

**TRUST BOARD**

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Title:	<b>Patient story that focuses on people living with HIV and their experience of group support.</b>
Action:	<b>FOR DISCUSSION</b>
Meeting:	<b>10<sup>th</sup> July 2019</b>

**Purpose:**

The purpose of bringing patient stories to Board members is:

- To set a patient-focused context for the meeting.
- For Board members to understand the impact of the lived experience for the patient, family and friends.
- For Board members to reflect on what this experience reveals about our staff, morale and organisational culture, quality of care and the context in which our clinicians work.
- To review and recognise any shared learning and recommendations relevant to this story.

**Recommendation:**

To receive the patient story and note the context and the recommendation from the outcome of this patient story.

	Name	Title
Authors:	Lisa Wright Dr Amelia Eleftheriades	Patient Experience manager Advanced Specialist Clinical Psychologist
Executive sponsor:	Julia Curtis	Chief Nurse

## Trust Objectives

Objective	How the report supports achievement of the Trust objectives:
Provide outstanding care	This paper demonstrates how working with service users enables better health outcomes and improves wellbeing through group interventions.
Collaborate with other organisations	Our clinician is currently undertaking a Collaboration for Leadership in Applied Health Research (CLAHRC) Fellowship programme and the service users have also been involved with this.
Be an excellent employer	This paper how the Trust has supported out Clinical Psychologist to undertake a Quality Improvement Fellowship programme and CLAHRC.
Be a sustainable organisation	Not covered in this paper.

**Trust risk register:** N/A

**Legal and Regulatory requirements:** CQC standards

### Equality and Diversity implications:

Objective	How the report supports achievement of objectives:							
Achieve an improvement in the percentage of service users who report that they are able to access the Trust services that they require	People living with HIV can experience psychological distress, stigma and social isolation and by providing the HIV Support and Information group the Trust is seeking to improve their health and well-being.							
To introduce People Participation in our diversity and inclusion initiatives to capture the experience of hard to reach / seldom heard / varied community groups.	Understanding and hearing the experience of service users who are living with HIV is an important part of our People Participation approach. These lived experiences, gained through feedback and participation, are a valuable part of how we understand what is working well and what can be improved. This can be used in the co-production and improvement of the services we offer, now and in the future.							
To introduce wider diversity on recruitment selection panels.	Not covered in this paper							
To deliver customised training and development for staff to further improve awareness of diversity and inclusion.	Not covered in this paper							
Are any of the following protected characteristics impacted by items covered in the paper – no								
Age	Disability	Gender Reassignment	Marriage and Civil Partnership	Pregnancy and Maternity	Race	Religion and Belief	Sex	Sexual Orientation
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **1. Introduction**

- 1.1. This patient story focuses on the journey of three individual service users who are known as 'People Living with HIV (PLWH)' and their experience of attending the Integrated Contraception and Sexual Health service (iCaSH) Norfolk HIV support and information group. The three service users are not named in this report for confidentiality reasons.
- 1.2. To help share their stories the three service users have agreed to participate in a film about their experiences and this will be shown at the Trust board.
- 1.3. Dr Amelia Eleftheriades is a clinical psychologist with iCaSH Norfolk. She leads a small psychology team which covers iCaSH Norfolk, with provision in King's Lynn, Norwich and Great Yarmouth and will be attending to support this Patient Story.
- 1.4. It has been recognised that PLWH experience more psychological distress, stigma and social isolation than others. This has negative implications for wellbeing, engagement, HIV transmission and the economic burden of HIV. National standards from 2011 tell us that PLWH should be:
  - Provided with information
  - Able to access peer support
  - Engaged in the planning, delivery and evaluation of services
  - Able to access care provided by appropriately trained professionals

