

TRUST BOARD

Title:	A patient story about living with an HIV diagnosis.
Action:	FOR DISCUSSION
Meeting:	9 January 2019

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:

Norwich iCaSH should share this story with all staff within the next month.

This success story should be shared across all iCaSH services within the next three months.

	Name	Title
Author:	Lisa Wright	Patient Experience Manager
Executive sponsor:	Julia Curtis	Chief Nurse

Trust Objectives

Objective	How the report supports achievement of the Trust objectives:
Provide outstanding care	The paper demonstrates where Trust staff have provided outstanding care in terms of their professionalism, non-judgemental attitude and excellent listening skills.
Collaborate with other organisations	This story demonstrates collaborative working between iCaSH and primary care colleagues.
Be an excellent employer	This story demonstrates how the Trust's investment in a Specialist Clinical Pharmacist has directly impacted the service user's experience of their clinical care.
Be a sustainable organisation	Not covered in this paper.

Trust risk register: N/A

Legal and Regulatory requirements: N/A

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	This paper is an example of how a clinician has empowered and supported a service user to inform primary care of their HIV diagnosis.
To introduce people participation in our diversity and inclusion initiatives to capture the experience of hard to reach / seldom heard / varied community groups.	Not covered in this paper
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 living with an HIV diagnosis and the care offered to a patient at our Norwich iCaSH (Integrated Contraception and Sexual Health) clinic. Our iCaSH service provides all aspects of sexual and reproductive health, including contraception, sexually transmitted infection (STI) and HIV testing and treatment. iCaSH is available from easily accessible single locations across Bedfordshire, Cambridgeshire, Norfolk, Peterborough and Suffolk
- 1.2. The patient will be attending the Board in person to discuss their positive experience of the iCaSH service. The patient will be accompanied by Dr Nelson David (Associate Medical Director) who has been part of providing this excellent clinical care. The patient will be referred to as BD for the purpose of confidentiality within this report.

2. Background to the iCaSH Service

- 2.1. Over the past five years the Trust successfully bid for integrated Contraception & Sexual Health (iCaSH) services retaining or expanding contracts for Cambridgeshire, Peterborough and Suffolk, whilst securing contracts across Norfolk and Bedfordshire, making this portfolio one of the largest service areas in the Trust.
- 2.2. Dr David had been working in HIV medicine since 1998 and been a clinical lead for sexual health and HIV since 2008. He has worked as clinical lead for iCaSH Norwich since 2015. He has recently been appointed as Associate Medical Director for iCaSH services.
- 2.3. The iCaSH service has a Specialist Clinical Pharmacist who provides a clinical service to HIV patients in Norwich and is responsible for advising on the provision of HIV pharmaceutical services across the Trust and maintaining an overview of medicines management issues in the Integrated Contraception and Sexual Health services in Norfolk (iCaSH), with a specialist clinical focus on HIV.

3. The Patient's Healthcare Journey

- 3.1. BD's story begins in February 2013 when he was diagnosed with HIV whilst living abroad. He commenced treatment, Atripla antiretroviral medication in 2014. BD stated that this diagnosis was very unexpected as he had always been extremely careful, taken precautions, and that his HIV test was part of regular, routine screening. He said that his initial reaction to the positive diagnosis was to laugh, as that's how unexpected & unlikely it was.
- 3.2. During consultations Dr. David outlined the benefits of sharing the diagnosis with BD's GP and recommended he do this in order to effectively support his ongoing health needs. Initially BD declined to do this as he was worried about the information not being kept completely confidential by the GP service. BD felt that there was no pressure on him to follow the recommendation and that his decision was respected without any judgement and that he has "always felt safe with Dr. David - as though he's got my best interests". When BD felt ready to share his diagnosis with his GP, Dr David facilitated this.
- 3.3. BD suffered side effects from the medication he was taking which impacted his kidney function and caused him to experience anxiety. His case was taken to the HIV Multi-Disciplinary Team (MDT) meeting where BD's case was discussed. This meeting includes HIV Consultants, Specialist Nurses, HIV Pharmacist and a Clinical Psychologist who discuss complex cases where patients need more expensive drug combination treatments. Here, agreement was reached to change his antiretroviral medication.
- 3.4. BD also stated that the Specialist Clinical Pharmacist iCaSH, Portia Jackson, "was very thorough". He particularly recalled her phone calls to check what other medication he was taking in terms of its impact on his HIV medication and feels this is a really important aspect of his care.

- 3.5. At one point BD had to undergo surgery, unrelated to his HIV, in a local acute trust. BD felt that one of the HIV Clinical Nurse Specialists in iCaSH, Richard Grey, had gone “above and beyond his day job based in a clinic” by offering to take any medications BD needed up to the acute ward to ensure medication continuity.
- 3.6. BD’s overall impressions of the service were that “everyone’s singing from the same hymn sheet”, it is “very human” and “not a sterile clinical environment”. Although this story has focussed on three clinicians involved in BD’s care he also mentioned how friendly and welcoming the receptionist, the “vampire lady” (phlebotomist) and “even the lady who’s waiting for your pee in the cup” are.
- 3.7. BD continues to have clinic appointments 2-3 times a year and has recently shared his diagnosis with his partner. In his own words, BD states “he feels safe living with HIV in the care of Dr Nelson”.

4. Patient’s Voice

- 4.1. The patient will be attending in person to present their story to the Trust Board along with Dr. Nelson David, Associate Medical Director.

5. Learning for Wider Trust

- 5.1. From BD’s perspective, the learning for the Trust that he wants to share is that whoever he met within the service from Sam on reception, to Ruth who is always calm and reassuring, to the phlebotomist, to Richard, to Dr Nelson, everyone involved has always been warm, welcoming, non-judgmental and professional. It should be recognised that BD’s experience has been one of outstanding care.

6. Recommendations

- 6.1. Norwich iCaSH should share this story with all staff within the next month.
- 6.2. This success story should be shared across all iCaSH services within the next three months.

Lead Author

Lisa Wright – Patient Experience Manager

Content and story provided by

BD - Patient