

VIDEO INTERVIEW TRANSCRIPT

## Neale, Kay: transcript of a video interview (18-May-2016)

**Interviewer:** Tilli Tansey

**Transcriber:** Debra Gee

**Editors:** Tilli Tansey, Caroline Overy

**Date of publication:** 05-Jan-2017

**Date and place of interview:** 18-May-2016; Queen Mary University of London

**Publisher:** Queen Mary University of London

**Collection:** History of Modern Biomedicine Interviews (Digital Collection)

**Reference:** e2017002

**Number of pages:** 7

**DOI:** 10.17636/01018375

**Acknowledgments:** The project management of Mr Adam Wilkinson and the technical support (filming and production) of Mr Alan Yabsley are gratefully acknowledged. The History of Modern Biomedicine Research Group is funded by the Wellcome Trust, which is a registered charity (no. 210183). The current interview has been funded by the Wellcome Trust Strategic Award entitled “Makers of modern biomedicine: testimonies and legacy” (2012-2017; awarded to Professor Tilli Tansey).

---

**Citation:** Tansey E M (intvr); Tansey E M, Overy C (eds) (2017) *Neale, Kay: transcript of a video interview (18-May-2016)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017002. London: Queen Mary University of London.

---

**Related resources:** items 2017003 - 2017011, History of Modern Biomedicine Interviews (Digital Collection)

**Note:** Video interviews are conducted following standard oral history methodology, and have received ethical approval (reference QMREC 0642). Video interview transcripts are edited only for clarity and factual accuracy. Related material has been deposited in the Wellcome Library.

© The Trustee of the Wellcome Trust, London, 2017

## Neale, Kay: transcript of a video interview (18-May-2016)\*

**Biography:** Ms Kay Neale MSc SRN (b. 1946) qualified as a nurse at the Royal Free Hospital in 1967 and was appointed as a District Nurse in Islington in 1969. In 1974 she started to work at St Mark's Hospital as a Research Nurse funded by the Cancer Research Campaign. She worked with Dr Michael Hill, who was studying gut chemistry and flora at the Centre for Applied Microbiological Research at Porton Down, and patients with polyposis were part of the group included in their research. In 1984 she was appointed to work alongside Dr H J R Bussey and Dr Sheila Ritchie in the Polyposis Registry, funded by the Imperial Cancer Research Fund. She gained a Master's degree in 1985 in survey research methods and helped with the computerization of data, collected since St Mark's Polyposis Registry began in 1924. This unique database has provided support for both clinical and laboratory based research, including the localization of the APC and MYH genes. She is currently employed by London North West Healthcare NHS Trust. She was a founder member of the Leeds Castle Polyposis Group (1985), which evolved into the International Society for Gastrointestinal Hereditary Tumours (2005), of which she remains the Honorary Administrative Secretary

---

### [1]. FROM NURSING INTO MEDICAL RESEARCH; STOMA CARE AND COLLECTING FAECAL SAMPLES

Having trained as a nurse I tried several different things including private nursing, district nursing. Whilst I was district nursing I was trying to get married, and decided to do something extra to earn some money. In fact I didn't get married but I did a little job working in a pub with some friends of mine. And during that experience I met a man that ran a driving school, and he asked me one evening to take him home, because he'd had a bit too much to drink. So I drove him home, after which he suggested I might learn to become a driving instructor, which I did. And I didn't want to do that as a full time job, so I looked for some part time nursing work. And some of that was private nursing, but eventually it led me into research. And I got a job with a man called Dr Michael Hill, who initially had a laboratory at Colindale, but was soon moved to Porton Down, the Bacterial Metabolism Research Lab, and it was based in the Centre for Applied Microbiological Research. He was a microbiologist and a bacteriologist, and what he was interested in was gut flora. And in order to study gut flora he needed some samples of faeces. So my job was to work at St Mark's hospital collecting samples of poo.

