Institution: Arts University Bournemouth

Unit of Assessment: D32 Art and Design: History, Theory and Practice

Title of case study:
Our Human Condition: Using photography to give those affected by genetic conditions a voice

Period when the underpinning research was undertaken: 2018 – 2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Professor Paul Wenham-Clarke	Professor of Photography	2007 to date

Period when the claimed impact occurred: 2018 – 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Our Human Condition is a practice-based research project by photographer Wenham-Clarke, which drew public attention to scientific advances in genetics research. Through a series of photographs, accompanied by narrative histories, the life experiences and views of siblings, where one is living with a genetic condition, were brought into the public domain. The impact has been to allow such families who are normally habitually underrepresented and 'silent', the opportunity to have their views seen and heard. As scientific research is poised to allow people with genetic disorders choices about therapies, the project raised public awareness about the range of genetic conditions that currently exist and the experience of living with them across the age range. It also impacted on policy makers and scientists by showing that people who have these conditions might not want to try therapeutics for their conditions as they saw their disability in a positive light.

2. Underpinning research

There are thought to be around 6,000 genetic conditions, spread throughout the population, most of the time hidden in our genes, undetected. With significant advancement of knowledge since DNA was discovered in 1953, and the mapping of the human genome in 2003, society is now poised on the brink of being able to alter its own genes and, by implication, the genes of generations to come. Gene therapies and screenings are already being applied to people with genetic conditions.

Long interested in the science of genetics, Wenham-Clarke undertook a practice-based research project *'Our Human Condition'* that addressed the personal stories of siblings in which one or more of them has a genetic condition. He sought to create a photographic record of the lives of these families to evidence how our society interacts with them. Over a two-year period of sustained engagement, Wenham-Clarke worked with seven specialist charities to recruit families willing to participate in the research, advertising the project through social media. The charities ranged from those supporting more common conditions such as Downs Syndrome, to less well known or rare conditions including Albinism, Alpha Thalassemia (ATRX) and Deafness, Onychodystrophy, Osteodystrophy, and Mental Retardation Syndrome (DOORS). The research focused not only on young families but those who had been living with a sibling with a genetic disorder over several decades.

The research aimed to bring the views of families and individuals with genetic conditions to public attention and also raise awareness of the revolutionary changes that are occurring within medical science and the short- and long-term implications of these. It also aimed to educate the

public about human genetics in order for them to have a more informed opinion, promote empathy and acceptance of diversity within society in general. Furthermore, as this generation may well be one of the last before many conditions disappear, it aimed to create an historic record of the lives of individuals in the UK who have a mental or physical disability due to a genetic condition,

The programme of research explored how the siblings' development influenced each other's lives; how they related to society; and how society related to them. It sought their views on new genetic therapies and screenings that are now available or might be introduced in the future, and the changes in society that families or individuals with a genetic condition would like to see. The project included one family whose son was taking part in one of the first human genetic trials for muscular dystrophy.

Unusually, for such a long-term research project, Wenham-Clarke decided to release some photographs from the project at an early stage of the research, enabling them to be put forward for nationally significant photographic competitions. An image was selected for the AOP50 exhibition run by the Association of Photographers in 2018 to celebrate their 50th Anniversary and was a winner in the BJP Portrait of Britain competition in 2019. The resulting publicity, particularly following exposure on the BBC website encouraged other families to engage in the research. In total some 130 families participated in the project.

Wenham-Clarke spent between two and three days with each family, taking part in their daily activities in order to gain trust and encourage the participants to lower any barriers. Some of the people involved had profound learning disabilities and great patience and kindness was required throughout. Wenham-Clarke created a series of photographic portraits of each family showing their life and relationships. Employing oral history, narrative history and qualitative interview methodologies the images were supported by written and/or audio interviews providing further insights into the attitudes of the siblings and families involved.

The research found there were unusually strong bonds between siblings across the age ranges and their lives although separate were deeply intertwined. The images and stories provided powerful and moving insights into the world of these individuals demonstrating a robust pride in their sense of worth and contribution to wider society. The images gave a compelling account of both what it is like to have a genetic condition and the stresses of having a sibling with such a condition.

The research also found there were differences between those with the same condition demonstrating that people do not always present in the way wider society expects or understands. For example, the three families with Down's Syndrome included two unusual cases, a family from India in which the boy affected barely showed any physical signs and another family in which the condition led to loss of hair, resulting in confusion over age and gender. Research participants spanned the age range and included someone with Down's Syndrome in their 50s to illustrate that people with the condition are now living much longer.

