Missed chances, lasting impact.

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Conflict of Interest

Please give details of any conflict of interest by way of financial support, gifts, organisational or research interests

Or

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Addressing late HIV diagnosis:

- In 2024, 42% of new HIV diagnoses in England were diagnosed as late (with a CD4 count less than 350).
- In Essex, 50% of new diagnoses were diagnosed as late- with higher rates within South and West Essex.
- Late HIV diagnosis remains a significant challenge within the East of England and the proportion of Late HIV diagnoses has remained stubbornly high.
- Outside of larger cities late diagnosis remains more common amongst heterosexual populations.

A collaborative approach

Discussion on a local level between services.

Exploration of impactful messages and stories.

Experience and local data suggested repeated primary care and health care contacts before diagnosis- that in some cases spanning back six years prior to diagnosis.

How could this be undertaken in a way that would be seen as collaborative rather than “GP bashing”

Acknowledging current landscape and demands upon primary care resources. How could we highlight this issue and prevent further mortality, morbidity and loss of life.

Capturing lived experiences

Scoping exercise to all Essex HIV services- to identify people living with HIV that had experienced a late HIV diagnosis and had repeated attendance to primary care prior to diagnosis.

Once identified participants were contacted and the project was discussed, support was identified and informed consent was gained.

Funding obtained from Essex County council Public health commissioner and Provide CIC.

Interviewing….

- 11 participants in total.
- All had a CD4 <200 at diagnosis
- Repeated attendance at primary care with key indicator conditions for testing prior to diagnosis.
- Age range spanned 45-80. Actors were cast to accurately reflect age, gender and ethnicity demographic
- No participants wished to be filmed.
- 50% Male, 50% Female
- 60% White British, 40% Black African.
- 80% heterosexual 20% Gay

Theme 1- Missed opportunities.

On average all the participants had attended primary care six times with HIV associated symptoms prior to diagnosis.

The issue was not lack of engagement with health care.

Key indicator conditions and thinking in a holistic manner

Lack of psychological safety

Medical silencing

Repeated presentation

polydoctory

Theme 2: The Human cost.

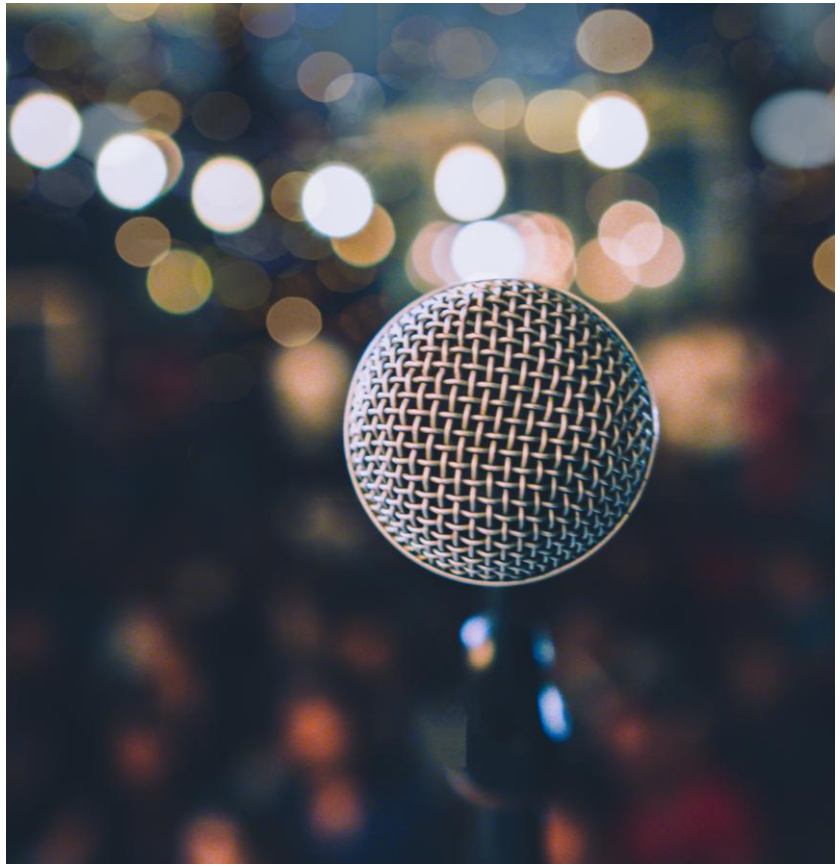
- Loss of confidence
- Core negative self beliefs
- Internalised shame
- Reduced quality of life
- Loss of quality of years lived
- Loss of confidentiality over diagnosis.
- Stigma recovering from acute illness
- Lasting disability
- Feeling disconnected

Theme 3: The wider impact

- Financial consequences
- Impact upon employment
- Impact upon wider family members and partners
- Engaging in HIV care and ongoing adherence
- Mistrust and breakdown with primary care.
- Attempting to access support with fear of disclosure and loss of confidentiality.
- Educating others whilst reliving a traumatic experience

“I was given antidepressants and told it was in my head”

- “The weight, the weight was falling off of me and they said nothing was wrong”
- “Within two years it was shingles twice, pneumonia, oral thrush and told well it’s not cancer- so that’s it?”
- “I felt like I was going to die and nobody would listen to me or help me”
- “I was made to feel like I was a timewaster, they didn’t want me there, but I could tell something in my body, something was wrong”
- “I had to go back to live with my parents they were told about my diagnosis. They made me have separate cutlery, cups and cupboard, I felt so dirty”
- “I didn’t want to live anymore and I attempted to take my own life”
- “I still can’t catch my breath now six years later, I can’t even play with my grandchildren”



Call to Action: Primary care we need you!

- Normalise HIV testing
- Routine offer
- Education
- Test when symptoms remain unexplained
- Continuity of practitioner
- Review of clinical history and medical records during consultations
- Communicating with other health disciplines
- Follow up on referrals and outcomes from referrals
- Targeted health promotion at older demographics
- Consider testing for all GP registrants and their children when entering the UK.

The path ahead….

- Video produced and shown to participants.
- Empowerment, advocacy and activism.
- Validation for participants.
- Collaboratively tackling the problem through local service provision, activism and local government.
- Working with local ICB’s to distribute video and training to primary care and pharmacies.
- Accessing primary care conferences and time to learn events.
- Working with local NHS trust surrounding patient safety alerts and HIV late diagnosis.

The video can be accessed here:

“Every missed HIV test is a lost opportunity to prevent avoidable harm”

With thanks to our wonderful participants for sharing their stories. A special mention to Sue Luty and Kerry McCabe for their support and work with this project.

Any questions?