



# Audience engagement and response

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## 1. Introduction and context

Responses to the Exceptional & Extraordinary performances were collected directly through response cards and interviews, and through the Twitter account @UnrulyBodies.

**Response cards** were handed out and collected back from audience members at each performance, except at the Royal London Hospital Museum. In total, 170 response cards were completed by audience members and collected by researchers.

The response card asked participants to respond to the question ‘What do you think about our attitudes towards difference?’ A few participants had issues with the question (e.g. who the ‘our’ referred to) or felt that they needed more time to reflect on their response. Responses were analysed without a prior framework or structure to explore the ideas emerging from them – these ideas were then developed into ‘codes’ or categories which could then be applied across the 170 responses. Responses were categorized in multiple ways, as some responses responded directly to the question as well as discussed the experience and impact of the performance.

Response rates have been estimated for each venue, and across the 12 public performances.

Venue	Number of responses	Number of performances	Final audience numbers	Response rate
Science Museum	23	2	314	7%
Royal College of Surgeons	29	2	171	17%
Thackray Medical Museum	32	3	164	20%
Royal College of Physicians	47	2	178	26%
Bethlem Museum of the Mind	6	1	32	19%
Surgeon's Hall Museums	16	1	102	16%
Langdon Down	17	1	76	22%
Royal London Hospital Museum (invited only)	-	1	21	-
<b>Total number</b>	<b>170</b>	<b>13</b>	<b>1058</b>	

Other events where elements of Exceptional & Extraordinary were presented and debated, including conferences and seminars for medical/arts/museums practitioners but excluding Museum Studies students.

Event	Date	Final numbers
Canadian Museums Association – Keynote Fellows lecture	13 April 2015	240 museum professionals
Michael Volkerling Memorial Lecture, Te Papa Tongarewa, National Museum of New Zealand	23 September 2015	200 museum professionals
HTW University, Berlin, Germany – invited seminar	11 November 2015	45 students
“With all the senses: the inclusive museum”, Historisches Museum	12 December 2015	150 professionals

Event	Date	Final numbers
Frankfurt, Germany – keynote lecture		
Hong Kong Study Week, Hong Kong, lecture and workshop	9 January 2016	16 Hong Kong museum professionals
Arts Council England Away Day	28 June 2016	23 ACE staff
London Medical Museums Group	22 June 2016	28 museum professionals
Medical Students training, University of Leicester	30 August – 2 September 2016	13 students
Waving Goodbye to Victorian Dad, MShed, Bristol Museums	15 September 2016	42 museum professionals and performers
InSEA Regional Conference Art & Design Education in Times of Change, University of Applied Arts Vienna	22 – 23 September 2016	250 art & design educators, Museum and Gallery Professionals
The Relevant Museum, Trondheim, Norway – lecture and workshop	19 October 2016	85 Norwegian museum professionals
Plus Tate Network, invited speakers, Tate London	10 November 2016	48 museum / arts directors and senior managers
Art& Accessibility: museums and projects for people with disabilities International Conference Florence, Palazzo Strozzi	10 – 11 November 2016	200 museum professionals
	<b>Total</b>	<b>1,340</b>

Fifteen **interviews** were carried out with 18 individuals (some of which were in pairs or small groups) at the end of 8 of the public performances. There was no standard format for the interview, as researchers were encouraged to have ‘a conversation with a purpose’ rather than a structured interview to reflect on, and capture, the interests of the participants. Interviews were short (no more than 10 minutes), and recorded on iPads capturing the immediate responses within the context of the post-event environment, reflecting the atmosphere of the venues. Interviews were immediately annotated to explore the main themes being discussed, drawing comparisons with the categories emerging from the response cards.

**Unruly Bodies** (@UnrulyBodies) was set up to tweet about the project and performances in May 2015 and to date it has 719 followers. Since the account was established, 783 tweets have been made or retweeted from the account. Analysis of tweets linked to @unrulybodies or marked with the hashtag #unrulybodies identified 123 responses, once tweets made by the museums, project team, artists and any un-related tweets (e.g. there was a conference using the same hashtag) were removed.

Twitter analytics can give an impression of how many people were reached by the Tweets made from @UnrulyBodies for the months of February 2016 through to 20<sup>th</sup> September 2016. The table shows that the month with the highest number of impressions (55.6K) and the highest engagement rate (2.1%) was (unsurprisingly) June, when the performances were taking place.

Month	Impressions <sup>1</sup>	Engagement rate <sup>2</sup>	Link clicks <sup>3</sup>	Retweets	Likes	Replies
February	5.0K	0.9%	2	13	22	4
March	4.4K	1.3%	12	16	14	0
April	11.3K	1.4%	24	27	40	4
May	33.5K	0.9%	34	91	84	6
June	55.6K	2.1%	95	231	291	30
July	10.9K	0.5%	4	17	37	1
August	5.6K	0.7%	4	14	21	1
September (up to 20 <sup>th</sup> )	3.5K	0.7%	0	2	11	0

The RCMG website also has a dedicated page for the Exceptional & Extraordinary project (<http://www2.le.ac.uk/departments/museumstudies/rcmg/projects/exceptional-an>) and this attracted 2358 unique page views between October 2015 and January 2017. The project also has its own website (<https://www.unrulybodies.le.ac.uk/>), which launched in December 2016 and to date has attracted 369 unique page views.

## 2. Key themes emerging from the evaluation

The artworks and performances proved to be a powerful stimulus for provoking public discussion, both as part of the panel debates and in discussions and interviews that followed. There is also considerable evidence that thinking and debate was enriched by engagement with the project and its key messages with participants taking up and discussing key ideas presented during the events. Excitingly, a number of participants were prompted by the events to express their demands for change and their intention to take some form of action to promote greater public understanding of and respect for difference.

### **2.1 Society's attitudes towards difference are complex, negative and damaging**

Through the response cards, 61 respondents gave their opinion on how society views difference (in direct answer to the question). A key idea emerging from these responses is that society has, at best, a complex, ambiguous or contradictory attitude towards difference, and, at worst, a very damaging, negative, even divisive attitude. Some respondents suggested that attitudes towards difference were much more positive today but largely, respondents were pessimistic about the way in which society views and deals with difference. Reasons for this included fear of difference (which is seen by some respondents as equally 'natural' or part of being human), the desire to conform to a version of 'normality' which excludes differences such as disability, and the power of the media, government and medical profession who help to shape the values of society.

At the positive end of the spectrum, some participants (and particularly older respondents) suggested that society has a much more positive attitude towards difference than in previous

<sup>1</sup> An impression is where a tweet has been delivered to the Twitter stream of a particular account – this does not mean it has been read but indicates how many times it showed up in users' timelines.

<sup>2</sup> Engagement rate is the number of engagements (the total number of times a user interacted with a tweet e.g. clicked on it, retweeted it) divided by the number of impressions

<sup>3</sup> How many times a link in a tweet was clicked / accessed

generations. For example, Conor, a Retired Prof. Paediatrician (Langdon Down Museum, 7 June) took a historical perspective to claim:

This item was extremely well acted and thought provoking. The subsequent discussion was unbalanced and it implied that individuals with disability are still rejected, treated without consideration of their needs and subjected to hardship in the same manner as in the 1850s. Individuals with Down's Syndrome who used to die aged 10 now live to be 60. They now receive a standard of medical and surgical care of which Dr Down would be proud. Discussion of this was not allowed.

Other responses were based on personal experience, for example KT (aged 58, Royal College of Surgeons, 8 June), who worked in a 'positive upbeat SEN environment' outlined her 'personal view' that 'we celebrate difference / diversity. I can see there is a place for historical 'fixing' but the parents / carers of the vulnerable pupil population I lead would look towards a better, more optimistic future - the film's 2nd half was more in line with my agenda.'

Some respondents expressed a more complex view of how society views difference. Shirley, aged 61 (Royal College of Physicians, 20 June), for example, emphasises the range of attitudes towards difference that can exist within society: '...many people have attitudes towards difference and that can range from an awareness, a curiosity all the way through to intolerance.' Jean, aged 74 (Science Museum, 29 June) had seen massive changes over her lifetime but suggested that there was still a way to go until society fully accepted all differences:

... Things have improved since I was young as can't remember seeing any disabled young people. There is a lot more that can be done to make buildings and work places much more accepting and children taught about disability at a young age. At home and school, hearing aids and disability aids have got a lot better, and disability sport has helped a lot, but employment opportunities haven't moved forward much so let's all pull together and put disability at the top of the agenda. For change for the better.