The resulting suite of 29 photographs was exhibited at The OXO Gallery, London during January 2020, and by invitation at the Scottish Parliament in Holyrood in February 2020.

3. References to the research

1. Prize and exhibition: Image of *Hattie and Charlotte*, selected from 10,000 images for AOP50. Shown at AOP 50, One Canada Square, 16 April to 1 June 2018. [Available on request].

2. Prize: Image of *Maureen and Aileen*, winner of Portrait of Great Britain, British Journal of Photography, 2019. [Available on request].

3. Exhibition: Wenham-Clarke, P. (2020). *Our Human Condition*. The Oxo Gallery, 204, Oxo Tower Wharf, Bargehouse St, South Bank, London SE1 9PH. 8 - 19 January 2020. Supported by the Genetics Society, £5k, 2019. [Submitted to REF 2021].

4. Exhibition: Wenham-Clarke, P. (2020). *Our Human Condition*. The Scottish Parliament, Holyrood, Edinburgh, EH99 1SP 3 – 7 February 2020. [Submitted to REF 2021].

5. Prize: Honorable Mention in the International Photography Awards in the Professional: Deeper Perspectives category (2020). [Available on request].

4. Details of the impact

The key beneficiaries of this practice-based research project were families, charities, scientists, policy makers and the wider public. The research was impactful instrumentally in giving families with genetic conditions, (in fact, those who are habitually underrepresented), a voice and the opportunity to be seen at a time when scientific research is poised to allow people with genetic disorders choices about therapies. It raised public awareness of the range of genetic conditions that currently exist and highlighted the work of charities in this area, particularly those supporting those with rarer conditions. The project highlighted the huge range and number of disorders found in the human population and that they are often hidden and can emerge in any family and so are a part of all of us.

Giving families living with genetic conditions a voice

The research allowed those living with a range of different genetic conditions to share their thoughts and feelings about their conditions. It also allowed their siblings to talk about their experiences of living alongside and supporting their siblings. The Down's Syndrome Association commented: *the project is a beautiful evocation of the beauty and joy of difference*. **(R3)** In particular the images illustrated the lived experience of living alongside siblings with genetic conditions that they had previously struggled to put into words:

I was delighted that my daughters had the opportunity to participate in the "Our Human Condition" project as people with PMLD and their families so often fly under the radar. We are essentially a forgotten population who very rarely have a voice. Lauren doesn't have a voice, not only because she is unable to speak but also because to be heard there has to be someone listening. This is very often not the case. And Jenna is part of that unsung and undervalued community of siblings who are also carers and advocates. **(R2)**

The photographs showed the closeness and understanding between the siblings, as well as their pain and frustration. We saw moments of joy, and difficulty, and love and it showed what many "normal" siblings have always struggled to put into words. **(R5**

This project gave my daughters the chance to not only be heard but to be seen. People in their position are often considered as people to be pitied but Paul's photographs portray them as they really are; young women who are full of life and positivity. The photographs also captured what may not often be seen with the naked eye, namely love, empathy, connection and courage. **(R2)**

The project has successfully given the families involved a voice and a platform to share their own experiences. These families often feel excluded or on the outside due to the challenges that they face. The written statements allowed them to tell their stories in their own words. I found them hugely inspiring and moving. ***(R1)***

It also highlighted that changes that scientific research into genetics might offer but that people who have these conditions might not want to try therapeutics for their conditions as they saw their disability in a positive light:

The project highlights the fact that through scientific research in many fields we are now on the verge of being able to offer people with genetic disorders choices about therapies. The statements from families with genetic conditions are a powerful insight into their opinions and reveals we should not assume all people will choose to try therapeutics for their condition. We

are all different, but having the choice is what's important. ***(R4)*** *Our Human Condition* raises important questions that we all need to consider. ***(R3).***

The images capture people living with genetic conditions that may not exist in the future and so provide an historic record of lived experiences captured through visual means:

Watching him [Wenham-Clarke] turn the idea into a piece of art and a record of history was fascinating. His empathy enabled him to capture authentic moments rather than construct staged poses. **(R5)**

Images from the project have also continued to help the supporting charities campaign such as in the case of the Scottish charity PAMIS. They were campaigning for changes during the covid lockdown for their relatives with learning difficulties who were in care homes. Images from the project were used in an article on Scotland Tonight television news. **(R10).**

Raising public awareness of genetic conditions

Wide dissemination of the research enabled the wider public to understand the circumstances of families living with genetic conditions that would not have been possible otherwise. It also drew public attention to developments in genetics that are currently taking place.

