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ABNORMAL

Live speech-to-text transcription will appear on this screen to give deaf, deafened and hard-of-hearing people access to the discussion. If you wish to use the service, please sit where you can see the screen clearly.

CHAIR: Ladies and gentlemen, welcome to the Royal College of Surgeons for this evening's panel discussion and Q&A on medicine disease and disability. It gives me great pleasure to welcome you to the college, to this event, some logistics first of all. My colleague tells me I should talk about "egress" a fancy word for exit! If there's a fire alarm, we will exit either through this door straight to the door opposite you or through the emergency exit signs that way.

If you need conveniences and we will take a break half way through this evening's 90 minute event, there are accessible conveniences around to the left, and other conveniences around to the right.

The only other thing I would ask is that you turn off your mobile phone including panellists of course! This evening's event came to us as an idea in association with the exhibition we currently have on in the Hunterian museum called Abnormal: Towards a scientific model of disability which has been brought to us by the artist Ju Gosling sitting furthest to my left. This got us excited in thinking about the links between museums and disability, and the links between medicine and disability, and the links between all three together. This is we think of particular interest to us here at the Hunterian museum because of the potential for medical museums to explore not only the technologies associated with medicine, surgery and disability, but also material remnants of the lived experience of disability. This is something that I hope will come through very powerfully in this wonderfully interdisciplinary panel we have lined-up today. And we lined up the people we thought it would be fantastic to have talk about this because of their associations with the college, their associations with the museum, and their research in the area. I'm delighted to say that all of our dream team were able to make it, and you see before you tonight. I will introduce each of them in turn as they chat to us in an introductory capacity for five minutes, that will be the structure of the evening. Each of them will talk for five or ten minutes, and then probably we will have a quick break at that stage and we will come back and I will encourage questions between the panellists, I don't think apart from our colleagues, I don't think you have publicly engaged with each other before. And we will of course invite questions from the floor. We know from those of you who know it will be a lively engaging debate, and about 8.30 I will try to call us to a halt, I know from experience that is for us to continue chatting a little in an informal way.

What we will get this evening are perspectives on medicines museums and disability from museology, from history, from surgery, and from artistic practice.

With that in mind, is everyone happy with the set-up of the evening, and can everyone see and engage with the resources in various ways? Excellent! So, it gives me great pleasure to introduce our first speaker who is Jocelyn Dodd who is director of the Research Centre for museums and galleries at the University of Leicester, for a long time has worked on museums, and a social role the impact of museums and galleries and she together with Richard Sandell our second speaker worked on a wonderful project around museums and disability, and I'm hoping they will speak about this evening.

Jocelyn Dodd: thank you very much and delighted to be here tonight and part of these discussions which I think promise to introduce some really exciting and interesting perspectives.

I had a little bit about my ideas which are framed around museum practice and around museum research as well. I want to really consider the way in which museums can begin to think about disability, and particularly to think about how they can also engage audiences in those debates around disability as well.

This really stems from work that I was involved with in the mid 1990s, I then worked at the museum in Nottingham which was one of the recipients of one of the early lottery-funded capital programmes. It was an interesting site, a site of a medieval castle which was an ancient monument. It was the building itself was a grade listed building as well and you can imagine some of the challenges of trying to create and develop a more accessible environment. As part of that Richard and I worked together we set up a disability consultative group to be part of that process to try and improve access. And that was our starting point, it was very much about thinking about accessibility. Very quickly the group of disabled people who were part of that group the Drawbridge group, the discussions the debates we were having we were very conscious quickly that this went much further than physical access, it was about the significance of what you would have access to. The chair of that group Anny, I remember her saying I want to have a mirror when I go into the museum, and see my experiences reflected in that mirror, where am I? Where are the historical roots of people like me? Where am I in those collections? So she was very much a very influential in shaping our thinking, and the image you can see here is an image by somebody we had, we didn't have any idea was in the collection, it's someone called Sarah Biffin who was in the museum's collection. It only came to light later that was part of the collection. She was somebody who was very established in her own right, her work was in royal collections. Really interesting for us as a museum to begin to think that we would have collections like this which showed disabled people and can you see from the representation here a self-portrait of somebody who presented herself and showed she was an artist and used her shoulders to paint, and her mouth as well. The work is displayed in a number of galleries. This led us to thinking much more about the way in which disabled people were represented in museum collections.

We secured funding from a project called Buried in footnotes, where we

wanted to begin to unpick some of these issues. By this stage both Richard and I were working at Leicester university and this is a research project which investigated museum collections. It set-out specifically to look at museum collections to see if there were collections that related to disabled people, and what kind of collections those may be. We wanted to find out where those people's lives were represented, and how accessible those were to the public. We wanted to get a sense of how they were... how the information related to those collections was presented as well. We wanted to know what factors had affected the collections as well. Were they made publicly available? What information was available? What factors did curators consider in terms of their dissemination as well. Some of the findings from Buried in footnotes were intriguing nearly 80% of the collections we looked at had collections related to the lives of disabled people. We found that those collections included all the museum collections, social history, art collections, military history, archaeology was evidenced and a few were on display not many but few. The ones that were on display, the objects tended to represent things like disabled people in their 19th century or earlier representation as freaks or specific characters like the giant, the large giant from the Manx museum at the Isle of Man, and they represented things like Joseph Merrick the Elephant Man at the Royal London Hospital Museum.

They tended to present history around medicine as well, and the idea of cure and treatment, and changing disabled people.

We also found disabled artists' work as well. But most of those collections about not on display, most of them were hidden away and not represented.