Alexis, a student from the US, (Surgeon's Hall Museums, 15 June) had a similar response, thinking that whilst attitudes towards difference 'have come a long way, there is still a lot of progress to be made. We recognise and see people for more than what they are, the disability, they are people who are contributing positively to society but at the same time we are taking away people's ability to access services and ways of getting around...'

Denise (Langdon Down Museum, 7 June) also suggested that whilst difference is not stigmatised in the same way as in the past, wider social issues and challenges can influence our attitudes:

We are more tolerant of difference now... even in the last 50 years attitudes have become dramatically different. Most people have a level of respect for the person, they do not see them as substandard or of less value because of their difference... People respect human life in its different forms. But as one of the speakers said today, it is not a linear line (*of improvement*), when there are other challenges or problems in society, people become more inward looking but that is not to do with disabilities but a natural reaction when times are hard.

At the other end of the spectrum were pessimistic responses about society's attitudes towards difference. Austerity, the cuts to welfare and support for disabled people in the current political climate – referred to in David's film and Francesca's performance, and talked about in many of the Q&A discussions - played a role in shaping these negative perceptions. Catherine, aged 55 and

disabled (Thackray Medical Museum, 18 June) agreed with Francesca that attitudes towards difference had got worse in the current political and media climate:

Loaded question! Assumes I think of myself as 'normal' in the first place. I am one of the Thalidomide survivors and I agree with Francesca that attitudes to difference are getting worse at the moment. Culture obsessed with 'body perfect' whatever that is?! Women abused online / in public makes it very difficult for any female - let alone a disabled one to put their head above the parapet.

Sheenagh (Thackray Medical Museum, 14 June) thought that the recent cutbacks to welfare and support showed that any change in attitudes towards difference had been tokenistic rather than constituting real change:

... If 'our' is wider society, including places which should value difference (e.g. local universities) then not so hot! Generally - cutbacks are showing that much earlier access provision and talk was tokenism.

Zoe, a member of the Deaf community, (Surgeon's Hall Museums, 15 June) talked about the differences between the disabled and Deaf communities but shared a similar frustration to the challenges they faced in the current social and economic climate:

Deaf people maybe have a different agenda (*to the disabled community*) as a language minority, although there are obvious parallels where we are fighting for the same thing, you know, sign language is normal and no matter what your body is, it's normal. Thinking about how society views disabled people, it's really quite ambiguous at the moment... people have to prove themselves, obviously there are funding issues and cuts so actually tonight was really thought-provoking.

Julie, an artist, (Royal College of Surgeons, 22 June) was shocked by the reality of being disabled in the current social climate:

I was pretty shocked, I think it was Francesca who talked about the non-linear progress (*of society's attitude towards difference*), in fact we're going backwards re the rights of people with disabilities. I thought it would be a linear move up, I mean I know about the cuts, austerity and stuff but hearing about people losing their cars and the rights to live their life, it's unacceptable.

Other reasons for society's negative attitudes towards difference included a concept of 'normality' which excluded many types of difference, the values held by society, and a 'natural' fear of difference (which some respondents linked to evolution). For instance, this medical student (Female, aged 20, Royal College of Surgeons, 8 June) suggested that the concept of 'normality' was to blame for negative attitudes towards those who deviated from the norm, made worse in the current political, social and economic climate:

I think negative attitudes towards difference have persisted through history due to a continual narrative of comparison to the 'normal.' This normality concept will continue to be damaging to social if deviation from a society defined construct forms the basis of judgement. A culture that views judgement as our prerogative is continually fed by the current political climate. Neoliberalist theory that state should be minimally intervening and support free markets is inextricably linked to this. The cuts to services now are a result of this and ignorance to the fact comparison to a norm is a reductive and unfounded basis upon which to assign worth to difference.

A lack of understanding, exposure to, or experience of difference was also suggested to contribute to society's negative attitudes, as these two respondents reflected upon:

Unfortunately, often humanity does not like what it does not understand. It does not want to take the time to understand unless it affects them directly. Things are changing slowly, very slowly. Often what people do not remember is that we are all different. So they go with the 'norm' / peer pressure. Some difference become acceptable but others sadly lack behind... (Female, aged 33, Royal College of Physicians, 20 June)

It's something that people don't know or have the skills to know how to deal with as in society it isn't mainstream or part of everyday life for a lot of people (Male, aged 31, Royal College of Physicians, 13 June)

This lack of understanding and exposure contributed to fear of difference, which some participants connected to persistent negative attitudes in society:

Difference is feared. Difference is often not valued. Disabled people are teaching the world to celebrate difference with pride. (Royal College of Surgeons, 8 June)

Often defined by fear / pity - rarely examined - perpetuates a cycle of hiding rather than celebrating. 'Normal' is a made up concept - and rather dull! (Science Museum, 29 June)

Fear is often caused by lack of knowledge and understanding - we fear what we don't understand and what we perceive as different (Sita, Thackray Medical Museum, 14 June)

For Diane, (aged 34, Surgeon's Hall Museums, 15 June), the curiosity towards people who are different was often channelled (by embarrassment) into pity or sympathy, or even relief at not having to undergo the same experiences:

I think we are curious, maybe fascinated and scared by people who don't look like / behave / are according to a certain norm or what's considered as 'normality.' We don't want to acknowledge the elephant in the room, to stare at people with difference. But we do it eventually. Those without a difference compare their life and probably feel some kind of relief not to be affected in the same way. Unfortunately we may express ourself with pity and treat those with a difference like 'poor little things', the worse and last thing to do. Still a long road to treat all of us the same way. (Thank you for this evening).

The devastating impact of negative attitudes on identity and of self and identity was expressed in several response cards, either from a personal, or family, experience:

My sister was born profoundly Deaf. I think that's "difference". Has led her to struggle to find her identity as an adult, not to be solely known for her disability (Female aged 45, Science Museum, 29 June)

Isolates you. (Depresses) or make you lose your sense of self. Eventually may internalise prejudice leads to self-hatred and suicidal thoughts (Premila, aged 66, retired, Bethlem Museum of the Mind, 17 June)

I agree with the idea that some of us have become better at hiding our difference and pretending it doesn't exist within us. We hide rather than celebrate difference which makes it difficult to have a discourse or change. Even in this room we feel uncomfortable displaying difference (Female, aged 32, Thackray Medical Museum, 21 June)

As we have seen, respondents suggested that negative responses towards difference are influenced, shaped or exacerbated by political and economic climate; powerful interests such as the government, media and medical profession were also seen as contributing to negative attitudes towards difference, in particular creating a 'norm' as a way of (for example) controlling people, selling them something or understanding human bodies as part of the medical model. These respondents were pessimistic that meaningful change could happen in society whilst what is categorised as 'different' is shaped by these powerful bodies:

Damaging - but unless we can engage those who establish the categories (ie medical profs) we cannot change them (Non-conforming, age 41, Royal College of Surgeons, 22 June)

I think attitudes to difference of course vary according to whether we have personal experience of it or not - but that the attitudes of society as a whole are shaped by society's major institutions: schools, government, mass media and the values spread by a given culture - including most importantly the economic system - and by the moral and spiritual ethos of a society. This is materialistic age and we have lost our moral and spiritual compass... (Female, aged 57, Royal College of Physicians, 20 June)

... the social context is frankly, at the moment, terrifying. Media narratives are so focused on any kind of difference - race, ethnicity, ability, colour, gender, sexuality etc. etc. - as though a negative / dangerous thing - we have quite a poisonous media discourse at the moment (Emma, aged 42, Thackray Medical Museum, 18 June)

Two examples of responses, below, suggest that creating a 'norm' is in the interests of certain sections of society, to ensure that people remain divided, rather than united:

I think the nub of our attitude to difference can be found in many of the powerful vested interests alluded to in the performances tonight; division and isolation are marks of a more manageable society. Difference and emphasising its importance facilitates dehumanisation and is a cheap mechanism for understanding lack of fulfilment. At the same time I think this process of othering can form the basis of a solidarity and strength from which a powerful coalition for change can be built. (Tim, aged 28, Royal College of Physicians, 20 June)

...our attitudes are changing slowly but of course for the powerful to continue to be the powerful they will try to get ordinary folk to beat each other DIVIDE and CONQUER. (Royal College of Physicians, 13 June)