Having started work at St Mark's I met a lot of the consultant surgeons and there was only one physician at the time, Dr Leonard Jones, but my work mainly involved working in the clinics with the surgeons. And Mr Ian Todd was interested in finding out what it was like to live with a stoma. And he asked me if I'd be interested in helping him with a research project. So I was interviewed by a couple of people and it was agreed that it should go ahead. In order to do the research we needed to develop a questionnaire, and realised none of us knew how to do that. So the department at City University was approached, and Richard Barron kindly agreed to take me under his wing, and helped me to design the questionnaire. Well, it was a big questionnaire, it involved sections for all types of people, working, students, housewives, people who were sick and disabled, and I had to go and visit them at home in order to interview them. It was fascinating because many of these people had had no-one to talk to about their experiences. They'd all had their stoma

---

\* Interview conducted by Professor Tilli Tansey, for the History of Modern Biomedicine Research Group, 18 May 2016, in the School of History, Queen Mary University of London. Transcribed by Mrs Debra Gee, and edited by Professor Tilli Tansey and Ms Caroline Overy.

for at least 2 years, some as long as nine or 10 years. And there were lots of things that they were unhappy about, and wanted to talk through with someone.

## [2]. FROM NURSING INTO MEDICAL RESEARCH: NURSE TRAINING THEN AND NOW

When I qualified as a nurse I really didn't know what I wanted to do. And one of the things that I did was learn how to teach people to drive. But I didn't want to do that full time, so I looked for part time jobs and one of the part time jobs that I became involved with was working with a lady called Eve Bendall. She was in the process of studying for a PhD and she was doing a research project. And she had a feeling, she was a nurse, and she had a feeling that some nurses who are very good nurses, were not very good at doing exams, whereas the nurses that were really good at passing exams were not necessarily so good at being nurses. And she employed three of us, young nurses, to help her with her project. And we, she chose some hospitals by sticking a pin in a map, and over a period of several months we went weekly to different hospitals, and we stood on the ward, we were told which nurse to watch, and which nurses to watch, and we had our various activities that we had to record. The activities had to be things that were done by the most junior and the most senior of nurses, all student nurses.

One of the tasks we had to watch for was 'does the nurse look at the thermometer and shake it down before putting it in the patient's mouth' of course nowadays I think thermometers are probably disposable, but in those days they were stored in antiseptic on top of the bed. I'm sure some of you young nurses watching this will be horrified at the thought. Another thing we looked for was 'does the nurse give the patient a bowl of water to wash his hands after using the bedpan'. That kind of thing. And Eve Bendall would then give the nurses a questionnaire to complete, a little test, and she would give them all a psychological profile to fill in. And of course the outcome of her research was that the really good nurses are not all that good at answering questions, they let themselves down. But I've always thought nursing is a very practical job. That's why most of us enjoyed doing it. That's why we chose to be nurses, we like looking after people. We weren't necessarily academic.

One of the things that impresses me now, working with the nurse practitioners that I work with in the Polyposis Registry at St Mark's and the other departments too, is the degree of professionalism. They are intelligent, interested, lively, funny, amazingly competent and dedicated ladies. We don't have any male nurses yet, but we're always on the lookout for one. They're to be admired.

## [3]. ST MARK'S HOSPITAL AND SCREENING POLYPOSIS PATIENTS

Having worked with Mike Hill collecting samples of poo, one of the groups of patients that I collected from were the patients with polyposis. As a result of that I met Dr Bussey, who at that time ran the Polyposis Registry, and was always keen to teach people about polyposis, and the patients, how to help them. Because the main aim of his work, as is our work now, is to prevent people from getting cancer wherever possible. So whilst I was in clinic I would talk to the polyposis patients, and encourage them to bring their children up for screening. It was in the days before we had to have referral letters from doctors, there were no contracts, the money didn't follow the patient in the same way that it does now. In many ways that made life a lot easier for us, and for the children, because they could come when they felt like it, rather than having it pre-set by a visit to the GP and then an important visit to the hospital. It could be seen as being much more casual. By 1983/4 the work with Dr Hill was winding down, and Dr Morson, who was the head of research at St Mark's wanted somebody to help Dr Bussey in the Polyposis Registry. At that time he worked with Sheila Ritchie, Dr Sheila Ritchie, but Sheila worked voluntarily, she wasn't paid, and so it was felt that a salaried person was needed to find out, as Dr Morson said, 'what Dr Bussey has got in his head'. In truth it wasn't all in his head. It was meticulously documented on various card systems, and various, in big family files. So I was asked if I was interested in doing that. While working with Dr Hill I'd embarked on a degree course in survey research methods, so I was seen as the ideal person to take over a small research department should Dr Bussey 'go under a bus', as Dr Morson put it. Although Dr Bussey pointed out to me that when Dr Dukes was getting older, that Dr Bussey was important in case Dr Dukes went under a taxi.

