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Remembering and responding on World Aids Day

Staff and students at Northumbria University will mark World AIDS Day by celebrating the life and work of a former academic, and launching two new initiatives aimed at highlighting the challenges faced by those living with Human Immunodeficiency Virus (HIV).

Held on 1st December each year, World AIDS Day is an international event dedicated to raising awareness of the AIDS pandemic caused by the spread of HIV infection, and commemorating the 35 million who have died of the disease.

On Thursday 29 November, a special screening will take place at Northumbria of the film *Bright Eyes*, written and directed by former lecturer Stuart Marshall who died in 1993, at the age of 44, from an AIDS-related illness.

The film explores the AIDS crisis through its homophobic portrayal in the British tabloid press in the early 1980s. It presents dramatic reconstructions and interviews to consider the history of homosexuality dating from the nineteenth century, and a historical perspective on the media representation of HIV/AIDS.

The event is being organised by Northumbria's LGBTQ* Network and will also mark the official launch of the group, which provides a forum for staff and postgraduate researchers to work together on LGBTQ*-related issues and projects.

James Bell, a Visual and Material Cultures PhD candidate from Northumbria's Department of Arts, is one of the event organisers. He said: "Stuart Marshall is an incredibly important artist in the history of AIDS and LGBT cultural activism. His films were broadcast on Channel 4 in the 1980s and early 90s at the height of AIDS stigma in the media. Marshall's work and ideas still resonate now, and his connection with Northumbria make's screening *Bright Eyes*, a fitting way to mark World AIDS Day."

As well as the film screening, there will be a panel discussion, including Chris Ashford, Professor of Law and Society at Northumbria, whose research focuses upon challenging normative assumptions about sexuality and Kiersten Hay, a PhD candidate who investigates how women living with HIV in the UK use digital technology.

Also taking part in the discussion will be Philip Dixon, a member of Thrive, a North East advocacy and support group for individuals affected by and living with HIV; and Dr Abigail Durrant, Associate Professor within Northumbria's School of Design, who researches issues of trust and representation around personal data sharing by those living with HIV.

Earlier this year Dr Durrant was awarded £1M funding by the Engineering and Physical Sciences Research Council (EPSRC) as part of a drive to further understand Trust, Identity, Privacy and Security (TIPS) issues in the UK Digital Economy.

The film screening event on 29 November coincides with the public launch of Dr Durrant's research project, entitled INTUIT: Interaction Design for Trusted Sharing of Personal Health Data to Live Well with HIV, which takes place on 30 November.

The INTUIT project aims to identify and address 'TIPS' challenges faced by those living with potentially stigmatising long-term conditions, such as HIV, in sharing personal data that they collect about their lives, with healthcare providers, peer support networks, and private organisations.

These challenges gain new significance with the roll-out of digital healthcare systems, and the increasing use of patient-generated data in the National Health Service (NHS) to support the self-management of long-term conditions such as HIV.

The interdisciplinary project is led by Northumbria's School of Design in partnership with the University's Department of Psychology, and four other Universities: University College London (UCL), University of Edinburgh, University of Bristol, and City, University of London.

The research is conducted in close collaboration with partners Public Health England, National AIDS Trust, Microsoft Research, Yoti, Central North West London NHS Foundation Trust, Terrence Higgins Trust, INTEROPen, and The HIV Treatment Advocates Network(UK-CAB), plus representatives from patients' groups, charities, and national organisations.

Together the project team will conduct foundational research that will inform the design and evaluation of new digital tools. These tools will provide people living with HIV, and other stigmatised conditions, with more opportunity and choice for managing how they share their personal data with others.

Dr Durrant said: "The INTUIT project aims to address some of the most challenging issues that we face in society today around the trusted sharing of personal data related to digital health.

"There are currently an estimated 36.7 million people living with HIV people around the world. Through effective treatment, HIV has been transformed to a condition with normal life expectancy. However, HIV remains highly

stigmatised, and therefore provides a specific clinical and social context for researching challenging data interactions.

“One aim of INTUIT is to promote a real-world understanding of these challenges, highlighting how they need to be addressed as a feature of people’s everyday lives.

“By marking World AIDS Day at the University, we also highlight the importance of supporting equality, diversity and inclusion in the workplace, plus the need for responsible research and innovation.”

Deborah Gold, Chief Executive at NAT (National AIDS Trust) is backing the event at Northumbria, and the INUIT project. She said: “Workplace support for World AIDS Day is one way that an employer can demonstrate a commitment to equality and diversity, as well as publicly show solidarity with and support for people living with HIV.

“This is particularly important given the ongoing stigma that surrounds HIV. That’s why we’re delighted that Northumbria University’s staff and students are working together to mark the day.

“We warmly welcome the launch of the INTUIT project which will make an important contribution to our knowledge of how to make best use of digital technologies whilst protecting the privacy of those living with HIV.”

People attending the event will also hear from Philip Dixon, a member of Thrive - a North East advocacy and support group for individuals living with HIV. Philip was diagnosed with HIV in September 2012 and has been on medication since that time, making him undetectable for nearly six years. He works full time and also spends a lot of his time singing, conducting and performing in choirs. Money raised at the event will be donated to Thrive.

Philip said: “It’s a pleasure to be involved in this event and to discuss attitudes and changes towards HIV. It’s great to be representing THRIVE and discuss the work that they do to raising awareness and providing support to people in North East England.”

The event on 29 November is being co-hosted by Northumbria’s student LGBT* Society.

For more information about the World AIDS Day Film Screening and Discussion event, please visit: <https://www.eventbrite.co.uk/e/world-aids-day-film-screening-and-discussion-stuart-marshall-bright-eyes-1984-tickets-52095524115>

For more information about the EPSRC INTUIT project, please contact Abigail Durrant by email at abigail.durrant@northumbria.ac.uk or visit the project website: www.intuitproject.org

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