Several respondents specifically addressed the role of the medical profession in creating negative attitudes towards difference (also see Non-conforming, age 41, Royal College of Surgeons, 22 June above):

Specimens should never be categorised by a number they should be addressed by their names (no matter how difficult student doctors find that!) It is VITAL that we never reduce people to being objects / things / it as when you dehumanise people you make it all too easy to treat them as 'less than' and unworthy. The student doctor's first answer made me so cross! (Female, aged 41, Royal College of Surgeons, 8 June)

I think an exploration of the motivation of the caring / medical worlds would reveal much. There is such a range - well-meaning, misguided, malicious, 'the business approach', practical etc. It is a complex matrix (Peter, aged 57, retired journalist, Langdon Down Museum, 7 June)

A few responses addressed the issue of language and labelling people, which can contribute to negative perceptions of difference, whether offensive words such as 'moron' used in Julie's performance to seemingly neutral medical diagnoses such as 'cerebral palsy' which Francesca deconstructs in her performance. Some responses were much more ambiguous about the role of labels – as Sean discussed after the Q&A discussion on the 13 June at the Royal College of Physicians, 'I picked up from some comments that it's easier in a way if you have a defined disability – you can say 'I am different' and be accepting of it...' Jennifer (Thackray Medical Museum, 18 June) was more certain that labels could be harmful, praising Francesca's performance which (in her opinion) 'really (*attacks*) the whole of PC culture, that awkwardness, the thinking that we to name certain things and if we get it wrong then... Francesca really hit home the whole point that we are all essentially the same, and like she said for a lot of people, the word disabled it implies that you can't live a normal life but everyone is disabled in some way. And as a gay woman - a label - I really relate to that thing of having to box myself up and instead to be open about who I am and not having that label.'

## **2.2 How we can change, or challenge, society's attitudes towards difference**

The performances inspired respondents to think about how we (individuals and society) can change, influence or challenge negative attitudes towards difference, which reflects, to a significant degree, the message that was given out by the performances. Forty-seven (47) response cards suggested that society's attitudes can be challenged through a range of actions - including positive role models, more disabled people in the public eye, or by embracing and accepting difference – and by individuals taking a political or activist stance:

Things are improving but we are all part of the solution - continuing to challenge ideas and attitudes. Positive and vocal role models (like Francesca Martinez and Alison Lapper) are vital. It is not just the media or the politicians who are responsible. Inspiring and thought-provoking stuff tonight. Thank you!! (Journalist, Royal College of Physicians, 20 June)

More needs to be done to allow individuals to communicate and express themselves through any language they want - written, dance, song, drawing - we can each find a part of ourselves interwoven within different heritages and understand individual and collaborative histories and stories. The Deaf Man Dancing performance was brilliant! (Female aged 30, Thackray Medical Museum, 14 June)

The need to embrace, celebrate, and value difference was a theme threaded through a significant number of responses:

We are at our best when we embrace difference, we see things in new lights, we learn about ourselves and we live to better values. This is at risk at the moment. We need more projects like this. Outsiders are the new avant garde! (Ann, aged 55, disabled, Thackray Medical Museum, 21 June)

We need to be more compassionate. We need to sensitively include those who are stigmatised in our working and social lives. It is possible but there is little enthusiasm in reality - that is what I think. The performance I have just seen was challenging - so raw - so personal - so motivating (Male, aged 55, Bethlem Museum of the Mind, 15 June)

Basically 100% agree with what Francesca has said. It is important to recognise and celebrate. To do so would be a radical act with huge, significant, positive implications (Livvy, aged 25, Science Museum, 29 June)

We need to move away from "access" and towards cherishing difference and the different perspectives d/Deaf and disabled people have. Not just tolerating them! (Katherine, aged 27, disabled, Science Museum 29 June)

For some respondents, fear of difference was learnt behaviour rather than innate to human thinking, and could be tackled through education:

From a young age we're all told that it's ok to be different but then we grow up and society tells us different. I agree with you, Francesca, we should all be taught dignity, respect, empathy and emotional intelligence at school (Frances, aged 28, Science Museum, 29 June)

The more people experience difference from a young age, the more normalised it is but segregating and not educating and dehumanising difference is more prevalent and dangerous (Emma, aged 28, Royal College of Physicians, 20 June)

Improving attitudes towards difference through the media was suggested by Allegra (aged 75, Langdon Down Museum, 7 June):

As the mother of a disabled child I have seen positive change during her life but the media could do more to portray both physical and mental health issues sympathetically. Using disabled actors whenever a part calls for it. Not necessarily highlighting the disability - just as one human being among others. Normalising. Neutralizing the differences. Celebrating diversity.

This member of the audience at the Royal College of Physicians, combines several of these themes in her response, bringing together the need for greater exposure to difference in everyday life, more people in the public eye and the use of media and performance to ensure that society is more open to difference:

I feel society is not open to difference enough. There should be more open-ness in work, people are afraid, shocked about the unknown. The more one is faced with disabilities, difference etc, the more open-ness there will be. More disabled in Parliament. I worked in social services and there was no discrimination, plenty of opportunities. Theatre and media is an excellent way to education. (Female, aged 68, Royal College of Physicians, 20 June)

Collaboration with disabled people, rather than making assumptions about their lives and needs, was stressed by Becki (Thackray Medical Museum, 18 June) as a critical way forward:

I also think that difference itself needs to be embraced more and there needs to be more collaboration. We need to talk to more people, we need to stop using preconceptions about what a person can and cannot do. We also need to reflect in our physical design of public spaces and also our intellectual access in public spaces because sometimes choice can affect not just one person but a whole range of audiences.

Two respondents in interviews talked about the need to change society's views as a struggle or fight for justice. Maria (Langdon Down Museum, 7 June) admired this aspect of Julie's performance; 'What really pleased me was seeing the character who had been shackled really fighting... a fight for justice.' Similarly, Julie (Royal College of Physicians, 13 June) praised the political nature of Julie's performance and David's film:

'The attitudes that are in this room (*referring to the Royal College of Physicians*) are still present today. I loved Julie's eulogy, her political-ness – as David said at the end, the only thing to do is to get political, to come out... name the barriers, and that empowers people to do something about attitudes. Hearing that tonight is a reminder of something that I can do – it's to protest.'

Julie was also struck by the issues of power highlighted by David's film, or rather, disabled people's lack of power. She was particularly struck by the experience of Baroness Jane Campbell, that someone as powerful as the Baroness can still be isolated and have no voice because she is perceived in a particular way because of her disability:

...when the Baroness was in hospital – if she'd not had somebody to fight for her... There's a question of isolation where people of difference are isolated by attitudes. I found that part of the film really frightening – she could have been put in the corner to die had not someone else been there to pull her back in. It's like a tightrope and it's really scary. It's great that there is an arena to talk about it.

After viewing the performance by Deaf Men Dancing and Francesca Martinez, Julie (Royal College of Surgeons, 22 June) expanded upon her initial thoughts, making a direct link to human rights and the kind of society that we want to live in – based on how it treats people who are different:

This is about human rights – it's the eve of when we vote for what kind of country we want to live in, what kind of society we want. We've been given this choice and people are not as awake as I think they are with what I've heard tonight. It's like Francesca said, get out there, be political and fight. There's nothing else to do, is there?

These comments from the response cards also emphasise the importance of individual action and actively challenging negative or divisive attitudes towards difference:

Very moved by both performances, the film and Julie - astounded to see the progress made from the past and excited to see where this work goes next. Get political - the only way forward (Royal College of Physicians, 13 June)

...This government is appalling, yes! But it is up to everyone of us in society to take responsibility in some way to advance fundamental human dignity, mentality and behaviour (Maria, aged 61, Langdon Down Museum, 7 June)

We have a long, long way to go but it was interesting to hear how progress has been made and how with hope and determination and positive action we can continue to force for better acceptance and attitudes. Loved tonight, thank you. (Hannah, aged 39, Science Museum, 29 June)

Some respondents articulated the need to change society's views of difference through the notion that difference and diversity was an inherent part of being human, sometimes expressed as 'we are all different' or 'there is no such thing as normal.' Maria (Langdon Down Museum, 7 June, rough interview transcript) talked about how we are 'all different' and suggested that 'the sooner we embrace that, the better we can live together.' She went on:

We're not normal because we're sitting here middle class white people, we all have our warts and all. The more that people understand that human dignity has to be fundamental in society, the closer we'll get to understanding about human differences – [and] the world will be more peaceful.'