So what issues did these raise for the museum? I think it raised a whole range of issues. One of the things that was very clear was that curators were very uncertain about how they should present those collections. They were very unclear what they should do, and they were aware there were many issues which made these challenging in many ways, and many display dilemmas and issues that need to be considered. One of the things around this was the notion of staring that museums are about staring and looking and yet the experiences of disabled people are also about being stared at often. There was also the idea of should museum displays out disabled people who had perhaps chosen not to represent themselves as being disabled in their lifetime. Should disabled people be named? Many of those collections in museums were of nameless disabled people, people who had been in particular institutions, or had been represented in particular ways where they weren't presented as people but just as something which is nameless. There were many very difficult stories to be told, and very many issues of this kind and one of perhaps the very difficult aspects of that was the shadow of the freak show which people were concerned about how they would represent these issues within the museum, these historical collections. And perhaps one of the other aspects that is particularly difficult and significant in the context of medical collections is the disabled person is a specimen in the medical collection, framed by a medical model which doesn't account for the individual. Thank you.

CHAIR: Thank you very much that is extremely like the challenges we

face here at the Hunterian and about shaping the shared history of the medical museum and freak show, and about the medical museum's function in objectifying the specimens in the way we want to be (unclear) today.

Our second speaker is Professor Sandell who as you gathered is Jocelyn's colleague at the University of Leicester, he is director of museum studies. He has worked in the areas around museums and social inequality and museums in prejudice for some time. His monograph 2007, museum and the Reframing of Difference I think was a landmark in this area of study and since then as you have heard he has word with Jocelyn in the Rethinking Disability Re-presentation.

Professor Sandell: thank you very much. I will take up the story from where Jocelyn finished it on the journey of research and practice in this field. I am going to look in particular about our interesting, and our thinking about... around museums. I think it's fair to say we were initially as a group of researchers we were very wary of the making of museums, that project. As Jocelyn described we were interested in why disability was absent from so many different kinds of museum given there was increasing interest in museums generally in hidden histories and engaging with groups who had been excluded and again disability was absent and appeared to be largely absent across that spectrum. So in our discussions with Jocelyn and myself, and a fellow researchers and disabled researchers we worked with on this project, we knew that medical museums would hold rich resources that would have the lives of disabled people but we had the broader interest, we included Making museums in our remit and included all kind of museums. We set-out to look in ways that disability was represented within them.

Our disabled colleagues had particularly strong feelings towards medical collections, and I remember both Anny Delling that Jocelyn referred to and our colleague Jacky Gain they went to see the medicine man exhibition at the British Museum and came back with all sorts of often strong reactions to the ways in which objects in that exhibition were displayed and interpreted and a couple of them came to mind.

There was an amputation saw (check), and Jackie was shocked I think it's fair it say the interpretation focused exclusively on the ornate design of the handle, beautifully inlaid pattern on the handle.

Also around the technology of the blade itself which was described in terms of being designed particularly to be able to separate bone from flesh. There was no space within that interpretation for her own response as an amputee and that curatorial voice was one she felt excluded by. Nevertheless, we included medical museums in our initial surveys when we started to take research further, we worked with the Royal London Hospital Museum and archives hastily and I went on the first visit with Anny Delling and her being anxious I remember, and her talking about her unease and she was excited about going to the other museum and getting into the stores and seeing what material they had.

She was rather more cautious about going to a medical museum.

Having said that, we found things in those displays which Anny felt uncomfortable with. She found them difficult but she was also very surprised by the way some of the interpretation helped to disrupt certain ideas about disability, which she had expected to find. I remember there was an early example of a hearing aid which was extremely large, huge box. It was in the story that the museum told but not to stand in and corrected to a patient but rather it was the hearing aid used by a patron or benefactor and it was used by a matron celebrated for her advances in the medical world and patient care and so on.

It was interesting I think quite political curatorial acts which were designed to not simply locate disability in an entirely medicalised way. That was interesting.

We employed the film-maker David Hevey to develop one of the interventions we spanned across different museums and the one intervention in a medical museum. He decided to focus on Joseph Merrick more commonly known as the Elephant Man and his relationship to disabled people today. I want to read you briefly what David said about his aims really and this film and then I will show you a short clip. The film-maker said early on in the project Jonathan Evans the curator at the Royal London Hospital Museum told me the various Joseph Merrick's interpretations from the well-known film by David Lynch, to the opera, say less about the real Joseph Merrick. And very early on it was apparent to me that in the cacophony of voices and told versions of Merrick's story the one voice not heard was that of those most like him disabled people. He set about creating a new narrative around Merrick and drawing on the collections in the museum and particularly to make that connection with disabled people today, and I will show you this short - a couple of minutes... clip.

Coming up now... maybe is it possible to dim the lights?

Video: (no sound yet...

Professor Sandell: we will see if we can fix the sound, we had a problem earlier.

pause...

Apologies for our technical disruption!

CHAIR: We will proceed without the film and have a go in the break, then we will try after the break, we had had it working half an hour ago, you will have to take our word for it!

Professor Sandell: no worries, we have the film... after the commercial break! And it's online for free with our website, we also have copies of the DVD which lasts around um... 15 minutes. We can tell you a bit more about that here.

What our attempt was um... in that project, was to interweave the more familiar authoritative curatorial voice of the museum alongside those very, very personal highly emotional responses to Merrick's story by three disabled people who offer experiences and made connections based on their own lived experience, particularly this is (pause) one of those participants in the project, Tina who talked about her experience and disfigurement and being stared at, and imagining as well on a fictional journey of shared empathetic experience with Joseph Merrick. What was interesting I think to see that situated alongside other films within the museum you can watch around Merrick, and to say as the film-maker said it was that connection, the voice that was privileged then with disabled people, and that had been largely absent from the museum until then. I should pause there.

