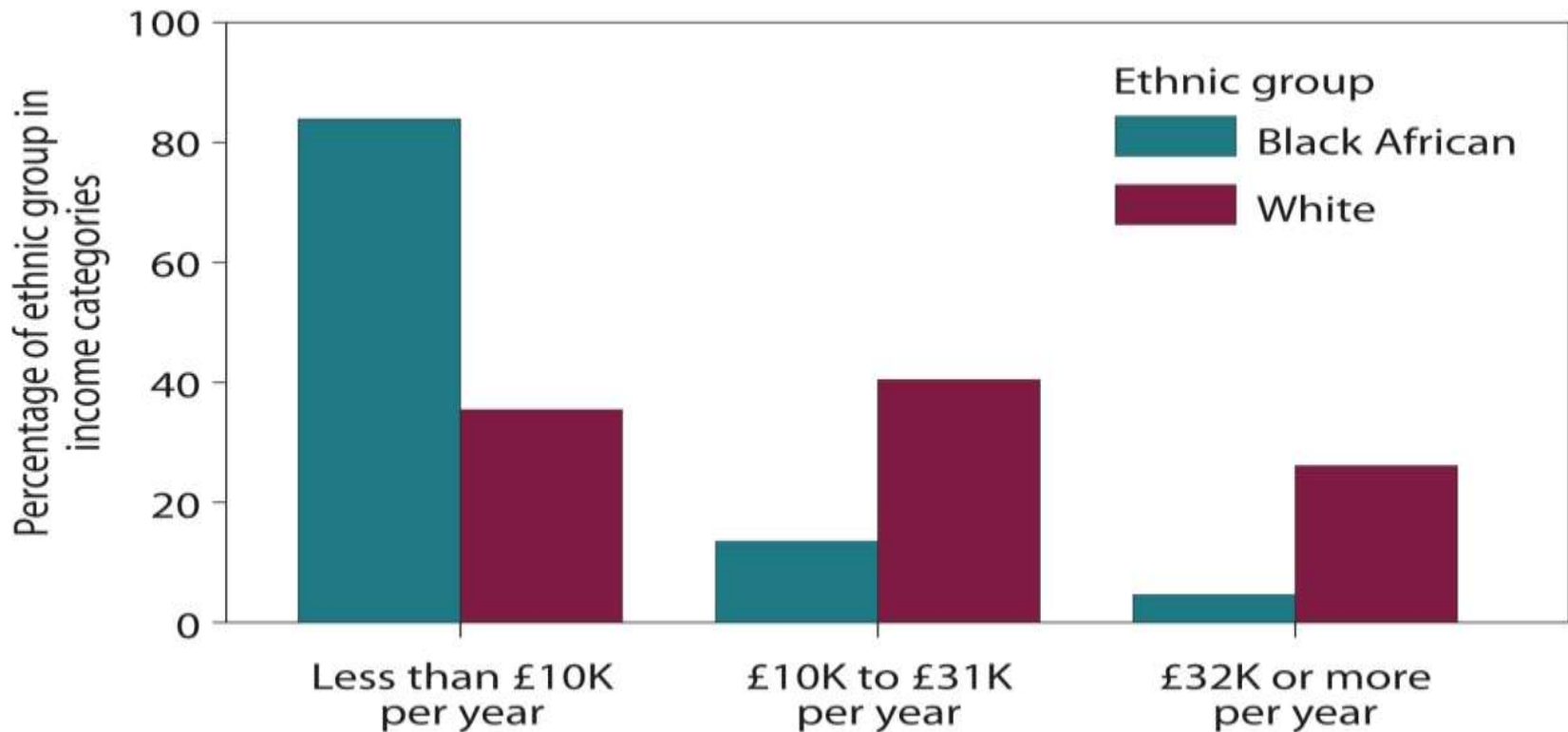
(e.g. Broom, 2015)

- ◆ Expansion & mainstreaming of palliative, hospice & end of life care
- ◆ How and where people die shaped by (growing) inequalities
- ◆ Dying is actually a very ‘social occasion’
- ◆ Our dyings stories written by a complex cast of patients, families, carers, professionals and institutions