Jennifer (Thackray Medical Museum, 18 June, rough interview transcript) emphasised that 'disability can affect anybody, which I think people do forget.' Francesca's performance reminded her that disability is not necessarily a tragedy but 'just life and we all have to be ready for that and help each other when we can.' Taking a slightly different perspective, David (Royal College of Surgeons, 8 June,) talked about his admiration for politicians such as 'Nye Bevan and Clement Atlee, British politicians who developed things like the NHS and had a vision that everyone in England were people and worked together and that pertains to the subject matter tonight. It does seem that removing that structure removes that principle and it opens us up to a 1930s version of society.' David suggests that society is moving backwards because many of the protections given to disabled people are being removed with the cutbacks to the NHS (the theme of David's film).

Being exposed to difference, and the lived experience of disabled people, was seen as a positive way in which to challenge attitudes – by getting to know people and understanding their lives, needs and interests, society would be more open to accepting people who are 'different.' This was a theme taken up by Jessica (aged 28, Royal College of Physicians, 13 June):

Probably the greatest factor influencing attitudes towards difference is whether a person knows someone with a disability or is different, personally. Knowing a disabled person means you are vastly more likely to appreciate and understand what disabled people can do, not what they cannot. As disabled people become more integrated, more visible and more vocal, this will hopefully have a positive impact on attitudes towards difference.

As Alexis, a student from the US (Surgeon's Hall Museums, 15 June, rough interview transcript) mentioned, the use of sign language by Deaf Men Dancing was, for her, 'so impactful because a lot of the time you don't realise that being able to use sign language is a valuable part of communicating no matter if you understand it or not. It's a big part of our society, people need it and use it everyday to be able to express themselves and with others.' The performance reminded her that people use many different ways to communicate and other respondents also talked about the diversity of human experience and how this enriches society – to paraphrase several responses, 'the world would be a boring place if we were all the same.'

Similarly for Bryan (Thackray Medical Museum, 18 June, rough interview transcript), people did not encounter or come into contact with disabled people enough in order for them to be accepted as part of society:

...I think that many people do not come across anybody with a disability in their life other than looking across the street... whether they have a conversation or not with anybody is, I would err on the side that they possibly would not. And to be able to see someone expressing such positive sentiments and having good ideas about how society can be more open, accepting and diverse would be great. But I think it would be great if more people got to actually see it and understand it.

Alan (Surgeon's Hall Museums, 15 June) also felt that interacting with, and engaging with, disabled people directly could help to improve society's views of difference, and he reflected on his own personal circumstances at the same time:

A couple of contributors in the film spoke about how they had been marginalised and made to feel invisible and that's true. Everyday we're out and about with friends who have the same abilities as us, I personally don't have any disabled friends so I don't get to hear their point of view all the time and that's probably true for a lot of people. We don't get to hear that side of the story and getting it out there is important.

Similarly to some of the response cards comments, Alan talked about the need for the voices of disabled people to be in the public eye, much more visible, and to ensure that a diversity of voices were represented:

These voices don't need to be heard in a special forum, they need to be everywhere because they aren't some special case that needs to be bubble wrapped. As we saw in the film, people were in a large number of positions, in Parliament, in academia, social work and they have exactly the same kind of roles as the rest of us. Every time we have people speaking and people involved in that sphere who are disabled and have challenges, they should be put on the same platform.

### **2.3 Is there a role for museums in challenging society's attitudes towards difference?**

Museum collections were at the core of the performances, although each artist differed in the way in which the collections were incorporated into their work. The response card did not directly ask audience members to comment on the role of museums although 11 response cards explicitly referred to the role museums might play in portraying, negotiating or challenging societal views of difference, for example by integrating difference into their displays, producing more high quality work (like *Exceptional & Extraordinary*), and providing a space in which to have conversations about difference and the impact of society's attitudes. The interviews provided an opportunity to ask audience members directly what they thought about the role of museums, and some interviewees did take advantage of the opportunity.

One theme was the use of the museum as a space for debate, discussion and reflection – several respondents were hopeful that museums could do more to contribute to conversations about difference, however challenging:

Despite the difficult feelings raised sometimes by the view of the difference, unfortunately it is rarely possible to have a place to speak about my own attitudes or share feelings, emotions and thoughts with others. Can museums become these places where conversations about difference (*happen*)?... (Royal College of Surgeons, 8 June)

We need to learn the ability to listen and be open-minded and debate. Not just piously fight our own corner and not be open to adjust way of thinking. Difference is potentially frightening and that human reaction needs to be accepted and accommodated before we can have a meaningful dialogue (David, aged 45, disabled, Royal College of Physicians, 20 June)

Making space for discussing difference is vital - silence can continue stigma and we all lose out. Dominant discourses of museums and medicine haven't reflected the range of humanity in us all - this series provokes, entertains, subverts (Liz, aged 56, works in cultural sector, Royal College of Surgeons, 8 June)

Alexis (Surgeon's Hall Museums, 15 June) talked about the need for museums to be more thoughtful about the ways in which they represent difference, about the messages they convey to their audiences:

It's showing that our society is not one-dimensional, we're diverse, we have multiple layers to us and by displaying objects and the way they write the cards can really convey to a larger audience that they don't have to limit themselves or be scared to say 'we don't want to fit in...' Sometimes I feel that museums have a hard time being able to open themselves up because they are scared of what negative (*responses*) they will receive instead of what positive they can receive from trying to build relationships or amend relationships that have been destroyed because of the fear, the hate, the prejudice...

Deb (aged 40, Surgeon's Hall Museums, 15 June) was inspired by a question during the panel discussion after the performance to think about the role and responsibility of museums in addressing the history of attitudes towards difference, particularly towards the body:

I found the Deaf Men Dancing performance both moving as well as joyful expression - that there was control by others then taking back that control. Showing the history was fascinating. An interesting question from audience member about more context to the museum displays was very thought-provoking - as the museum has the responsibility of displaying altered bodies it would be responsible / useful / educational to discuss / present the social / cultural

changes and impact of difference throughout the ages as these changes surely affected the way surgeons worked / their emphasis on certain conditions. Thank you. Really enjoyed it.

Alan, who also watched the performance at the Surgeon's Hall Museums (15 June), reflected on the challenges of combining narrative, lived experience and factual information – how best to get the message across to audiences?

I think definitely putting it in the context of the museum's collections here, it is an issue of representation – how do we represent not only the individual but how can we handle language around difference but also as a more general thing, how do we bring in experience in collections of remains and tissues that come from bodies? These people were alive, they had lives but we don't even know the extent to which their lives were affected by their conditions which we see in the specimens back there. I'd like to think about that more – I'm an artist myself, a sculptor, so issues of presentation and context is something that I have a lot of questions about.

Julie and Tom (Royal College of Physicians, 13 June) talked about the power of using stories from the past to shed light on the present. Julie in particular raised the issue that whilst Julie's performance had highlighted one story, it had made her think about all the other powerful stories that are 'hidden:'

Julie's performance was really powerful and that came from an archive, that story, and it made me think what about the other stories, and the stories that are being created here today? Where are they going? Are they going to be treated in the same way?

This audience member at Surgeon's Hall Museums (male, aged 35, Surgeon's Hall Museums, 15 June) enjoyed the opportunity to visit the museum before the performance and contrast two very different approaches to presenting and engaging with the human body:

It is good to see and hear stories that are authentic, from artists who are experienced in their field and challenging institutions like medical museums in how they present and engage with different types of bodies. The chance to explore the museum beforehand amplified the experience bringing bodies up close and encouraging a different type of consideration towards the 2 new artwork.

However, there was a sense of frustration from other audience members at Surgeon's Hall Museums that the response of the museum to questions raised about its role showed a lack of engagement or real connection with the issues highlighted in the performances:

Very interesting concept and performance was excellent. However, not enough exploration of issues especially of museum collections. Curator / Director did not seem engaged or open to dialogues for change. A real shame (Male, aged 27, disabled, Surgeon's Hall Museums, 15 June)

I felt the video and dance had good, critical attitudes were put across. The museum itself was perhaps less invested in the debate around disability even if they are 'accessible' (Surgeon's Hall Museums, 15 June)

In an interview, Heather (Surgeon's Hall Museums, 15 June) expanded further on her reservations about the commitment of the museum to responding to the aims of *Exceptional & Extraordinary*,

particularly as the museum for her was not somewhere she could choose to visit because of the way in which the specimens are presented:

I felt that the connection between the institution, the museum, and the event was not as strong as I thought it might be. There was perhaps a little bit of distance between where we are and what happened, and that was just a feeling and I wanted to ask a question about the aims of the museum and how would you engage people with disabilities to come here? I personally never come here and I've lived in Edinburgh for a while and would never choose to come, except for something like this. I found the specimens sickening, that for me was not fascinating in a medical way... I didn't really want to look around, there was nothing that I felt engaged me when I walked in. I didn't want to explore it so to be honest with you, I just talked to my friend.