**[4]. ST MARK'S HOSPITAL AND THE POLYPOSIS REGISTRY**

The consultant pathologist before Dr Morson was Dr Dukes, famous for the Dukes' classification of cancer. And Dr Bussey told me that when it was thought that Dr Dukes might pass away, so Dr Morson was approached to take over from him, it was said that Dr Dukes might go under a taxi. Dr Bussey thought it was quite appropriate that he would go under a bus. So I joined the team, and at first Dr Ritchie asked me why I was there, because she could see no need for another pair of hands, and Dr Bussey was very fit and well, although increasingly getting older. But gradually I learned what was going on in the Registry. Dr Ritchie had started up clinics called polyposis weeks, and the consultants had their own groups of patients. The consultants' clinics were on certain days, so every 3 months we had a whole week of polyposis patients coming to clinic. And Dr Ritchie and I would collect the information about what happened to them in clinic, how many polyps they had, whether the polyps needed treating, whether the families had got new members, new babies, whether people had died, what other illnesses and operations people had undergone. And we would take all the information back to the Registry, record it in the family files, and update Dr Bussey so that he could update his cards. Not long after I started work at the Registry, in 1984, it was decided that we should have a computer system. And Dr Ritchie and I were given the task of, not exactly designing it, but telling the designers what information we needed to gather from the computer. Once the computer was in place we would have little competitions with Dr Bussey to see who could find the information faster. And the computer in those days was so basic that Dr Bussey could usually get the information quicker from his cards that we could get it from our computer.

**[5]. ST MARK'S HOSPITAL: POLYPOSIS, AND DESMOID TUMOURS**

So in 1985 St Mark's hospital celebrated their sesquicentennial with a big international meeting at the Barbican centre. And all doctors, surgeons, gastroenterologists interested in colorectal disease came to London. At that time Ian Todd, the senior surgeon had a young patient with adenomatous polyposis, as it was called in those days, adenomatous polyposis coli, who also had a very large abdominal desmoid tumour. She looked 9 months pregnant, and he really didn't know how to treat her. We'd heard reports from people who said that if you cut into desmoid tumours they would grow even faster. Even if you biopsied them it could result in very fast growth. So it was arranged that the weekend following the meeting at the Barbican, a meeting would be organised at Leeds Castle in Kent. This was partially arranged by St Mark's, and partially arranged by the Imperial Cancer Research Fund, and I don't know if he was Sir Walter Bodmer at that stage, but certainly he was Dr Walter Bodmer at that stage. And at first I wasn't invited but Dr Ritchie pointed out that if I was to have a long term involvement in polyposis I should attend the first international meeting on polyposis, which I did. That turned out to be advantageous to me because I met all of the important people who were involved around the world, and they met me, they knew who I was. I also discovered that people who were thought to know about the disease didn't necessarily know as much as I would've expected them to, as a junior person.

One of the surgeons from a prestigious American university put up a slide and said 'this is an adenoma' and the St Mark's pathologist Dr Morson banged on the table and said 'Mr Chairman that is not an adenoma'. 'Oh' said the American, 'I'm so sorry, my pathologist must have put up the wrong slide' and he put up another slide and said 'this is an adenoma' and Dr Morson said 'that is not an adenoma'. And I realised that actually it's quite important to know who you're working with, and to know that they really do know about their speciality.

