USE, AND MISUSE, OF PATIENTS ON DISPLAY

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Medical objects have been used in museums to tell clinical, technical and personal stories. This presentation will reflect on the ways prosthetics, asthma, genetics, and the users of these medical technologies have been represented in recent museum projects in the United Kingdom including at National Museums Scotland. Users of these medical technologies are part of our public audience but their voices have routinely been ignored in museum interpretation and collecting policies. This paper will contrast use, and misuse, of patient voice in collecting, interpretation and display. How can we responsibly display medical objects and their users in museums? What can we do to make sure their experience, and voice, is represented?

The social and medical models of disability can be used as a method of categorising the ways in which museums choose to display not only disability but also patients and users of medical technology. The social model of disability has had a huge impact on disability activism and empowerment in the United Kingdom. As opposed to the medical model, where physical disability is the disabling factor and something to be fixed, the social model embraces the notion that society itself is the disabling force (1). Museums themselves have been accused of adhering to the medical model by displaying medical technology used by those who are disabled rather than focusing on another aspect of their being (2). These displays often focus only on clinicians, designers and technological ‘fixes’ to medical ‘problems’. However as museums, whose primary currency is objects, we must look to tie together objects with the experience of their owners, enriching the collection and display possibilities (3). Patient voice has been represented in the literature but is often limited to specific examples of disability on display and not patient experience more generally. The ethics of displaying these patients' conditions and experiences, collecting their stories and the responsibility we have to interpret it correctly have seldom been addressed. A note: I try and use as often as possible the word 'user' as opposed to patient in relation to medical technology, but in this instance patient is a more descriptive word.

There are three main ways patients are portrayed in museums: clinical, where the patients act as specimens; technological, where the invention, or marvel, of the technology and how it 'fixes' patients is in the forefront, and personal, where patient stories are used to add a 'human element'. There are benefits and pitfalls to all three of these approaches, which can be seen across the museum sector. Clinical approaches can be seen in museums like the Mütter Museum in Philadelphia and the specimen hall in Surgeons Hall, Edinburgh. Technological and personal approaches can be seen including institutions like the Science Museum in London and the Charité in Berlin.

At National Museums Scotland there have been a range of different approaches taken. National Museums Scotland is made up of four museum sites: The National Museum of Scotland, The National Museum of Flight, The National Museum of Rural Life, and The National War Museum. Recently the Science & Technology and Art & Design galleries at the National Museum of Scotland were redeveloped as part of a masterplan project. The ten new galleries opened in July 2016 and focused on broad themes, like the Enquire gallery which explores the spirit of scientific enquiry as opposed to a particular topic, for instance chemistry. These galleries included biomedicine as a theme for the first time, allowing us to try new approaches to using patient voice on display. In our previous galleries at National Museums Scotland we had taken a technological approach to displaying medical technology, highlighting the inventors and engineers behind remarkable objects. The interpretation in the gallery had to navigate an acceptable path between the museum and the object donors, a situation common to contemporary and historic donations.

In this new approach on gallery we were not seeking to silence the voice of the clinician or inventor but to redress the balance and give patients the chance to tell their own stories in their own voices (4). In order to avoid this work being purely 'additional' I worked with patients to find out, and hear from them, what objects they felt represented their experience and, more importantly, which did not.

In order to do this I worked with patients and users of medical technology dealing with asthma, genetics and prosthetics. This was accomplished through a series of group interviews, one-to-one interviews and online surveys. The information and discussions centred on objects which had been already identified as potential display objects but I was also open to suggestions from patients. The conversations with patients were enlightening for me as a curator as some of the objects identified as important were not those I had anticipated. For example, surprisingly the object which genetics patients identified with most with one of our most popular objects, Dolly the sheep, not any of the genetic technology objects which are used as port of diagnosis. These conversations and data capture helped to influence the stories we chose, and chose not, to tell on gallery. As a result members of the patient groups were asked to contribute by telling their stories in their own words and these can be seen (both written and video interviews) on the interpretation screens in the new galleries.

After speaking to people from all these groups some were physically involved in the new galleries, through contributions, both written and verbal, to our interpretation screens on gallery where they told stories about their experiences in their own words illustrated by images they themselves had chosen.

In the past patient voice has not been a loud presence in museums. Giving patients and users of medical technology the ability to tell their own story in their own words is much more powerful for visitors than a curator interpreting their experience for them. Despite the time commitment and planning this process takes there is always time to work with these groups. Of course we aren’t passive in this, we are curating by working with specific patients and users. We haven’t done it perfectly with our new gallery, there are challenges. We continue to steer between valour and victimhood, the perils of boring objects whilst trying to reflectively highlight user and patient stories while still including clinicians. We will continue to question our practices and seek to redress the balance.

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