Jill, a member of the Deaf community, (Thackray Medical Museum, 14 June) equally did not enjoy the setting for Deaf Men Dancing's performance, she commented that it was 'painful' to see the medical model so prevalent within the museum because it is not about acceptance but changing people to fit the norm:

the medical model is all about treating us or changing us like making us hear again, or making us walk, making us see, so of course it's painful to have the medical model here in this museum because we've got a relationship with the medical model...

There was also some criticism of the role of museums in shaping attitudes towards difference from Jacques (aged 20, Royal College of Physicians, 20 June); he considered that the performances were much better quality than other approaches, for example exhibitions:

I think that there's a lot of lip service towards redefining our attitudes towards diversity from, say, the Royal College of Physicians. Their exhibit on 'Re-Framing Diversity' is a great idea but they clearly didn't invest much work into it - it gets rather sloppy at times, especially in its presentation of the artwork. That's why it's so great to see shows like E&E. To see performances choreographed by people with disabilities and performers with disabilities is incredibly empowering. As you emphasised during the Q&A, it's about communication. And having (*unclear*) control over your own image. Both shows were incredible and emotional. Thank you!

Taking another perspective, Amy (aged 27, Langdon Down Museum, 7 June) considered that museums are not able to effectively address issues of representation and difference, because of the social, political and economic context which does not value difference – with lack of funding in particular severely restricting what museums are able to do:

Order / classification / collection - Difference. Capitalism does not support difference which is why museums / heritage are under resourced and under-valued. Disability and heritage are good partners but it does not address the key point. They simply aren't part of the system. PS Great performance, very moving - I particularly felt involved when compared to a jar on the shelf, I felt different, exposed, pitied.

## **2.4 The power of performance to challenge perceptions and convey complex ideas**

The overwhelming response to the events conveyed in the response cards (64 responses), on Twitter (75 tweets) and through the interviews (15) was an incredibly positive one. Respondents praised the power of the performances to open minds to the experience of being 'different', to challenge perceptions and change negative social attitudes towards difference and disability. A significant number of these responses praised the different formats (film, theatre piece, contemporary dance and comedy show) for conveying complex ideas and enabling them to encounter the real, lived experience of disabled people, to enter their worlds and understand from their perspective.

There was a real sense that the performances had the power to change people's attitudes towards difference, to open people's minds and help create a better society – as encapsulated in this response card:

Powerful – performances have the capacity to change society - They're very important as they're eye opening and will help to forge a more civilised, inclusive society in the future (Male, aged 60, Royal College of Surgeons 22 June)

Heather (Surgeon's Hall Museums, 15 June) suggested that the power of the performances lay in the 'challenging and critical attitude towards difference and disability' which she thought was 'really important for society to think about in general better than we are doing right now.'

For some participants it was coming into contact with the authentic, lived experience of disabled people which made the performances so compelling. Elisabeth (aged 27), who watched the performances of Deaf Men Dancing and David film at Surgeon's Hall Museums on the 15 June, commented:

We (my husband and I) felt that the most valuable aspect of the pieces shown (David Hevey and DMD) was the platform they gave for first hand experiences of disability - it was not a sterile description but rather an inclusive experience, which we felt is what ultimately fosters understanding and change. Very interesting and thought provoking discussion - thoroughly enjoyed the experience and will be reflecting upon it.

Hassim (Bethlem, Museum of the Mind, 17 June) felt that after watching Julie's performance he understood a bit more about the issues disabled people faced, particularly as he trusted the performers to 'reflect some kind of reality and I could learn from them.' Having disabled people leading and writing the performances was critical to the authenticity, as Mary (Bethlem, Museum of the Mind, 17 June, rough interview transcript) suggested:

It was really interesting as a service user having those voices so central and interactive (*in Julie's performance*) – I thought it was interesting how the two people had adapted very differently to their situation, they came together but then separated again. The signer too was excellent – there was almost too much to take in but I was very impressed.

*The Fight for Life* was particularly powerful for Alexis (Surgeon's Hall Museums, 15 June, rough interview transcript) because it revealed the complexity of disabled people's lives, and the challenges they face in a society that is not always accepting of difference:

And it showed you there is not one true face to disability there are multiple people who are facing different ways of living with it but they find ways to cope and deal with their disabilities and lead a successful life no matter how much it impacts upon them. But at the same time

they are facing problems with health insurance and having proper access to medications, to things that they need for survival.

Denise, Chair of Mencap in Richmond (Langdon Down Museum, 7 June) could also see the potential of drama (in this case, Julie's performance) 'to challenge perceptions, dispel myths and stereotypes' about disabled people.

Deaf Men Dancing's performance, *Let Us Tell you a Story*, was very positively received by both Deaf and non-Deaf audience members. Jill, a member of the Deaf community, (Thackray Medical Museum, 14 June) considered that Deaf Men Dancing's performance would send out a powerful message to the hearing community:

It's definitely... the perspective of the Deaf community, the political issues have had a huge impact really and it had affected us (*throughout our lives*). So this does actually show it to hearing people. It's good more hearing people see this, Deaf people already know these stories, they've got these stories inside their own experiences.

From Alan's interview (Surgeon's Hall Museums, 15 June), we get a sense of the impact on the non-Deaf community. He talked extensively about the value of encountering 'first-hand accounts, not just a list of historical facts or bullet points of medical conditions, but of human experience.' He went on to add:

...we got to see that especially in Deaf Men Dancing. There was a change in the feeling when you had segments that were explanatory about an event, but others were about personal experiences that resonate more. We can all access facts and information about these things if we want to but it's actually getting a chance to see through another person's eyes, what does it mean (*to be disabled*), what's it like everyday? This is what is lacking in how we perceive difference, disability – we can get data, numbers, but we don't get a chance to hear from these people. The more we do that, I think that's what will break down barriers and misunderstandings. It was great to see that and have it in this context as well, at the museum.

Sita's response card (aged 49, Thackray Medical Museum, 14 June) reflects a similar importance attached to the exposure – through performance - to real, lived experiences and the potential impact this can have:

DMD's work helps hearing people to begin to understand something about the experiences of deaf people, which helps to reduce fear - even just fear of doing the wrong thing and being embarrassed! The show is a beautiful, inspiring piece of work that tells very personal and engaging human stories.

Similarly, Becki, (Thackray Medical Museum, 18 June) enjoyed watching Francesca's performance because she considered that it was very honest, truthful insight into the reality of being disabled:

I really enjoyed listening to Francesca Martinez because I felt she had a very true view of what is happening in disability and society at the moment, but also in regard to what she felt as a person in how difference is all around us and disability is not a helpful label, but sometimes we need that label because of society's barriers. So I felt that she was extremely relevant but also very, very thought-provoking particularly in respect to education. That was such a key thing, the idea that education can actually destroy self-confidence, it can almost be like a public arena for difference where you are judged. That is something I do feel very strongly about...

Across the response cards and in tweets, particular words were used by respondents to describe their response to the performance – words such as powerful, thought-provoking, inspiring and moving were used across the response cards and tweets (shown here as a word cloud).



There were a few negative responses to the performances. Some respondents seemed discomforted by the political nature of the performances:

It is interesting to use public money to make a political film trying to stop the cuts (Royal College of Physicians, 13 June)

...Francesca was powerful but more of an evangelist than a comedian. Fewer expletives would be nice. The discussion was not very good. We should have gone to the bar and chatted informally. (Helen, aged 66, Royal College of Surgeons, 22 June)

This respondent did not understand the use of offensive language (e.g. moron, idiot) in Julie's performance:

I thought that the programme was strange, the words used to describe disabled people upset me (Royal College of Physicians, 13 June)

There were a few negative comments about the film in terms of its subject matter (which one person felt had been covered elsewhere) and its focus on the medical model:

Why was diabetes, a medical condition, included in a film about disability? I thought we had moved away from a medical model of disability? Puzzled? (Surgeon's Hall Museums, 15 June)

Interesting! I do think there was a lack of a more rounded picture of experience in the film, particularly lacking a learning disability voice / leader and those on the sharper edge of disability and society. It was very focused on the medical model, understandably in many ways of course, but therefore lacking a rounded view (Female, aged 38, Thackray Medical Museum, 21 June)

I am glad that work continues around and about disabilities. However I felt almost everything in the film had been said before in many, many different forums – sorry... The

play/performance felt difficult and not quite as authentic as we usually get from Julie (Royal College of Physicians, 13 June)

## **2.5 How it affects me – impact on personal perceptions of difference**

Several of the response cards (12) and interviews specifically talked about how the performances had challenged the participants' perceptions of difference or disability, opened their eyes to new ways of seeing the world or had an impact on their professional practice.