**[6]. THE LEEDS CASTLE POLYPOSIS GROUP, HNPCC AND InSiGHT**

At the meeting at Leeds Castle, one of the important things that we discovered was that no-one knew how to treat desmoid disease. It was therefore decided that Dr Ritchie and I should develop a series of questionnaires to be sent round to any registry that we could learn about or know existed around the world, to find out exactly how much information did the various registries have. How many patients did they have, how many desmoid tumours did they know about, how many patients with upper GI [gastrointestinal]

polyposis did they know about. And it was decided that we would call ourselves the Leeds Castle Polyposis Group, and that the condition adenomatous polyposis coli needed to change its name, because it wasn't obviously restricted to the colon, and the name familial adenomatous polyposis was suggested and agreed. Following on from the Leeds Castle meeting in '85, Dr Jerry DeCosse from New York arranged a meeting of experts in Washington two years later, for Dr Ritchie and I to report our results. After that meeting we arranged another meeting back in London, where it was agreed that the Leeds Castle Polyposis Group should become formal, and should have a membership base, and a chairman. And the first chairman elected was David Jagelman of the Cleveland Clinic in Florida. We held meetings regularly every two years, but over the years the people who were very interested in hereditary non-polyposis colorectal cancer also started to hold annual meetings.

At St Mark's there are two groups, because we have so many patients, we have one department caring for the polyposis patients, and another department caring for the hereditary non-polyposis patients, now known as Lynch syndrome. So we didn't realise in the Polyposis Registry, where I'd become the honorary administrative secretary, that the same people were going to the Leeds Castle meeting every two years, and the HNPCC [hereditary non-polyposis colorectal cancer] meeting every year. And of course it became natural that the two groups should merge. And we had a couple of meetings, joint meetings, and then in 2005 at the meeting in Newcastle, hosted by Professor John Burn, the new International Society for Gastrointestinal Hereditary Tumours [InSiGHT] became a formal entity, with a new constitution.

That international society became known as InSiGHT, and in 2010 we became incorporated as a company, and became a registered charity. We still hold our meetings every two years, and currently are building a new website with the aim to offer help and knowledge worldwide, much more so than it is now, because it's very expensive to come to meetings.

#### [7]. **ST MARK'S HOSPITAL: WORKING WITH FAMILIES**

By 1995, St Mark's had moved from the City Rd site to Northwick Park, and we found funding. By this time Robin Philips was a director of the Registry, and he was setting about to do a study, a chemo prevention study, with a company who had agreed to fund a new computer system. The wonderful thing about this for us was that we were able to build into it fields that enabled us to trace and monitor the patients more easily. One of the most satisfying parts of working in the Registry was our, my contact with the patients. Getting to know them, getting to know the families, taking the family history, and then attending the clinics and meeting them year after year after year. Watching the children grow, and being introduced to children in their pushchairs, and gradually watching them grow up until it was their time to be examined. Sometimes the patients would treat me and my colleague, at that time was Judith Landgrebe, they would treat us like members of the family. They would bring us little presents back from their holiday.

Some of the patients would treat us like members of their family, bringing us little presents back from their holiday, sending us cards. But of course the most important thing for us was that they would keep us up to date. And trust us enough, sometimes to tell us family secrets, like the existence of illegitimate children, who were of course at risk of getting polyposis. And if not warned and treated, or tested to find out if they were affected, the first time they might know about the condition was the development of cancer. So there were several occasions where through the social services, or some of the religious organisations that dealt with adoptions, we were able to trace children that had been adopted. We would always write and say that we understood that a certain person had adopted the child, we didn't need to know where they were, we didn't need to know their name, but we would like them to reassure us that the child had been referred and screened.

In dealing with the families, I don't think that I was always, in fact usually not aware of how much they valued my involvement, or my various colleagues' involvements in their care. Just a few years ago I met a lady when I was going home from work. She was standing at the front door waiting for a taxi with her teenage son, and she greeted me with great pleasure and said 'Oh Charlie, this is Kay, you have to meet Kay, because if you're ever in trouble you just ring up and ask for Kay, and she will sort everything out for you'.