CHAIR: Thank you for bearing with us with our technical difficulties. I'm delighted now to move on to our third speaker Dr Ruth rout Richardson who is an independent scholar, and associated with a number of august institutions the University of Cambridge, and Hong Kong, and the book *Death dissection and destitute* which peaked my interest in the history of anatomy in medical museum, and to blame for my presence here today! And among her other books were the *Making of Mr Gray's anatomy* and she's working on a book on Dickens and the workhouse. She has had a long association with the Hunterian here, and it's on those associations you might chat to us today.

Dr Ruth: yes, if you can see my slide, if it's too light please tell me... yes, now this is all... a specimen which I actually love, it's upstairs in the gallery, and there's a post card of it as well. I love it! It upsets me very much because it's only a partial skeleton the head has gone and the arms and legs are gone. It doesn't say who it was, and like so many specimens it's anonymous. I think it's a lady because the pelvis looks like it to me but I might be wrong. It's also she's got scoliosis, I say "she" do you think it's a lady too?

GUS: NEW SPEAKER: I wouldn't like to put money on it! Laughter...

Dr Ruth: but there are more women with scoliosis than men aren't there? Yes probability yes. Well the reason I'm so engaged with it is because I have got scoliosis myself. Although I can walk about, and I don't look too disabled, it is a pretty disabling thing to suffer. You can also live a fairly decent life without labels because you can hide it more easily than someone who is in a wheelchair or who has disfigurement that is constantly on display. You wouldn't necessarily know I have got the problem but then you see the X-rays of me it looks rather like this lady's spine, I think it is a lady, I'm sure! Laughter... anyway, I like her, for me it's... the ribs are sort of wings. And there's something rather wonderful about it. There's also the sadness of not knowing who she was, not knowing where she lived, what she... how she managed the pain, and disfigurement of it. I mean having scoliosis is a funny condition. Although you don't look disabled you are. There's lots of things you can't do like walk long distances or stand in queues for any length of time or go around art galleries for any length of time. You can't stand up for long. Sitting still is difficult. You

have to keep shifting because you are so asymmetrical whatever way you sit is uncomfortable. The same with sleeping, it dominates your life but you try not to let it. So, I would like to know how she managed, I have a feeling she might have been a bit happier than me in so far as ladies of that age, in that time could wear corsets, and be unashamed of it and wear nice things that straighten you up and make you look even straighter than you might pretend to be. It might have been easier to have scoliosis then than now. No-one has called me a scoliotic, but that's what I am. I'm sorry for this lady, I don't think she wanted to be in the museum. I think a lot of people from that generation, which is 18th century she's from or early 19th, she would probably have been body snatched for the museum. Somebody knew she had scoliosis and wanted her skeleton for the museum like the Irish giant upstairs, and collected her body and cut off her head and arms and legs and kept the spine which was the bit they were interested in. It's hard to see this person as a whole person, it's hard to know... I mean, as a scoliotic myself I know that person must have suffered pain and all the disabilities that go with this condition. There's nothing in the gallery that says that, nothing upstairs that says that. To have a process like that developing within the core of your body... it is difficult! You get more and more... I'm shrinking with age and I know she must have shrunk there's four inches missing in height she would have had. That's the same for me. What else she couldn't do, and yet also what she could do. You know, disability, the word disability focuses on "dis". Whereas what is so extraordinary about what you can manage when you are "disabled" and yet you can still do things like Ju doing her artwork and so on. It's actually you don't want to be labelled but you can't help it, one is. And one labels oneself, and one limits oneself because of one's own lack of abilities. Then again, we think what the hell I'm still going to go on and do all these other things, and as a human being whether one is disabled or not. And that's what I loved about Ju's things upstairs you have the normal and the abnormal, I'm wearing my brooch and here we are with our labels and I think I should stop there!

CHAIR: Thank you very much, and I think why we were so pleased Ruth was able to join us this evening was to talk about the long-term connection with the collection and the experience, if you hire our audio guide at £3.50 a bargain, you will hear Dr Richardson relating the specimen at the time! Our fourth speaker whose slides I will manipulate here is Professor Gus McGrouther, Professor of plastic and reconstructive surgery research at the University of Manchester, he has a background in both surgery, and bioengineering, and is a specialist on wounds and wound healing, and is both an academic, and a practitioner up in Manchester. He is also a Council Member here at the Royal College of Surgeons. Those of you in the profession will know what an august position he therefore holds and the profession in England and Wales, and for Scots present! And what makes us pleased is he is chairing the museums and archives committee, and even more than the rest of the fellows members and council members he sees the nitty-gritty of what goes on in our department. I am delighted he is able to join us today.

Professor Gus: and I have my normal badge here and on the back it has a mirror and I can see a quarter of my face which means I have some sort of disability visually, long sighted or something. And I suppose none of us are completely normal,

and it's a question of how well we hide it. This is kind of the normal... and I trained originally as a plastic surgeon, and I do virtually all accidents and things nowadays. And this is the way people want to look, people want to be beautiful, and symmetrical. There's a huge pressure on the medical profession, particularly plastic surgery to sort of try and drive people along the norms that are dictated by the fashion of the age. Next slide... in fact, sometimes you can't make people very symmetrical. These are war-wounded soldiers from the First World War where the common injury was to stick your head above the trenches and have your face shot. Nowadays, that tends to be more explosives and coming up from below which are even more disabling. The challenge was to try to reconstruct these people to get them back into society, to give them dignity and self-confidence. These incidentally are not the British wounded but the German wounded who we shot and shoot the up and that's the trouble with wars, everyone suffers.

