



Pictured l-r, Heart Transplant Co-ordinator Kirstie Wallace; Newcastle Hospitals Charity Director Teri Bayliss; Heart Transplant Co-ordinator Hazel Muse Associate; and Professor Jamie Steane, of Northumbria University's School of Design.

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## New eLearning website supports transplant patients through life-saving surgery

Undergoing a heart or lung transplant can be an incredibly worrying time, for both patients and their family and friends, and the information which needs to be explained by surgeons and understood by patients before major life saving surgery is lengthy and complex.

But a new eLearning website, created for heart and lung transplant

candidates at Newcastle's Freeman Hospital, aims to transform the patient experience – providing advice, support, and information, before, during and after surgery.

The online resource was designed following research by academics at Northumbria University's School of Design, in partnership with Heart and Lung transplant surgeons and transplant co-ordinators at Freeman Hospital, and has been supported with a grant of £75,000 from Newcastle Hospitals Charity.

The website allows patients to find out everything they need to know about their surgery from the comfort of their own homes. This is particularly important due to the specialist nature of the <u>Freeman Hospital's Institute of Transplantation</u>, with patients coming from all over the UK for life-saving surgery.

As well as carrying out a virtual tour of the transplantation ward, theatres and intensive care unit they can meet members of the surgical and nursing team, find out how they can prepare for surgery, what to expect during recovery, and listen to stories from other patients about their lived experience.

Each patient is given an individual login when they are accepted for assessment for their transplant and asked to complete a three-part online workbook, covering the assessment process, the operation itself, and life after a transplant.

Each section is broken down into bitesize chapters which are marked as complete once finished, meaning the surgical team can identify anyone who may need additional support or advice. Patients can share this with their families and revisit sections as many times as they wish to help their understanding.

The new website replaces a largely paper-based system and was initiated by <u>Professor Stephen Clark</u>, a heart and lung transplant surgeon at the Freeman Hospital and a Professor of Cardiothoracic Surgery and Transplantation within Northumbria University's Department of Health and Life Sciences.

Speaking about the need for a new patient resource to support transplant patients and their families, Professor Clark said: "The way in which we convey

complex information to patients and their families as they are assessed to have a heart or lung transplant had not changed for many years and relied on basic printed materials and long face-to-face conversations to impart difficult and complex concepts around major surgery.

"Developing this cutting-edge digital resource allows families from all over the country who are referred to Newcastle for their surgery to access understandable information, aided by virtual tours of the transplant unit and intensive care, interviews with staff and patients, and animations of the surgery to be performed.

"This allows more family members to be included in the process to support those waiting for a transplant, lets patients view the information more than once if they wish, and frees up staff to focus on the important questions that patients have.

"This is a huge step forward in the transplant assessment process, and is not undertaken in this way anywhere else in the UK. It also opens up opportunities for research into how complex information can be best explained and shared with patients waiting for life-saving major surgery."

The finished website, which was launched in September, follows several years of research and development, led by <u>Associate Professor Jamie Steane</u>, of Northumbria University's School of Design.

He said: "It was vitally important that in designing this new resource we truly understood the patient journey, so we spent a week shadowing the heart and lung transplant team at the Freeman, speaking to hospital staff and patients.

"We discovered there was a real information challenge – hospital staff were going through all the details of the surgery with patients on paper and face to face, which we found was not always the best environment or format for patients to properly absorb or retain that information, as well as being very time consuming.

"The new online resource really brings the service into the twenty-first century – it is easy to use, can be shared with family and friends, and allows staff to spot if anyone might be struggling to understand or engage with any element of the process."

The website was funded through a grant from <u>Newcastle Hospitals Charity</u>, which works to make a positive impact on the experience of patients across Newcastle's hospitals and in the wider hospital community.

Speaking about the project, Charity Director Teri Bayliss said: "It is a key aim of Newcastle Hospitals Charity to champion innovation at Newcastle Hospitals, as well as improve the patient experience, so we were very happy to support this new website. We are very proud that transplant patients from across the North East and beyond are benefitting from the fantastic new resource."

Following the initial research process, Northumbria University appointed digital agency <u>Enigma Interactive</u>as a development partner to create the website, based on the academic team's findings.

Enigma drew on their prior experience of working in health and education sectors to build an innovative solution. It uses a 'teach-back' method of assessing patients' learning by asking them to select statements, written in familiar language, that best reflect their understanding of the transplant process.

Discussing Enigma's involvement in the project, Managing Director Steve Grainger said: "This was a fantastic project to be involved in, and a great example of how well-designed digital resources can make a genuine positive difference to people's lives.

"Working closely with the clinical team at the Freeman, and consulting directly with past patients and carers, has allowed us to shape an online resource that provides an extra layer of 24/7 support and reassurance to patients and their families that will hopefully make the daunting prospect of organ transplant that just little bit less daunting."

Following the official launch of the website in September it is now hoped that the concept can be shared with other hospital transplant centres, or even within other areas of patient care, including diabetes treatment.

The website can be viewed at <a href="https://transplant-resource.newcastle-bospitals.nhs.uk/">https://transplant-resource.newcastle-bospitals.nhs.uk/</a>, although only patients and people within their support networks with approved login details will have access some of the features,

such as the workbooks.

The Northumbria University team involved in the project included <u>Associate Professor Jamie Steane</u>, <u>Assistant Professor Andrew Frith</u> and <u>Professor Mark Blythe</u> of the <u>Northumbria School of Design</u>, as well as Dr <u>Stuart Barker</u> from <u>Northumbria's Department of Nursing</u>, <u>Midwifery & Health</u>.

The Freeman Hospital team included Professor Stephen Clark, Consultant Anaesthetist Dr Vikrant Pathania, and transplant co-ordinators Kirstie Wallace and Hazel Muse.

The Northumbria University and Freeman Hospital team's work will continue for at least the next six months to understand and research the impact of this digital information resource on the patients, their families, friends and clinicians in their circle of care.

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## **Contacts**



Rik Kendall
Press Contact
PR and Media Manager
Business and Law / Arts, Design & Social Sciences
rik.kendall@northumbria.ac.uk
07923 382339



Andrea Slowey
Press Contact
PR and Media Manager
Engineering and Environment / Health and Life Sciences
andrea.slowey@northumbria.ac.uk
07708 509436



Rachael Barwick
Press Contact
PR and Media Manager
rachael.barwick@northumbria.ac.uk
07377422415



James Fox
Press Contact
Student Communications Manager
james2.fox@northumbria.ac.uk



Kelly Elliott
Press Contact
PR and Media Officer
kelly2.elliott@northumbria.ac.uk

## Gemma Brown Press Contact PR and Media Officer gemma6.brown@northumbria.ac.uk