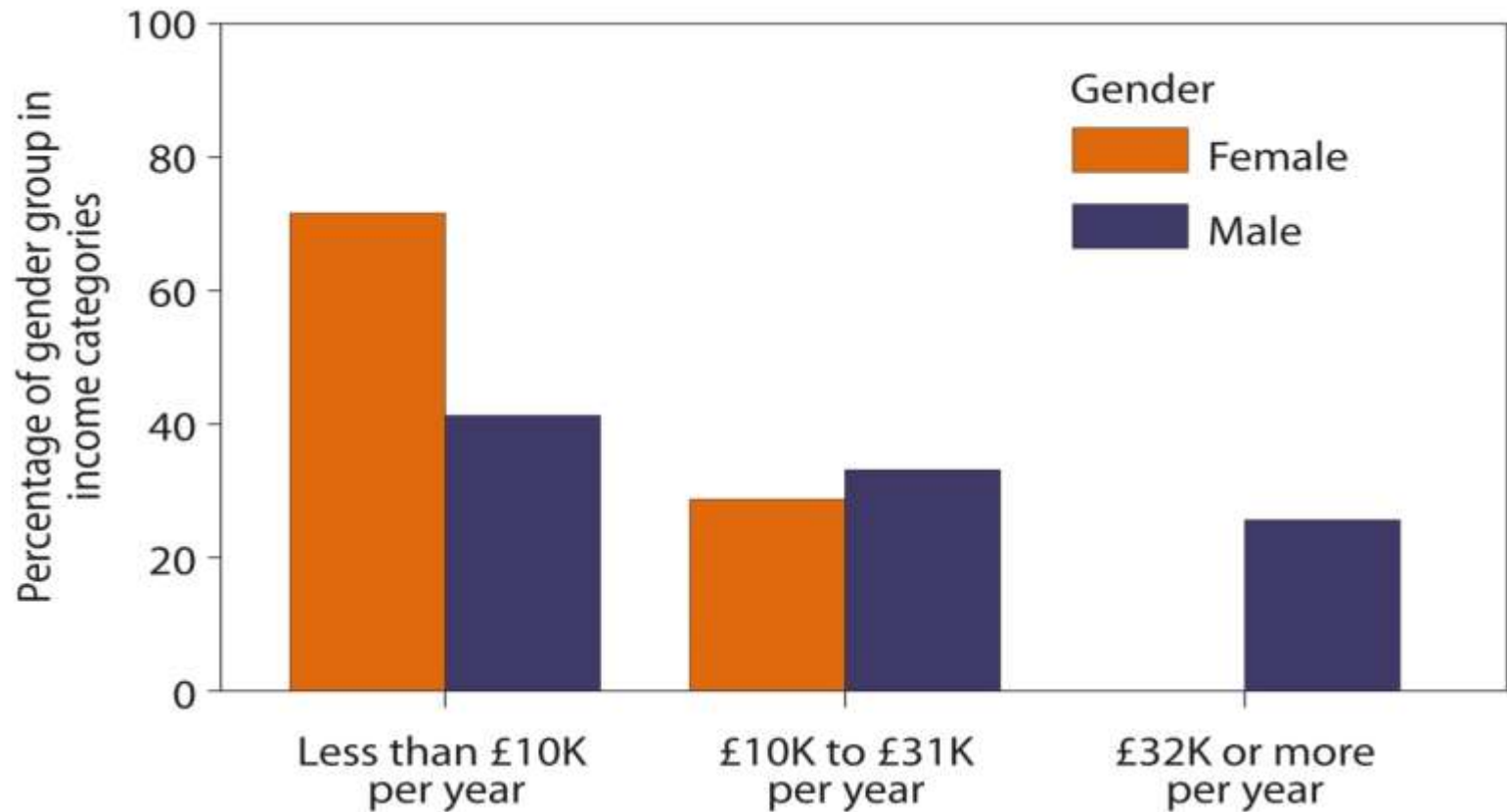
HIV & END OF LIFE

- ◆ HIV still causes death (e.g. late Dx), and people with HIV do become frail, accumulate multiple morbidities, accelerated ageing
- ◆ Half of all persons infected with HIV are at risk of making end-of-life decisions without prior discussions with professionals (Wenger et al. 2001).
- ◆ LGBT patients may not receive appropriate end of life care (e.g. uncomfortable staff, lack of recognition of partners in medical decision-making) (Elk 2015).
- ◆ Little known, but inequalities flow into older age, with impacts on quality of life (and dying) (consider HALL study)