These response cards talked about the impact of the performances on personal perceptions of difference, in the first example reawakening childhood experiences of being partially deaf:

I was blown away by the performance by Deaf Men Dancing - it powerfully told some of the histories of the deaf community, which I wasn't aware of. I have personal experience of deafness, being partially deaf up until the age of 5 - the performance, particularly the 'beep tests' brought back memories that I had forgotten - a good reminder that none of us are 'normal' - also a reflection of David Hevey's film (Female, aged 34, Surgeon's Hall Museums, 15 June)

Shakespeare in Hamlet said how a play is a mirror in which the audience will see / not see their own reflection. This powerful play freed me to think about my own attitude to the words moron.... Etc, repeated at the end. And, moreover, the difficult question, what is difference? The use of sign language highlighted the sense of difference however - I am different, I am "illiterate". PS should have been on stage - saw only the heads of performers (Pirrko, aged 54, Langdon Down Museum, 7 June)

When asked what she would take away from Francesca's performance, Jennifer (Thackray Medical Museum, 18 June, rough interview transcript) commented that it would help her to become a better person and to think more about the impact of language and labels:

Number one, to be more grateful that I am on this planet and I'm alive. Number two, to stop using certain words to describe people and stop being so fixated on labelling. Number three, to start spreading more love and more joy between myself and other people and start being a kinder, more compassionate person.

The performances resonated with people's personal experiences of difference and disability, giving a new perspective or highlighting similarities, including Alexis (Surgeon's Hall Museums, 15 June, rough interview transcript):

To hear the hearing test (*Deaf Men Dancing*) really caught my eye because I remember as a kid having those hearing tests and it's always been so annoying to hear that sound and be told 'Oh you're fine, next one please.'

Zoe, a member of the Deaf community, (Surgeon's Hall Museums, 15 June) talked about how David's film opened up some new issues to her about the Disabled community, giving her a greater understanding of the parallels and differences with her own experiences:

...the film screening that was talking about society's view of disabled people and looking at the issues of the cuts, there were some issues that were actually quite new to me. As a Deaf person within the Deaf community we do have an affinity with the disabled community, we campaign on a lot of the same issues as well but even though we are fighting for the same thing in a lot of areas, we do actually have a different lived experience so it's nice to see those parallels. But we also see differences...

Paul Darke's experience in the film of being medically examined really struck a chord with Zoe, as it helped her to reevaluate her own experience of being tested frequently for her hearing:

...there was one story about children being medically examined every year at school and actually how unnecessary that was. And actually when I looked at that, it made me think about my own experience growing up and attending audiology appointments and going through all these hearing tests again and again. And that was really unnecessary as well. And before I thought it's just a boring appointment, that's what you do, and my mum's from a Deaf family as well (*and she was like*) it's just what you do, and I did that throughout my childhood. And now I'm realising that actually that process wasn't necessary... it gave me a different perspective on my experience, on an issue that I hadn't thought about before that I had experienced as a Deaf person.

Mary, a service user (Bethlem, Museum of the Mind, 17 June) identified with the characters in Julie's performance, based on her own experiences of being a patient in hospital:

It reinforced in some ways the way we internalise things, and the importance of language. For example, how Walter Riddell said 'I'm a good boy.' That's what you do in hospital – if you're a good patient, your life will be straightforward and simple but if you're not good, i.e. you try to retain your sense of self and what is happening to you, you might get into more problems if you are resistant. Despite Julie's character being in restraints she was very clear what her distress was about and could trace it back. It made me think about how often we do know what is at the core of things but we don't get asked to go there because people are telling us that's part of our psychosis. But when the doors open for you a bit, it might help you to make sense of it even if it doesn't make it better – you've made sense of it.

Julie (Royal College of Surgeons, 22 June) was profoundly affected by Deaf Men Dancing's performance, again because it resonated with some of her own experiences but at the same time opened her eyes up to a community and history she did not know much about:

Oh my god! I was upset by some of the imagery used in the performance and their smiling faces. I don't know anyone who is Deaf, I don't have experience of that. I've become more aware, more heightened of what their lives might be like. The hearing test section – I remember those sounds from hearing tests I used to have and I haven't visited that place for 45 years and to go back and see that many things have moved on in the world and some haven't.

Julie also reflected on her own professional practice as 'an artist who works on themes and loneliness and connecting people back into society' and how the performances raised issues about how being different can affect your worldview and give you an alternative perspective on life:

The power of bringing people together for this project – and I've also seen the other performances – is (amazing). I've always felt, because I'm a large person, on the outside but Francesca talking about we're here now, nobody knows what is going on, on the planet, it's a really great reminder... Also that thing about being different, you see things differently, (*being outside of society*) you can see more and do more. And what's wonderful about these artists is that they are doing more than so called able bodied people, they're doing more, seeing more and putting it back out there. I've got nothing but admiration for them, I'm really blown away.

Professionals and practitioners from a range of backgrounds – including social work, museum and cultural sector, adoption, medicine – used the performances as a basis for reflecting on their own and thinking about how they might improve things or support people better in the future. Jane (aged 49, Thackray Medical Museum, 18 June), a social worker in adoption, talked about the

challenges of placing disabled children and the need to support families to understand the value of all children and young people:

As a social worker in adoption an ongoing challenge is about finding families who have a disability. Families in search for 'normal' - this is a challenge - as the wonderfulness of some little people is overlooked. Francesca's session serves as a reminder of the importance of educating / enlightening people to the value and uniqueness of each individual child / person. Thank you.

Two comments from people who work in the museum sector talk about the importance of embedding ideas from the performances into their future practice, as well as changing the way they think about how museums deal with, and embed, difference in their mainstream work:

I work in the museums sector and wonder why we only represent disability as a separate issue, not integrated in the broader narrative of life in its rich diversity. This will definitely inform my work. Thank you (Royal College of Physicians, 20 June)

The first film made me think about the affects of government cuts on disability and how different people have / do react to these cuts and the powerful nature of sharing experiences with politicians to make change (even if slowly / doesn't always feel like it!) The second performance made me think about the notion / concept surrounding the ethos / ethics about putting people in jars against their will / without their families consent. Has changed my notion / made me re think notion of medical museum and the necessity in the past to keep these / them. Thoroughly enjoyed this insightful evening (Female, aged 30, works in Museum Sector, Royal College of Physicians, 13 June)

Two teachers / lecturers mentioned that they would use the performances in their teaching:

I came tonight because I am a special education teacher and wanted some insight into the issues in the UK regarding Disability Rights as compared to the US. Thought provoking and also entertaining! Would you consider putting this on Youtube for people in other countries? I would love to share! (age 42, teacher, Royal College of Surgeons, 8 June)

I brought 10 students (all Americans studying in London). It was a terrific evening as they got to visit the collections, watch the film, watch the performance and participate in the Q&A. I'll follow up in class tomorrow with many of the BIOETHICAL issues raised (Donna, aged 59 and a half, professor, Royal College of Surgeons, 8 June)

Shirley (aged 61, Royal College of Physicians, 20 June) reflected on the power of dance to tell an engaging story – she commented that she had seen a lot of performance but there was something really special about Deaf Men Dancing that caught her eye:

I saw three brilliant dancers telling a very personal story and realised that I was very aware of their deafness, so different from my feelings when watching other dancers - and I have seen a lot... It is so good to see the message given through dance. Why not try to get the performance in the new space in Tate Modern?