I have become very interested in looking at... not just looking at people and people's faces in terms of symmetry, and in a statuesque way and trying to look at how the body works, and we have done a lot of studies on the face, and limbs as well and looking at normal function.

When you are thinking about your hand you look upon it as a tool, it grips.

The surgeon it's pretty easy for them to restore that, you want something that grips.

You look at somebody's face, and it's a mystical thing nobody analyses what are all the muscles and what are they doing, and the eyes, and so on... and how the face works, it doesn't work like this, it's not a trap door! It works like this... and this was a slide that the Sunday Times got hold of in our collection, and there's a lot of subtlety and fine movements in the face which we would love to be able to restore as surgeons.

Of course, it's not just in recent times that people have been interested in facial movement, these are drawings of Leonardo da Vinci, and we can see he analysed the facial shapes, and the people on the left are probably disfigured and would you probably be meeting the people in the streets of my medieval town before there were dentists, and a lot of the minor things surgeons can achieve weren't treatable then... and history has moved forward. We see the detailed anatomical dissections of an anatomist... and so it's important for doctors to realise really the context of the age in which we live that the history of how we have developed an anatomical knowledge and how we apply to the treatment of patients. Museums are extremely important to teach doctors, we are a little bit disparaging nowadays about the acts of time gone by a huge amount of knowledge was derived from those activities which we have all benefited from to a greater or lesser extent. It's rather difficult to go back into history and know when you draw a line and punish the past. We do things differently nowadays. We consent to give bodies to science, and not yet consenting to bits of ourselves to museums, not very much, and we probably ought to be doing more of that and showing what modern surgery can do and you can have

any bits of me you want but not yet! Laughter... and I do think we should be showing things like hip replacements and things. Very interesting the point you make Ruth about the focus being on the spine, and one thing that's changed dramatically in museums and a microcosm of what's happening in society, museums were for doctors, surgeons, just to focus on one little thing and look at it, of a mental picture of what a (unclear) lay born looks like, and nothing attached to this and it wasn't part of a patient but I suppose I learned my patient communication skills at the bedside and learn my pathology in the museum. And it's all changed now and we should tie that together. Also museums are also for the public. Because the knowledge that is kind of kept away from all of you by us our predecessors, is no longer the way that things happen, there's knowledge out there on the web, the doors of this institution are open to the public, you are all welcome to come and see. I think we need to display material in a rather different way, and give it a human context. And perhaps doctors are frightened of that human context in the past, and things you couldn't really challenge. You know... in the past, we were really trying to keep ourselves emotionally detached from the pathologies we were treating, and I think now that's changed I think doctors are much more... they have to be much more aware of the whole patient context, and we are treating a patient and a lifestyle, and a family, in different situations.

Next slide. So having learned a little bit about anatomy and how things moved and we have done scientific studies, and we have done the study on how lips moved, this was a volunteer medical student, I wouldn't have failed his exams if he had refused to take part, and they put on the probes that look at how the facial muscles worked, and this was for facial reconstruction. So... the things we do now as surgeons we are trying to reconstruct people, and go as far as we can to shift people back into the body of society, and afflicted suddenly with an injury and get them back to near normal anatomy. We get partway there, and again just to show what surgery can do, this is a girl... and put up your hands anybody who has not seen CSI?

Oh! Channel 5! Laughter, you will enjoy it! And you don't want to sit in front of television every night of the week. This was a passenger in the car, and the driver felt so bad she offered a bit of her scalp and it's moved to the donor... and you see the scalp and we put balloons under the scalp next slide... the balloons are out and they both have a good head of hair. So these modern things are all based on our anatomical knowledge we learn from museum, that's why doctors come to museums. We can do all sorts of reconstructive things nowadays. But there are limits. This gentleman for example... the cement mixer at the top, and the diagrams are all the fractures and things, but they took off both hand and a leg, and on my side that's his left hand and the thumb... we couldn't do anything about that and we take all the spare parts and put them together. We can do these things now, and surgeons have to learn a lot of detailed anatomy, and they learn that from coming to place like the museum. We should actually be showing a lot of these operations in museums nowadays. These are the modern things we do. Also upstairs we have simulations. So they can practice... and doctors aren't practising on patients any more, young surgeons aren't practising on patients you will be pleased to hear, they practice on simulations. At the end of the day you won't get a patient who is

completely normal, and there are limitations we can't control this guy. What we are trying to do is we use the knowledge that's there from anatomy, and use the learning from museum, and try and go as far back to what's normal as you can, and try and boost their self-worth, and psychology, and this is a friend of mine called James Partridge who runs a charity called Changing faces, and he runs courses to give people confidence about any disfigurement they may have, and he did turn over a land rover some years ago, and this is his mark two face, and hands.

He is completely convinced he is normal, and he is and he has lovely children and runs this charity, and spends his weekends in Guernsey and basically has a wonderful life. He would not admit to any thoughts of dis-ability. So there are many forms of disability, and they may be functional, they may be unclear... at the end of the day what we are all trying to do really is to have people back in normal society, and have society accept them.

And one night I was in the tube and a chap was staring at James, and James turned to me, and said... and the chap immediately looked away, and he said don't turn away. If I saw me in the tube I would be looking at me too it's the normal reaction, and he started explaining he turned his Land rover over and I think by the time we came off this chap was ready to give a donation to the charity!

LAUGHTER

So... and it's a disability, everyone has a disability and we are really normal thank you.