HALL: PERCENTAGE DISTRIBUTION OF ETHNIC GROUPS BY INCOME CATEGORY



HALL: PERCENTAGE DISTRIBUTION OF GENDER GROUPS BY INCOME CATEGORY



HIV & END OF LIFE

- ◆ Hostility of religions to sexual minorities & HIV positive people (Ridge et al. 2008), e.g. *“I’m a bit confused because I’m not religious. I don’t believe in an afterlife as such, although I do believe that there is a life force, and that life force has to go somewhere.”* [HALL, MSM, 50s, LT Dx]
- ◆ Spiritual beliefs/religious practices shape PLWH end of life, forgiving Gods useful/HIV as punishment unhelpful (Kaldjian et al. 1998)
- ◆ What matters in End of life care?: Trust in professionals, avoidance of unwanted life, effective communication, continuity of care and life completion (Heyland et al. 2006).
- ◆ “Relationships [are] a spiritual need, cause spiritual distress when broken and [are] the way spiritual care was given.” (Edwards et al. 2010)

CONCLUSION

- ◆ People with HIV frequently doing well as they age
- ◆ Our ageing group generally 'young' (mid 50s on average)
- ◆ Ageing, HIV and EOL increasingly an issue
- ◆ Lack of research on HIV and end of life
- ◆ Many die around time of diagnosis – traumatic
- ◆ Stigma, mental health issues, and inequalities shape EOL experience
- ◆ Experiences vary between (and within) groups of PLWH
- ◆ Our participant narratives show that person-centred care is priority



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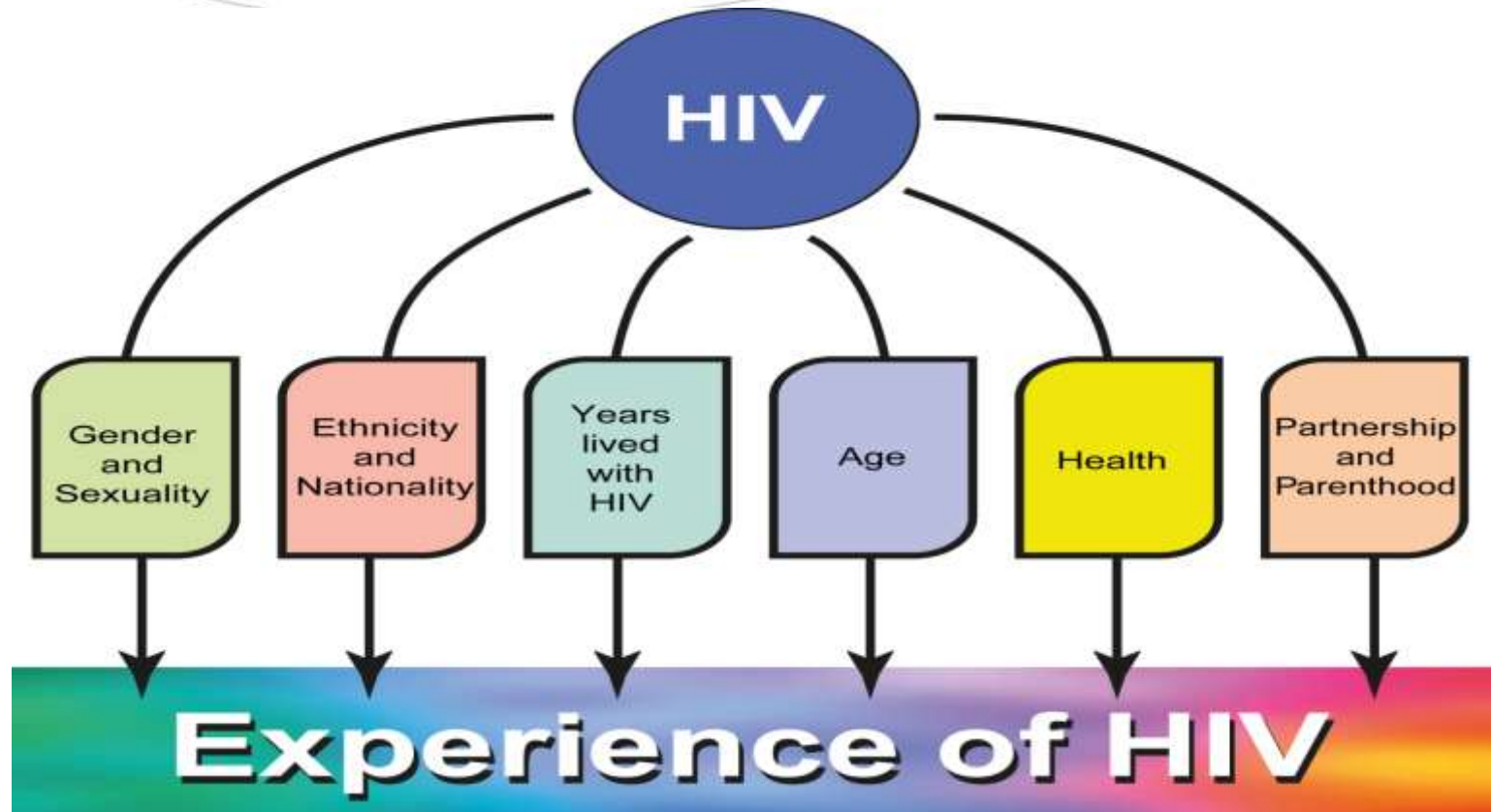
HALL RESEARCH TEAM