And I had no idea that that was how she viewed me, and the amount of, well I felt very little involvement in helping her during her time at the hospital, but obviously she viewed it differently. And that's very nice feeling to have, that I have been helpful to people during their, it's a difficult, difficult condition to live with, and it's nice to know that I've helped.

#### [8]. GENETIC TESTING

The most important change that's occurred during my time working with the families with polyposis, the various polyposis syndromes, is the advent of genetic testing. In the early 1990s, the APC gene was discovered, and the exact site of the mutations. Different families have different mutations. But the fact that by 1996, we set up a, or Robin Philips set up an NHS genetic testing service, with the Kennedy Galton laboratory, based at Northwick Park, and we were able to offer patients a genetic test. And I remember particularly one gentleman who had been coming every year for his examination of his colon, to see if he had got polyps, he was married but had refused to have children on the basis that they would be at risk of inheriting the disease. And when we were able to test him and reassure him that he had not got polyposis, his wife was still young enough that they could embark on having a baby. That's a marvellous advance to the scientists who did that work. Since then the genes for the other syndromes have been discovered, and genetic testing and even pre-natal diagnosis is now available for people who want it.

Thinking about that particular patient makes me realise how very much things have changed. Because I remember a story that Dr Bussey told me about Henry Thompson, who was a surgeon at St Mark's, who was an Oxford blue for boxing. And in the days when Henry Thompson was interested in getting people to be screened to see if they had got polyposis, the surgeons would go and try to visit people at home, and he did go to visit a relative of that patient's father, I think it might have been his cousin. And the cousins were boxers, and they really did not want to have a sigmoidoscopy. They did not want anyone looking at their bottoms. And Henry Thompson said that he would challenge this man to a boxing match, and the prize, or the bag I think they called it, would be the examination. So he'd either have it or he wouldn't. And Henry Thompson was very confident that he was going to win over a sort of amateur boxer.

#### [9]. POLYPOSIS - PREDICTIONS FOR THE FUTURE

Genetic testing has been the major advance in the last 30-40 years that I've been involved with polyposis. And I think over the next 40-50 years it's going to be the next big move forward. I think people will have genetic profiling, everyone will be told what they are at risk of, we won't just be screening people we know to be at risk, everyone will know their risk. There are polyposis syndromes now, that we are diagnosing clinically, sort of, such as serrated polyposis syndrome, where the gene, the causative gene is not yet known. That will be found.

There are other patients with polyposis, where they have mixed adenomas and serrated polyps. And we really don't know enough about them, we're collecting the information about what type of polyps they have, what age they get them, but we really don't have these patients fitted into any particular syndrome yet. The genes causing those types of polyposis will be discovered, and I think the thing that's perhaps most close to my heart will be finding the cause for these terrible desmoid tumours. Some of our patients have a very miserable life, living with large desmoid tumours. They can look pregnant, they are treated by other people as though they are pregnant when in fact they have got a tumour. And we really don't know how to treat them. Some patients with extreme desmoid disease have undergone small bowel transplant, with varying degrees of success. So to find a cure for those patients I really feel that will happen within the next, hopefully sooner than 30-40 years.

[END OF TRANSCRIPT]

**Further related resources:**

1. Jones E M (2015) Register of interest: Bowel cancer and the Polyposis Registry. Blog post at: [www.histmodbiomed.org/blog/register-interest-bowel-cancer-and-polyposis-registry](http://www.histmodbiomed.org/blog/register-interest-bowel-cancer-and-polyposis-registry), 31-Mar.
2. Jones E M, Tansey E M (eds) (2013) *Clinical Cancer Genetics: Polyposis and familial colorectal cancer c.1975-c.2010*. Wellcome Witnesses to Contemporary Medicine, vol. 46. London: Queen Mary, University of London.
3. Tansey E M (intvr); Tansey E M, Overy C (eds) (2017) *Neale, Kay: transcript of an audio interview (18-May-2016)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017001. London: Queen Mary University of London.