CHAIR: Thank you very much, and extremely revealing about the surgical attitude towards museum which is interesting. And also running through it sets there the (feedback of mike...) unsurprising urge in medical profession to er... verify the normal, and the surgeon can get back to normal and reconstruct what that is. I think in that respect I think this is part of what Ju's work responds to. Ju Gosling is our final speaker for today. She is an artist, an activist, and a writer, and her exhibition Abnormal towards the scientific model of disability is climaxing its international tour here in its ninth venue at the Royal College of Surgeons. It's also I'm very pleased to say the subject of her recent book which is available at all good book stores or at the very least at our book store, and will be available as you depart today from the front hall. Ju I think will speak today about her responses to planting her work in this most medical of contexts.

JU GOSLING: Thank you. I reread the advert for this event I knew exactly what Sam was talking about when he said that within medical museums the human specimen is shown as an example of a disease, injury or illness, little consideration is given to the person who was once connected to a broken limb or a tuberculous spine. Now that was my initial response when I first visited the Hunterian museum, and led me to make a piece called the Memory Jar Collection. This is a piece that has been installed for the duration of the Abnormal exhibition in the centre of the museum's Crystal Gallery, which contains Hunter's collection of body parts.

However, it was only my initial response. As I began the research and development for the Memory Jar Collection, I realised just how valuable Hunter's collection must have been to generations of trainee surgeons. I also realised how radical and daring Hunter's collection was at a time when the church had only recently and grudgingly lifted its prohibition on autopsies. At best Hunter was operating on the edges of the law when he began his collection even when he was using body parts from his own patients. It would have been extremely unwise of him to draw attention to the provenance of the body parts by labelling them with the details of the person they had come from. And it would have been risky, to say the least, to remind anyone of the humanity of the person from whom the part had been removed particularly given the prevalence of beliefs about the literal nature of the resurrection. People might argue they would be resurrected without their arm. Within my research it was interesting too, to contrast Hunter's and similar collections within other medical museums with the role and nature of photography.

Because photography, even more than collections like Hunter's, has been used to categorise human beings or their body parts as either normal or abnormal since the first known medical photograph was taken in 1847. Indeed the vast majority of photographs that exist of disabled people throughout the 20th century are either medical or charitable, and the charitable images are closely linked to individual medical abnormalities.

I explored this use of photography to categorise human beings within the first piece I made when I was doing residency at the National Institute of Medical research that led to the exhibition. That's a piece called Abnormal 1 which you have a copy of in your packs. Within the Memory Jar Collection though, I question whether photography can really preserve identity any more than Hunter's collection does? Each of the 90 preserving jars within my collection contains a photograph of an animal or a human, focusing on one part of their body. Each jar is numbered, and visitors can consult the online catalogue next to the piece within the Abnormal website to read about some of the memories that attach to the images and so the identity is apparently very clear and you can see who the person was what the relationship is with me as the artist or collector.

However, I also encourage visitors to reflect on the fact that we have no idea of the identity of the majority of people in the photographs that exist today.

We have all seen huge boxes of photographs when relatives die with no labels whatsoever, and I have been working with another exhibition in Camden where they have a box of photographs from a society and one of the people from the early 20th century and the captions say things like "tea on the lawn"!

So you know, in the future, will photographs really preserve identity any better than Hunter's collection does? With digital photographs most of us don't even print the photographs out. And so, when you also me to reflect for a few minutes on the subject, I thought well the real issue to me is as I think people have identified, how medical museum present their collections. To what extent are the collections

presented uncritically? To what extent are visitors encouraged to reflect on the sheer diversity among human bodies, and to what extent are they encouraged simply to divide humans and their body parts into either normal or abnormal? To what extent are disabled people encouraged to engage with the exhibits and the way in which they are presented? Are disabled people visible within the museum's staff and volunteer workforce? Above all, does a medical museum encourage its staff and visitors to believe in disability as being a medical condition, a personal problem that only the medical profession can solve? Or does it present impairment as a normal part of the human condition, and encourage staff and visitors to recognise the attitudinal and environmental barriers that prevent disabled people from participating fully in society? This in turn is reflected in the extent to which museums ensure that humans of every age and physical type are included in their activities, for example by ensuring that events like this are made accessible by providing interpretation and other services like a Palantypist as standard. I would argue that the collections themselves are neutral in their meaning. We are all capable of seeing the connection between the macro and the micro, of recognising the enormous contribution to human knowledge that medical collections like Hunter's have made. What gives the collections their meaning is the way in which they are curated and presented, and the historical and social contexts in which museum operate. But really I'm interested in learning about what everybody else thinks.

CHAIR: Thank you Ju and to all our speakers, I suggest we digest this buffet of different opinions on medicine, museums and disability, and go away for just a moment or two, and then we will reconvene and perhaps have some questions or and discussion thank you very much to our speakers.

APPLAUSE

Break.

CHAIR: If you care to take your seats, ladies and gentlemen? What we will do first, we think our colleague has worked his magic wanders over the computer. We will have a go at starting this...

Video: the hat is made of felt and the bottom the veil is made of linen, it's got a single eye hole and has a peak as you can see.

Tina: when I had long hair I used to hide my face lot with my hair, a security blanket. I felt protected by it. He was literally thought of as a thing, an animal, and people actually think that now sometimes about disabled people.

I guess that he just had to hide away from it through that hood to protect himself against the harsh comments and stars.

Jonathan: the hat is the size of the circumference of a man's waist, and it indicates how large Joseph's head was, it caused him great difficulty throughout his life the overgrowth of bone.

I think it's natural to be interested in difference.

When I look at a picture of John Merrick I want to know what his face feels like I want to touch it, I want to know whether it's lumpy or squigy or hard. I think that's natural. What I don't want to do is fear him or ridicule him as so many seem to have done.

But what is it like to be stared at and isolated this way?