## **2. Background to our Team and service mention within this story**

- 2.1. The Trust's iCaSH HIV services operate in Cambridgeshire, Suffolk, Bedfordshire and Norfolk. The Multi-disciplinary HIV services are commissioned by NHS England. In Norfolk, Clinical Psychology is an integrated part of this Multi-disciplinary Team (MDT). Patients are referred to a psychologist by another member of the MDT if psychological support is required. We are also working towards offering routine mood screening to all PLWH, as per national guidance.
- 2.2. The initial proposal to develop a group support network for PLWH was put on hold whilst the Norfolk Sexual Health Service moved into the Trust in 2015. The opportunity arose in 2016 to trial a support and information group over a 6-month period whilst a trainee clinical psychologist was on placement with the Psychology team. The trial was proposed to be a small-scale, service-development project with recommendations for future direction. A review of the project found we should offer more group support and we should improve the ability to measure wellbeing more effectively and we should continue to look at how we can empower PLWH to own future developing support and information groups.
- 2.3. In 2017 Amelia continued to develop this service in Norfolk as part of a Quality Improvement Fellowship, funded by Health Education East of England. This is when the group in Norwich started. The project aim was to improve the wellbeing of more people living with HIV in Norfolk by mobilising the power of peer support: a relevant approach in the context of national guidance, local need and limited resource.
- 2.4. Currently Amelia is completing her Collaboration for Leadership in Applied Health Research & Care (CLAHRC) Fellowship and the service users within this story have been involved as part of this fellowship.

## **3. The Patients' Healthcare Journeys within the Team**

- 3.1. The three service users, whose journeys will be heard through the film and in person at the board, joined the Norwich group in 2017. They each have different stories to tell about the information and support they were given in the past and at the time of diagnosis. HIV is now considered a long term condition, but when it first became a public health issue, over

thirty years ago, nothing was known about how to treat it and many people viewed it as a death sentence. For some this had a lasting impact.

- 3.2. The service users within this story were consulted about the group development from the beginning and shared ideas about what topics the group sessions should cover and what form the group should take. Topics chosen included: revisiting the basics of HIV; medication side-effects, interactions and adherence; stigma; disclosure; stress and coping; mindfulness; adjustment and acceptance; healthy eating; physical activity; memory and ageing and new developments in HIV research. Various MDT members have facilitated sessions.
- 3.3. The three service users were part of the monthly meetings held throughout 2018 and have continued to meet in a less structured format this year. Stigma has been a significant topic of discussion in group sessions. The service users have spoken openly about the impact of stigma: their reluctance to disclose their status to people close to them; their loneliness and isolation; negative emotions and their perceptions of being viewed negatively by others. You will hear how for one of our service users the impact of stigma was so great it nearly prevented them from attending the group. Speaking about stigma with the group, having their story heard and recognising that they were not alone in experiencing stigma was an empowering opportunity. Making the patient story film was a brave move for all three men involved.
- 3.4. The group have discussed and addressed various aspects of psychological adjustment to HIV directly in the sessions. These sessions have been well-received, and the service users have experienced increased confidence in their ability to speak about HIV and an increase in the range of coping strategies they have available to them. One service user discussed feeling more informed about his medication and feeling more actively involved in looking after his own health.

#### **4. Learning Points for the Wider Trust Services**

- 4.1. We should continue to share the learning about the power of co-production and patient involvement in all areas of our service delivery. There are health and wellbeing gains to be made by becoming pro-active about engaging and empowering patients to contribute more to their own and others' future, as highlighted by this story.
- 4.2. If we listen to our patients' stories, we will recognise that it is important for us to give clear, strong messages about the full and healthy lives PLWH can live. We will understand that newly diagnosed patients may be emboldened by hopeful stories from others who have been there before and found ways to thrive. And we will understand that early attention to psychological as well as physical aspects of people's treatment can contribute to their long-term health and quality of life.
- 4.3. Now that medical treatment of HIV is so effective, we need to make some real shifts in how our staff conceptualise the condition and gain the knowledge to be able to understand and communicate that HIV is a long term condition that can be managed.

#### **5. Recommendations**

- 5.1. Within the next six months the service will carry out a review of how they can further embed the successful elements of this project, so it can continue and where possible look at setting this up in other iCaSH areas that see HIV patients.
- 5.2. The Service will share the outcome and video of this patient story with all iCaSH areas and stakeholders (where appropriate) within the next 3 months.
- 5.3. Once Dr Amelia Eleftheriades, Advanced Specialist Clinical Psychologist concludes the findings from the associated CLARC research project (due to finish next year) the aim will be to share the learning and outcomes, with a view to understanding how people who use our clinics experience support and what we can do to improve this experience.