Bryan works with disabled people (Thackray Medical Museum, 18 June) and he was inspired by Francesca's performance to think more carefully about the way he interacts people, 'not just with disability but with race, religion, the wider spectrum, and talk to more people... As Francesca says, everybody's different so we should take away the tags that go with people...' He also talked about

the importance of having disabled peoples' voices at the forefront of his work because whilst he is there to support them, he understood the importance of disabled people being able to speak for themselves, to 'self-advocate':

Francesca verbalised a lot of things that... because I've worked in the disability area for like the last 15 years you live in that bubble. So you have a bit more of an understanding, so the fact it's been highlighted by someone with a disability themselves rather than us doing it on their behalf... Who is it better coming from, me or the actual person? It's better coming from the actual person isn't it? I think advocacy ends up being really important but it is more important for the person to advocate for themselves. People do need support depending on the severity of the disability but we're trying to encourage the self-advocacy side of it as well...

## **2.6 Responses from the medical profession**

Two specific opportunities to engage with *Exceptional & Extraordinary* were provided for the medical profession; a discussion with invited medical professionals and students held at the Royal London Hospital Museum and Archives following a viewing of David Hevey's film *A Fight for Life*, and a week-long training session with medical students held at the University of Leicester 30 August – 2 September 2016.

The focus group discussion at the **Royal London Hospital Museum and Archive** (23 June 2016) raised a variety of issues around the way in which the medical and clinical profession treats patients with bodily and mental differences. There was a common theme running through the discussion about the way in which students are trained and the reliance on 'tick box' approaches to patient care and treatment which meant many assumptions could be made about patient care and needs. Often the patient's voice was lost in the need to complete necessary paperwork or because of other pressures experienced by the medical professional. As one medical professional remarked, 'As medical people we are in a powerful position... The film reminded me of how important it is to take the backseat and allow our clients to have that opportunity to say what they want.' One of the most powerful scenes referred to in the film was the experience of Baroness Jane Campbell – 'And it was particularly painful hearing somebody say that it was only when I reached for my doctorate and they showed what an intelligent person I was that they realised they must save me' – which for this medical professional raised questions about patients who did not have that support or background – 'Is it about employment and being able to earn and being able to write important lectures and influence people, or is it just about being who you are and being allowed to live in whatever state of disability you're in?' She was reminded of the importance to keep making 'reasonable adjustments' to ensure that patients get the attention and, 'whatever it is that you need to make your life a little better.' Another medical practitioner raised the issue that tick box approaches to evaluation and patient assessment risked reducing people into boxes and trying to fit them into a structure which might not be suitable for them, rather than working with the patient to 'find out what is possible, suitable, appropriate, not appropriate... but we have this attitude that everything has to go on a form before anything else happens.' The need to be more imaginative, creative and patient-centred was stressed.

Another important discussion was around the medical model and how that influenced attitudes towards difference, as this participant suggested:

I'm wondering if it's more that if you take a strictly medical model, disability... difference is something which flies in the face of the medical profession because they can't always cure

it. And there is a need to assert the supremacy of the medical model and that is often at the cost of things like care and responsiveness to someone's human condition or an ability to recognise what kind of things they bring with them.

She went on to explain that it was often linked to the 'embarrassment that medical professionals feel' to not be able to help someone and the desire to 'take away' any difficulties or indignities that the person is experiencing, also connected to the 'ideal that we will somehow eradicate disability.' However, it was agreed that instead of thinking in this way, the medical profession should accept diversity 'not keep separating it out and trying to get it to go away.' Medical students highlighted how this way of thinking started in their training:

Instead of looking at the patient as a patient and learning from them, we feel like we've learnt so much from the classroom, having to study for exams, knowing the normal ranges, that we actually forget that everyone is different and there is a different approach to every single one.'

The group debated how the profession could become more patient-centred and accepting of difference; it was suggested that students could have placements as part of their training that would bring them into contact with a range of people with different experiences, including learning disabilities, improve evaluation forms so that these enable medics to engage with the person rather than a tick-box approach, and patient comments about their care and support could be incorporated into the students' work folders. As the chair [name] summed up, the most important point was to not lose sight of the patient, to make sure that if students or medics do not know what to do 'you ask and you explore things from their perspective... what they might need and what's important.'

Medical students from the University of Leicester took part in a week-long training course that explored issues around medicine, disability and medical museums, and was designed to have an impact on the students' thinking and medical practice. Responses to the course were very positive; some of the comments that students made about how the course would inform their practice included:

Not to assume that disabled people necessarily would want a fix or cure. Or that they even necessarily see it as a disadvantage. Subtle differences in how I approach a consultation make a big difference.

Considering an individual's perceptions and wishes is paramount. We all would have agreed with that before but actually translating it to practice is the challenge.

Disability... as a term has been redefined for me. I believe that having highlighted my previous pre-concepted (sic) stereotypes of conditions has led me to particular thought patterns. Being aware of this I can actively overcome this.

Most students were able to appreciate the social model of disability as a result of taking part in the course, which would also feed into their practice and help them to communicate and support disabled patients more effectively, as well as realising that disability is much more varied than they previously considered or is only one aspect of a patient's experience. There was a clear sense that students were thinking about difference in new ways as a result of the training. However, this one student could still see a tension between the medical and social models that would need to be negotiated:

A lot of medicine is 'normalisation', trying to restore a person to as close a state as possible to 'normal' (good health). This concept is at odds with the social model of disability but a balanced approach is necessary.

A study visit to some of the medical museums in London that took part in *Exceptional & Extraordinary* was also eye-opening for some students, as one commented:

I am particularly struck by the portrayal of disability in museums and the lack of humanisation behind the pieces on display.

### 3. Conclusion

The question 'What do you think about our attitudes towards difference?' provoked a thoughtful and reflective response from audience members through the response cards and interviews (tweets were left much more open). The clear narrative emerging across the cards and interviews is that society has, at best, a complex, ambiguous relationship with difference, and at worst, a damaging, divisive and negative attitude. For some watching the performances, this negative attitude had been improving (and some older respondents pointed out the changes in their own lifetime) but, for many others, the present political and economic climate of cuts, austerity and changes to welfare threatened to stifle or reverse any progress, and more needed to be done.

More excitingly, respondents not only reflected on society's attitudes towards difference but thought about how negative or ambiguous attitudes could be changed or challenged, which to a significant degree reflected the aims of *Exceptional & Extraordinary*. Greater exposure to the lived, authentic experience of disabled people, better integration of disabled people into mainstream society and ensuring that society was accessible and welcoming to all were common themes threaded through the responses. Respondents talked about the need for greater education around diversity and difference, to open people's eyes and increase their awareness so that difference is not feared but understood as part of what it means to be a human being. The idea that there is a 'norm' we must live up to was also seen as a barrier towards acceptance of difference – various powerful interests were connected with the creation of the 'norm' including the education system, the media, the government, society's values and morals, as well as the medical profession. Various ways of challenging these powerful views in society were given, including more disabled people in the public eye, a media that celebrates difference, and a values system that embraces diversity and gives support to those who need it. At an individual level, protesting, challenging society's views, being more political and fighting for justice were also suggested as ways forward.

Responses were incredibly positive towards the four artists and their performances (in response cards, tweets, and interviews), an overwhelming sense that the performances touched a nerve and resonated powerfully for their audiences. Respondents talked about being 'blown away', of being 'shocked', provoked and moved by the experiences portrayed on stage and screen. Their power was directly connected to the authentic, lived experiences of disabled people *told by* disabled people, through the museum collections and stories. Some people talked about having their eyes opened, or used the performances to reflect on their own experiences and professional practice, detailing how the performances would affect their thinking and work as a result. Deaf Men Dancing in particular attracted much praise (including from those who said they did not usually like contemporary dance) because of the skilful blending of real life experiences, 'hidden' histories, sound and visuals, that enabled the audience to participate in, and at the same time be distanced from (e.g. because of the use of sign language), the experience of the Deaf community. This approach (which led some

audience members to feel 'shut out' as Deaf people might in a hearing world) was very effective at getting the message across, in a way that the other performances did not always achieve.

The role of museums in exploring society's attitudes towards difference emerged from some of the comments, and the consensus seemed to be that museums could do much more to openly challenge ideas about the 'norm' and show how (historically) attitudes towards difference have fluctuated, and been shaped, over time. There was a real sense that these ideas of normal and difference are not fixed – although some aspects of human behaviour such as fear of difference may be innate according to some respondents - they can be changed and museums need to play a role in contributing to a more diverse, accepting society that embraces and celebrates all types of difference as a fundamental part of human nature.

## **Appendix 1: Response cards**

### **Response cards coding themes**

The following themes emerged from the response cards completed after the performances and were used as a flexible coding framework for the interviews.