Tina: oh public property! You know I like many other people we are public property. We get on a bus, we are a spectacle. From the moment we open the front door we are a spectacle. You have to be prepared for that. Be prepared for the onslaught.

Richard did you want to reflect on the video?

Richard: just to really reemphasise he is trying to insert a new story on top of the other stories which are there around Merrick, and which were privileged with a personal emotional and human response to a collection, and story and seeing that alongside the more familiar curatorial course through the archivist.

CHAIR: Thank you and very glad we can show you that and we have a good 30 minutes for questions and discussion, I know our panellists are eager to ask questions and in the interests of democracy I would like to open it to the floor. I will seek to give everyone the opportunity to ask a question my colleagues will get to you as quickly as they can with the microphones. If you will be patient with us, if you would like to ask a question just wave at me, I will try to come to you in the order in which you have asked the question please the first question at the front.

Audience: Thank you, I'm Ms McBride an international broadcaster and covering the Film Festival, and many movies there not saying good or bad, but um... this year for some reason many movies have to do with the mind and dysfunctions of the body and mind, Let's talk about Kevin, Take Shelter, and the Hut in the woods, and even one in which someone kills a disabled person because they look different. So I'm glad that the doctor mentioned the television, and my question to the panel is the art is due, I saw the exhibition last time I was here, is um... how much do the media, and the people in communications have a responsibility to address the issues that you yourselves are suggesting, and how to make the rest of the world through media help in changing attitudes in challenging prejudices? I myself would very much like to help, so that's one of my questions.

CHAIR: Ju? Do you want to respond?

Ju: it's an interesting question... I think you probably have to distinguish between the purely commercial media, and the responsibility to their shareholders and the publicly funded media and responsibility they might have to the rest of us.

It's certainly something I feel very strongly about, it isn't simply disabled people who are largely invisible. All sorts of people are invisible within the images we see around us. But I think what we tend to get in the 21st Century is very much freak show television. I think in terms of responsibility, I would very much like to pick on Channel 4! I would link you know what I would describe as freak show television back to what I have described in the exhibition as a scientific model of disability where we believe disability and ageing are things that will shortly become part of our past, and every day media have new stories about drugs for mortality and research that will prevent ageing, and... if you believe that disability and ill health and ageing are shortly going to be something in the past then they will be of curiosity value now, and you go back to programmes which show you what a 19th century freak show, and disabled people doing ordinary things, and because they are disabled this is somehow felt to be extraordinary. And also there's also a huge focus on their impairments. I public on Channel 4 because they are publicly funded and also because a great many of us as disabled people were quite I don't know not happy I should say, to put it politely when the Paralympic coverage was taken away from the BBC who have an outstanding way of covering sport.

The first campaign they did was called Freaks of nature.

I don't think that's helpful from Channel 4's position having to refuse to apologise, Channel 4's position is when you see the programmes... you know, it's all very different, and with a we have is exciting new science about their disabilities. I just sit there in despair, I think well there's nothing exciting or new about focusing on people's so-called inabilities, and you know highly inappropriate I would have thought when you are looking at them in terms of sport. But everybody who watches Channel 4 sees the marketing campaigns and very few people actually watched the programmes around Paralympic athletes. As co-chair of the national charity, I have an appeal from them recently they wanted to make a series called the "Undateables" and there's a paragraph when you watch the programme the graphics will show the "un" disappearing but I don't think that gets through to the population. But it's not simply disabled and deaf people who are invisible but the vast majority of us are invisible within those images.

CHAIR: Ruth you had a comment?

Ruth: no I just wanted - wondered if people wanted to make a comment

CHAIR: Yes you are very welcome and you don't need to do the academic thing of making a comment and pretending it's a question!

LAUGHTER

A comment or a question... here and then here...

NEW SPEAKER: Funnily enough Ruth this is a comment! And just to pick up on what you were saying before, I was actually quite involved with that the initial

freak show, the faces kind of er... programme and also, I was invited to audition for the dating show but I wasn't disabled looking enough! For their show...! And I had a very direct conversation with the people who run the people who do the shock and awe shows, and I had a frank conversation with them about the naming and portrayal of those shows. Because I think it's really important that that sort of experience is out into the world and more people get to see the lives of disabled people and kind of to normalise disability in society, and so I kind of had this conversation with Betty about naming. And they gave me the classic response the way they name the shows is to make people who want to see a freak show watch the show, and then give them this kind of like reversal on their opinion of the show. But... to be honest I reckon that they failed in that fact! They seem to have just made their shows exactly what they are trying to stop people seeing, and it's a terrible thing to see.

CHAIR: Thank you, comment here?

You first... no you...

Audience: I will try and be quick, I have been deaf all my life, and I have had a lot of support from my mother who tried to lessen the disability, and say it's only hard-of-hearing. And I had to train in speech and so on which has helped me. Something wrong...?

CHAIR: No I thought I heard a telephone sorry.

And it might surprise you when I was a very small boy I thought that liars were disabled in some way in the mind, have you any comment about that. People who told lies were disabled.

CHAIR: Any comment?

Gus: I had a colleague whose father had an amputation in the war, and when she was about three or four she went swimming and she said, your father has got two legs! It's all a question of what you are used to...

Ruth: yes something you mentioned about your mother... helping you... so much, when I saw the picture on here about the lady and her beautiful collar, and appearance, and I thought she must have had help to dress so beautifully as that. That's the other thing we lose, we might see the disabled person and we don't see their helpers. You know the lady with scoliosis I have talked about in the gallery, we don't know, there's no record of the social background of that specimen or most of the specimens actually. There's only a few where we do know about their stories. You can't rebuild them and I think the idea of getting other disabled people to comment is interesting.