- ◆ Professor Damien Ridge – Co-investigator (Westminster University)
- ◆ Dr. Dana Rosenfeld – Principal Investigator (Keele University)
- ◆ Professor Jane Anderson – Co-investigator (Homerton University Hospital)
- ◆ Dr. David Asboe –Collaborator (Chelsea & Westminster)
- ◆ Dr. Jose Catalan – Co-investigator (Chelsea & Westminster Mental Health Trust)
- ◆ Mr. Simon Collins –Collaborator (HIV iBase)
- ◆ Dr. Valerie Delpech – Medical Epidemiologist (PHE)
- ◆ Dr. Genevieve von Lob – Research Associate (Keele University)
- ◆ Ms. Kelly Prince – Project Coordinator (Keele University)

Funding: ESRC/MRC Life-Long Health and Wellbeing Cross-Council Programme (2011–2013)

QUESTIONS?





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HALL RESULTS AVAILABLE

- ◆ Report online now, qual & quant (www.keele.ac.uk/hall/)
- ◆ Current journal papers: *Health Sociology Review*, *Journal of Aging Studies* (in press)
- ◆ Quantitative QoL paper submitted



(MORE ON METHODS)

- ◆ 17 Stakeholder interviews
- ◆ PLWH recruited through 3 clinics, and several HIV organisations, in London
- ◆ Older PLWH: 4 focus groups
- ◆ Older PLWH: Life-history interviews with 76 people (100 QoL questionnaires):
 - ◆ 12 BA men/18 BA women; 9 White men/9 White women; 53 MSM
 - ◆ Aged 50–87 (median age 56 years, mean age 58.4 years)
 - ◆ Years since diagnosis (excluding focus groups): 1–32 years (median 10 years, mean 11.4 years)
 - ◆ Age at diagnosis: 24–79 years (median and mean age at diagnosis 47 yrs)

HALL METHODS & DATA



- ◆ HIV Community Advisory Board (CAB)
- ◆ Interviews with stakeholders in the HIV and/or ageing arenas (17)
- ◆ 3 focus groups with older PLWH (23 participants)
- ◆ Life–history interviews + mental health/QoL survey (76)
 - 12 BA men/18 BA women; 9 White men/9 White women; 53 MSM
- ◆ 24 stand–along mental health/QoL/social support surveys