<b>Society's attitude to difference (61 responses)</b>
negative / damaging / divisive / dangerous / ignorant
Used to segregate and divide people e.g. media, governments, values and morals
creation of a norm, get people to conform
complex, ambiguous - aspects of negative and positive
context and time e.g. attitudes getting better or worse
contradictory - some differences are valued, some are not
fear of difference is a fundamental part of being human
Progress is being made but more needs to be done
Role that language plays in shaping attitudes towards difference

<b>What can we do about society's attitudes towards difference? (47 responses)</b>
individuals can make a difference
should not label / categorise people
everyone is different
we should celebrate / respect difference, see it as the 'norm'
greater experience and exposure to difference (e.g. from a young age, lived experience of disabled people) to encourage understanding and acceptance
need for education, awareness

<b>Role of museums in supporting change (11 responses)</b>
Museums could (do more to) integrate difference into their displays and exhibitions
Produce more high quality work like E&E
Museums could provide more context to the impact of attitudes towards difference in society and culture over time
Museums could provide a space in which to have conversations about difference and impact of society's attitudes

<b>Response to the performance</b>
Very positive responses to the performances (64 responses)

A few negative comments - performances (e.g. film) too political for some viewers, Francesca not funny enough, film not broad enough e.g. in range of voices
Leads to a change in thinking - greater awareness of issues e.g. issues that disabled people face and impact on their lives, reflecting on personal experiences, reflecting on professional practice
Lived experience of disabled people - leads to understanding, trust because authentic

**Descriptive words**

Words used to describe the performances, captured from response cards and Twitter.

<b>Descriptive words</b>	<b>Response cards</b>	<b>Twitter</b>	<b>Combined</b>
Inspiring	8	4	12
Thought-provoking	13	19	32
Provoking / provocative	1	4	5
Challenging	2	2	4
Stimulating	1		1
Moving	5	2	7
Honest	1		1
Illuminating	1		1
Emotional		1	1
Funny / fun		3	3
Inventive		1	1
Gut-wrenching		1	1
Stunning		1	1
Powerful	1	5	6
Dramatic		1	1
Beautiful		1	1

**Who completed the response cards?**

Response cards asked for demographic information but left the categories open for respondents to use their own terms when describing their age, gender, and ethnicity.

<b>Age</b>	
Youngest respondent	15

Oldest respondent	78
Average age of respondent	40.54
Age given	146 responses
No age given	24 responses

<b>Gender</b>	<b>No. of responses</b>
Female (including lady, woman, Cis woman)	101
Male	43
Other (e.g. non-confirming, non binary femme)	4
None given	22

<b>Employment</b>	<b>No. of responses</b>
Employed or working (full time, permanent or part-time)	85
Self-employed or freelance	18
Student / postdoc	17
Retired or semi-retired	14
Unemployed, between work, on benefits	11
None given	24

Specific professions given by respondents included dancer, actress, charity manager, writer / blogger, business analyst, journalist, social worker, artist in residence, Psychotherapist and charity CEO, professor and fund raiser.

<b>Ethnicity</b>	<b>No. of responses</b>
White British / UK	57
Other British/UK (including British mixed, British Asian, Black British)	13
English, Welsh or Scottish	3
White / Caucasian	34
Other White (including White Irish, White Asian, White Indian, Pale)	9
European (including Swedish, Italian)	7
Indian	4
Mixed (including Italian / Brazilian, Asian-Kenya)	3

Filipino	1
Australian	1
American	1
Asian	1
None (including ?)	3
No ethnicity given	30

<b>Do you consider yourself disabled?</b>	<b>No. of responses</b>
No	115
Yes	25
Fellow wobbly	1
A bit, 50/50, Sometimes	4
Not yet	1
No response	24

<b>Do you consider yourself deaf / Deaf?</b>	<b>No. of responses</b>
No	127
Yes (including age-related)	8
Slightly, bit hard of hearing, deaf in one ear only	4
No (but I have tinnitus, have been involved in Deaf community)	2
No response	29

## **Appendix 2: Overview of Twitter responses**

The 123 twitter responses in connection with #unrulybodies were categorised into four main types:

Positive response to performance	75
Promoting the performance	25
Quote from performance	7
Description of performance	7

Other key ideas emerging from the tweets include:

New perceptions of difference that come from the performance	3
Performances challenge what it means to be normal	1
Lived experience of disability comes across in the performance	1
Great access and inclusion (venue)	2
Needs to reach a wider audience	1
Participant had an emotional connection with the performance (DMD)	1
Changing / stirring perceptions	1
Disabled people are at the forefront of change	1
We can change perceptions of disability	1
Questioning display / narratives in medical museums	1

### **1. Examples of positive responses to the performance**

Moving discussion following @UnrulyBodies and a personal and thought provoking performance @julievitalxpose (Phil Cave @cavephil)
@unrulybodies thanks for the great&thought provoking drama on disability&difference in museum collections at Langdon Down museum (Kingston Museum @KingstonMuseum)
We embrace hope, not pessimism in changing perceptions of disability, after an insightful evening @shapearts @UnrulyBodies @HunterianLondon (Ioannis @athannis)
#@UnrulyBodies thank you to @chessmartinez for the brilliant advice and outburst of love and positivity tonight #wobblyisthebest (Jennifer Carss @JenniferCarss)
#UnrulyBodies tonight at RCP...someone throw shedloads of money at Deaf Men Dancing & let them fly. Brilliant, inventive, gut-wrenching.Wow! (Barbara Lisicki @wanda_barbara)
#unrulybodies simply stunning I'm now signed up for the Wobbly Maniifesto and strangely a bit weak at the knees

😊 (Anand Madhvani @dosima_org)
Such an interesting and relevant project, starting where collections meet experiences #unrulybodies (Amy Louise Chang @AmyLouiseChang)
New ways of presenting lived experience of disability, inspired by museum collections. Fab #unrulybodies performed @sciencemuseum #Smlates (EmilySD @RaisingGinger)
Laughed & cried w/ @DeafMenDancing1 & @chessmartinez last night at the @sciencemuseum #unrulybodies. Well-behaved people rarely make history (Katharine @eliza_kath)

**2. Example of tweets promoting the performance**

Really looking forward to seeing @UnrulyBodies tonight. Important contribution to #InclusiveHeritage debate (Jo Reilly @JoReilly00)
'Disability isn't the problem, the cuts are... Normality doesn't exist.' I urge you to check out museum-inspired @unrulybodies #DavidHevey (Esther Lie @Esther_lie)

**3. Examples of tweets that used quotes from the performance**

Qu in response to @Julie_McNamara performance 2day. Should human specimens like discussed in show, be on display at all 1of2 #unrulybodies / or is the manner of display today and the story told about #disability that is problematic? 2of2 #unrulybodies (Steph Evelyn-Wright @archaeowright)
'I'm glad to be #wobbly & outside of a system run by bullies & which measures us by our lack' - @chessmartinez @UnrulyBodies @thackraymuseum (Dr Kai Syng Tan FRSA @kaisyntang)

**4. Examples of tweets that gave a description of the performance**

At @chessmartinez 's Wobbly Manifesto launch as part of @UnrulyBodies. Post show discussion at #unrulybodies (Anzir Boodoo @anzrboo)
@GraeaeJennyS calls for @chessmartinez For Prime Minister campaign @UnrulyBodies @RCPLondon Vote Chess! Vote Wobbly! (Dea Birkett @DeaBirkett)

### **Appendix 3: The interviews**

<b>Venue</b>	<b>Date</b>	<b>Description</b>
Langdon Down Museum of Learning Disabilities	7 June	Interview with Denise Carr, Chair of Richmond Mencap Interview with Maria, support worker (community arts)
Royal College of Surgeons	8 June	Interview with David and Marcella
Royal College of Physicians	13 June	Interview with Julie (artist), Tom and Sean
Thackray Medical Museum	14 June	Interview with Jill, member of the Deaf community
Surgeon's Hall Museums	15 June	Interview with Alan, artist and sculptor Interview with Alexis, US student studying in Edinburgh Interview with Heather, PhD student at Heriot Watt University studying BSL and interpretation Interview with Zoe, member of the Deaf community
Bethlem, Museum of the Mind	17 June	Interview with Hassim Interview with Mary, a service user
Thackray Medical Museum	18 June	Interview with Becki Moss, disability activist Interview with Bryan, who works with disabled people Interview with Jennifer
Royal College of Surgeons	22 June	Interview with Julie, artist