The research was initially disseminated through exhibition in London, and reported widely in the news media and via online platforms including the 'Evening Standard' (printed in all city publications) and the 'Metro', the latter describing it as a 'powerful' exhibition **(R6).** It also featured in publications supporting those with disability including the USA based 'Sibling Leadership Network', and 'Rare Magazine' contributing to the discussion around new gene therapies. The images were shared at The World Congress of The International Association for the Scientific Study of Intellectual and Developmental Disabilities 2019, by policymakers and scientists.

The British Journal of Photography's Portrait of Britain Exhibition run on JCDecaux public digital screens, including shopping malls, highstreets and bus shelters, enabled the images to be seen by many shoppers and commuters right across the UK throughout September 2019. **(R8).** With around four thousand people attending the OXO show, hundreds of thousands of people were able to view one image (Maureen and Aileen) projected on a large digital bill board at Waterloo Bridge with other images displayed on billboards along the South Bank, 2020. **(R8).** The Genetics Society noted that: '*The Exhibition has a significant part to play in drawing attention to developments in genetics and their future implications*'. **(R7).**

The image *Sisters Hattie and Charlotte* was selected for the prestigious peer-reviewed exhibition AOP50, celebrating the 50th Anniversary of The Association of Photographers, London in 2018 and received wide geographic reach through inclusion in coverage of the show on the BBC website, the Guardian and the Daily Mail. **(R6).** The image *Brothers Rishabh and Kaustubh* was shortlisted in the British Journal of Photography's Portrait of Britain exhibition in 2018 and the image *Sisters Maureen and Aileen* was a winner in the same competition in 2019. The image *Sisters Maureen and Aileen* went on to gain an Honorable Mention in the International Photography Awards in the Professional: Deeper Perspectives category (2020).

My daughters have been featured in two exhibitions so far and in other publicity material. The supporting narrative written by Jenna about her relationship with Lauren has consequently been read in conjunction with the photographs, by many people who were otherwise unlikely to have been aware of their circumstances. **(R2)**

It was also good to talk to the general public who came to the exhibition; we feel like they benefited from it, not learning about genetic conditions from the media, but the people who live with it every day. It gave the opportunity for the siblings to voice their actual experiences rather than people's preconceived ideas of genetic disorders. ***(R5)***

The work was also shown, by invitation, at the entrance of the main debating chamber at the Scottish Parliament in Edinburgh in 2020. It was aimed at the legislators rather than the public, informing policy makers about siblings supporting family members with genetic conditions, and helping to raise awareness of advances in genetics' science:

I have also been supporting Paul in negotiations with the Scottish Parliament to host a significant exhibition of the project and this has provided an unprecedented opportunity to heighten awareness of genetic conditions, learning disabilities and the role of siblings and carers with Members of the Scottish Parliament. **(R2)**

The photography exhibition created by Paul Wenham Clarke on 'Our Human Condition' is a beautiful display of very powerful images showing the relationship between siblings and family members where one or more of the subjects had a genetic condition or additional support needs. The photos were a powerful statement of both the struggles and achievements of families who have been affected by genetic conditions, and informed the thinking of my colleagues in the Scottish Parliament. ***(R1)***

It also helped to inform decision makers in respect of the advances in genetic science:
Paul's project drew much needed public attention to not only the advances in genetic science but also how far we still have to go in carrying out studies and research. The advances that have already occurred have had huge and positive impacts on the lives of the families included in this photo series. Having the photos displayed within the Scottish Parliament allowed for politicians and policy experts to become more informed about what the next steps to take are in relation to genetic science. ***(R1)***

5. Sources to corroborate the impact

R1). Statement: Scottish Minister and Deputy Leader of the Scottish Labour Party [Informed decision makers of the impact in genetic science].

R2). Statement: Mother of two of the siblings photographed and Chair of PAMIS [Enabled siblings to share experiences of living with a genetic condition].

R3). Statement: Down's Syndrome Association [Sharing of lived experience; seeing disability in a positive light].

R4). Statement Professor of Neurogenetics, UCL Institute of Neurology [Images and oral history provide a powerful insight into opinions of people with genetic conditions].

R5). Statement from family living with a genetic disorder [Giving families a voice].

R6). Media coverage [Public understanding of families living with genetic conditions].

R7). Genetics Society News [Drawing attention to developments in genetics]

R8). Rare Magazine [Contributed to discussion around new gene therapies].

R9). Billboards in London and digital advertising displays across the country [Images seen by 100,000s of commuters and shoppers in London and throughout the UK].

R10). Scotland Tonight [Helping charities campaign for people with genetic disorders].