CHAIR: A very patient lady here.

I'm Grace and I work in the learning department of Natural History Museum. So... the thing I'm trying to get across to are my supporters is the fact we have animal that are real but not alive and children find that hard to take in that fact. I was really interested by Gus' talk you showed a picture of the soldiers injured in the First World War. I don't know if you know... but I'm researching about the history of the learning of the Natural History Museum. And it was the soldiers injured in the First World War who were responsible for first handling collection for education at the Natural History Museum in the 20s in the basement when they first started to be able to handle some of the objects and it's going into our database today and looking at how you can help people with a particular need it helps things for everybody.

CHAIR: Thank you.

Gus: I'm going a bit deaf too and I couldn't follow the end of that,...

CHAIR: It was a comment!

Gus: thank you... and obviously you see my hearing... I'm being nagged to get a hearing aid...

CHAIR: The lady at the front.

Audience: I'm 86 years young! And I would like to challenge the medical profession. Three years ago, I was given a knee replacement, a dynamic hip operation... which sounds painful but the thing is the mental and emotional aspect after every operation is not taken on board. Although I'm registered severely disabled my brain says get on with it girl! I do, and I lead a very full life writing poetry, and letters and articles, and so I think that you don't do your job properly, and you should really take on board the mental and emotional aspects of every operation! I still love you but....! Applause...

CHAIR: Professor Gus: I will quote a book about Jonathan Sachs who wrote... oh Oliver Sachs sorry who wrote a book about her broken leg, and he described how the orthopaedic surgeons came round every morning, and looked at his X-rays and said um... not much change or um... maybe getting a bit better and walked on. And never spoke to him. He kept trying to say that he had lost feeling in his leg, and eventually got the message across, and they just completely ignored it all they were interested in was the bone. Now... this is a problem with orthopaedic surgeons, and actually, it's a problem with all surgeons. But there are doctors who are very good bedside manner, and by and large the gynaecologists and obstetricians have great bedside manners. Any other specialities do, it's a strange thing, and people are a bit typecast in general surgeons are not terribly good at thinking about the whole patient. We are doing our best and getting more girls into the profession, I think that's changing our attitude as well. I think through meetings like this, and through realising that we are opening the doors of our institutions to the

public, I think we are actually getting better at communication. But we have a long way to go.

Audience: I think the nurses ought to get back to bedside manner.

Gus: I think nurses are getting worse, and I hope the doctors are getting better.

Ju: and can I add something? I was really interested when you were saying you didn't feel disabled, and I think you know one of the things we try and do as disabled artists is say well none of us fit the stereotype, you know this imaginary disabled person, I don't think a single disabled person on this planet feels disabled if you think of the stereotypes. Again, the difficulties even complete absence of images and focus on medical images and charitable images and freak show is that we still can't actually get our heads around the fact to be disabled is just a normal part of the human condition, and we are just normal people just like everybody else, thank you for that.

NEW SPEAKER: I'm not sure if I'm being fair but I get the general impression by the committee there that it's on the visual side of disability? But... what about deafness? Or what about disability like mental illness why isn't this mentioned?

Richard Sandell: I will start, it's a really good point we had a lot of discussions around... um... our early research into this area. We were asked by a number of people particularly museum curators how do you define disability? Who is in and out? Do you want to look at... we were asking what is held in collections, and so... you know curators would come out with trays of spectacles, and say does this count? Is this - does this fall within the boundaries of your project, we discussed that we had a think-tank of disabled people at the heart of the project. We were very quickly urged to challenge that response in museums, and to resist the temptation to have fixed boundaries of who is in and out and what counts as disabled, and what doesn't. And instead to keep a loose and open definition, and I'm slightly dodging the question but at the same time, we made an effort without going through a kind of very laborious tick box exercise, we made an effort in our project to bring in people with very diverse experience, which included sensory impairments, and to tell their stories through museum collections. But without trying to kind of have one of every group, we did want to reflect that diversity of experience.

JU GOSLING: I get the impression museums often, historically not so much today but object-based they are, but I was struck with the idea that somebody's chair or hearing aid was on display, and you know I think that also brings in the idea that we as disabled people are part, our equipment is an extension of our body, as if they couldn't get the body parts on display, almost the next best thing. I think the difficulty is when you tell the story of deaf people or people with learning difficulties or the stories of the asylums there are very few objects left. We

have in terms of the asylums we have the buildings, and they themselves can be evocative, and I think that's why the modern museums and oral history of disabled people and the history of disabled people today is so important because we can't always go back, and find those stories where they haven't been recorded.

We did some research for Colchester museums who were interested in disabled people's view of museums and heritage, as part of that research we did work with deaf communities as well. One of the big things that emerged from that was many deaf people were not identified as being disabled but as a linguistic minority. That was a very strong finding from that research of a desire to be seen in a different way, and to have experiences presented in a different way as well. I think there's a very politicised aspect as well.

Audience: a question... but a point really interesting that's come out of all panel discussions is this relationship between the past, and the present. Hold the microphone up to your mouth please... and the idea that museums sit a cross-section between past and present and dialogue between past and present. And thinking particularly about the Hunterian museum as a relic, and historical model in itself, how do we reflect our current thinking in the way that disabled people are represented and treated by society today whilst preserving the historical contingencies in which that collection was created and it stand for, is the way to do that through the exhibitions and interventions that provide a different perspective on historical collection or something we can do that's more embedded and permanent to address that balance and create that dialogue?

CHAIR: I find my colleagues looking at me! Laughter... I think your question is framed excellently you have noticed the way we do it is to leave little interpretation around the original Hunterian specimens, and to bring excited contemporary work like Ju's as a temporary exhibition and bring in perspectives like Ruth in the audio guide. We haven't adjusted the core, very medical interpretation in our central collection. We don't plan to because we would like to leave it as flexible as possible. All interpretation in museum as we know is very layered. What we would like to do imaginative exciting things with the layers.

Richard: I think it's a great question, and to add to this or think about this is prompted by Gus thinking about the museum in the past being for doctors, and I think we are all convinced of that value of the collections for medical advancement. I think that's something that's come out from all the speakers.

That was then, and the museum was closed and to the public, and it was for doctors only and now the museum is open to the public, and so we have got the events like this and temporary exhibition and so on beginning to reconfigure the stories that the museums tell us for the massive change of reality which is that the public in all this diversity can walk through those doors, and have the responses or perhaps not enabled to have the responses we want. I think you know maybe... as well as the wrap around stuff you end up needing, and I think this goes with all kind of museums to think of them, they tend to lag behind the times, and maybe it's time

we should embrace that fact and they should change and be achieved to the sensitivities of the day really. In this context that's a demand from disabled people to be able to see different kinds of stories in there. Otherwise the problem with the temporary stuff is it goes, and that's... and this event is really stimulating but we can put it on the web and so on but a more permanent thing to carry on which is troubling sometimes.

CHAIR: I think we should undertake some academic partnerships to fix the situation! Perhaps with the memorable University of Leicester!

Can I say that I think perhaps what we don't do enough in museums is to ask questions.

Often we think about interactivity in museum as doing what I think are clunky interventions often. And the most interactive development is when you get people to engage and think. We don't even pose questions about the significance of collections like this, and they are of historic significance and the relevance and significance in the contemporary world. It's those questions we need to ask, we need to ask them in a way and whilst technology and the context in which the historical context gives I think much more privilege to contemporary values, and context and I think that we can't have specimens of parts of people on public display without answering some very, very challenging questions about those.

Audience: hi this is perhaps a mean question but follows on a little bit from what was said I wonder how public the museum really is? I realise I came with a colleague, we have been studying in London for several years, and my colleague didn't know where we were going, and I'm just... I mean it's kind of a mean one to ask but...

CHAIR: No it's a very good one, and one that we are very keen to answer because we are working to expand our audiences and diversify our audiences and my colleagues at the back here you see before you our excellent learning events team whose job it is to expand those audiences. We have increased our profile and visit figures four-fold in the last decade we look to continue to do that. What we will need of course is resources, and support from the council and Trustees of the Royal College of Surgeons and we will continue to try and do so with their support...

LAUGHTER

JU GOSLING: I think when I brought the exhibition in my opening concern was it, what kind of audience will it be? I have to say I have been to three events here since the exhibition opened six weeks ago, I have been astonished at the diversity, big draw on Saturday and so many people of every age and description, I didn't know this museum was here till two years ago, and apparently it's for visitors too, you have a very big and diverse and interested audience, of literally every age.

CHAIR: May I ask how many people if you have raised your hands if you hadn't visited the Hunterian museum before this event series?

Gold dust!

LAUGHTER

CHAIR: Any further comments or questions?

I have got two comments, one is that I think the collection is absolutely priceless. There's been such a terrible disruption of medical museum in the last 20 years or so and institutions not valuing their collections and looking after them. Although I would be more sympathetic with the person in the bottle and thinking oh dear how awful it must be it to be a person in the bottle but the museums are priceless. To lose the objects that are in bottles because there's no funds or no commitment to them is worse than having the person in a bottle in the first place, and just to neglect them is to me a criminal act. So I'm very worried about medical museums in general. The other thing I wanted to say is that anonymity is a funny issue, a strange issue, it's there at the time of Hunter because of body snatching, and he didn't want to identify whose bodies he had stolen he was interested in the pathology.

But now we have people donating body parts and so on to museums, and I know of a case at Royal London of a woman who donated her skeleton, and someone who did to St George's but in both cases the one in the Royal London I wanted to tell the woman's story. I wasn't allowed to use her photograph unless I blacked out her eyes and she donated her body in the 1940s and she was one of the first benefactors as far as I'm concerned of the National Health Service. I refused to black out her eyes, and if the Queen gives money they are a benefactor, but I wasn't allowed to publish the photograph because of anonymity rules about specimens!

It's bizarre.

And the other one the... person who is in the dissecting room in St George's in his little glass, and the other side was me with my scoliosis there standing next to the egg on the plastic dwarf in the dissecting room (achondroplastic).

He is not named!

Unless you ask about him you are not told who he was, what the nature of his bequest was, you know, there's no caption to say this man whatever his name was... donated his body to this room. He is in this room to be sociable with medical students that's why he was there! Applause...

CHAIR: You leave us hanging there with a provocative question, on an evening that I hope has been full of provocative questions. If you come away from this evening with more questions than answers I think we have done our job well. I

would like to bring the formal part of this evening to a close by thanking my colleagues both within the college, and from the logistical support, I would like to ask you if you have found on your chairs a small card relating to speech-to-text, there's a green tray to put it in if you found the speech-to-text useful. The red tray if you did not. I would like to ask my colleague Amy to plug our next event?

Well the actual next event that fits in with this theme is Friday 11 November when Ju is holding a free full-day workshop. It's free! No charge! If you have the time book onto it. You can find information about that on our website and Facebook, and can you find all the information about the events on our website that we have coming up. Please do look up on our website events not just about Abnormal but wider issues within the RCS as well.

CHAIR: I would like to thank you all for coming and reserve our last thanks to those who have generously given their time to our panel this evening, thank you.

APPLAUSE

If you have found the text useful, please place the card in the green box, if not then red box. Thank you.