 AUDIO INTERVIEW TRANSCRIPT

Neale, Kay: transcript of an audio interview (18-May-2016)

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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: e2017001
Number of pages: 21
DOI: 10.17636/01018374

Acknowledgments: The project management of Mr Adam Wilkinson and the technical support 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).


Note: Audio interviews are conducted following standard oral history methodology, and have received ethical approval (reference QMREC 0642). Related material has been deposited in the Wellcome Library.

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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, initially based in Colindale but moved to 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 computerisation 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 localisation of the APC and MYH genes. She is currently employed by London North West Healthcare NHS Trust as the Manager of the Department of Inherited Intestinal Cancer Syndromes. 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.

TT: Tilli Tansey

KN: Kay Neale

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KN: Before we start, can I just clarify why you’ve asked me because I personally can’t understand why you would want to interview me.

TT: There’s a very good reason why we should have you.

KN: In your email, you said that you wanted to ask me about why am I doing my job, and my achievements, that sort of thing. Now really I’m quite a low level person in all of this, so a lot of my achievements, I think some have been achieved through me because if I wasn’t there to implement it, it wouldn’t have happened, but, they wouldn’t have happened with me alone, if you see what I mean. So I’d quite like to make sure that other people do get credit.

TT: This whole project is called ‘Makers of modern biomedicine’, which includes the Witness Seminars like the one you contributed to, and we’re doing lots of supplementary interviews with people who came to these meetings. We’ve done about five or six in clinical genetics, like Peter Harper, Bert Bakker, Malcolm Ferguson-Smith. And so the point of these, it’s kind of like a witness seminar, getting behind the papers, behind what you read in papers, that sort of thing. You’re real people, even if, as you say, you’re only one cog in the whole thing.

KN: In the whole wheel, yes. Yes, yes, exactly, I can see that.

* 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.
TT: It's putting it all together.

KN: Yes, the professors have all the great ideas, but if somebody’s not there to do the groundwork it doesn’t happen.

TT: Sometimes it’s not just the professors having great ideas. I think it’s very varied. I have done several interviews, all fascinating stories. Some of the things I want to ask is to inspire young people into science and medicine? So it’s trying to get all of these voices, as many different voices as possible, who've contributed. And so, particularly thinking of your career and your contributions, particularly to the polyposis register, that’s something I really want to know about.

KN: Well I made some notes, because one of your questions is about my ‘achievements’?, but I haven’t achieved anything. And I had to think really hard, what would I say is my main achievement? And of course once you start thinking about it you do, you know I did come out with things and then I showed it to a friend of mine who worked with me in the Polyposis Registry for 10 years, and she said ‘but Kay’ she said, ‘what about all the lives you’ve saved?’ I said ‘well I haven’t saved any lives’ she said ‘well if you didn’t trace them, they would’ve got very sick you know’ and so she kind of gave me some more thoughts.

TT: At the end of the day we’re all on the same side, we all want to do as, you know, as good a job as possible to get as many voices as possible. We all know science and medicine is not just all the Nobel Laureates, and all the FRs [Fellows of the Royal Society].

KN: Well, Dr Bussey, the man that I worked with for so long, he taught me an awful lot about polyposis, and how he started the registry and how it was run. And I never felt that his story was properly told, and it was nice to be able to give him some credit when we did the other interview (Witness Seminar and blog piece). Because people do get lost over time, and so it’s to record their contributions. I don’t think polyposis, well it would be where it is now without him doing what he did, which stimulated other people’s interest?

TT: And it provided that continuity, because if you didn’t have a long series of records, that informs so much and has been such a valuable resource. So I just want to start with where you come from, did you, as a child want to go into nursing? Did you want to go into a caring profession?

KN: No, not really, I don’t think I was the sort of person that really had goals. My parents both of them lost their fathers when they were children, when they were young, and they both had big families. Both of them left school early and went out to work early. I was brought up with the view that if you work hard and you’re honest, that’s really all you need. And I wasn’t brought up with the idea that I should go to university because I don’t think the money was there to send me to university. My older sister went to nursing and I think I probably felt quite suffocated at home, and so it was a wonderful opportunity to get away.

TT: Could you just tell me a little bit more about where you were getting away from?

KN: Warwickshire, from Leamington Spa. That’s where I was born. I went to school in Warwick, and it was a new school and the headmistress was ill quite a lot, and I think, I don’t feel that we really had a wonderful education, through nobody’s fault. It was a difficult time, it was one of the post-war bulge years, so there were a lot of us, and the school was finding its feet, and I decided to leave. After leaving I became a cadet nurse, went to college one day a week, where I got some of my O levels, and then went to the Royal Free Hospital as a student nurse.

TT: What is a cadet nurse?

KN: I don’t know if they have them now, but it’s when you’re young, pre-student, so I was 16 to 17 and I did bed making and bed baths and washed the bandages, something you’d never do now. I was responsible for keeping the linen cupboards tidy, I enjoyed that. It was in an eye hospital, we weren’t allowed to work in sort of a mainstream general nursing, it was an eye hospital. And I was quite frustrated, because they
TT: So you went to the Royal Free, had your sister been to the Royal Free?

KN: My sister had been to the Royal Free, she was eight years older than me, so by this time she was married. So I went to the Royal Free.

TT: And what was your life like at the Royal Free? Were you in nurses’ accommodation?

KN: Yes, nurses’ accommodation. I started off sharing a room with two other girls, and two of us became very friendly, so I had a good friend throughout my training. They lived in Essex, in Buckhurst Hill, so we spent quite a lot of time at her parents’ house, and her parents were very very kind to me, treated me if I had days off where I couldn’t go up to Warwickshire, they would allow me to spend time with them, they looked after me, fed me. It was a good time, I don’t remember a lot now, it’s difficult, so much has passed.

TT: Did you enjoy your training?

KN: Most of it I did enjoy. I had some good friends and I enjoyed caring for people. Then when I qualified I became a staff nurse on the gynae ward which I didn’t enjoy so much, and, I’m trying to remember why I decided to leave.

TT: You were a student nurse and then you went in to midwifery?

KN: I then went to do six months midwifery, which I didn’t enjoy. I enjoyed delivering babies but I didn’t enjoy being so much with the women who were very hormonal. I always enjoyed surgical nursing much more than the psychological side of things, so, you know, treat them, get them well, send them home happy, rather than long term, things where people need a lot of psychological support, which I’m not so good at.

TT: Was this all in the Royal Free hospital?

KN: No, this was in the Whittington hospital in Highgate. And, I think it was from there that I became a private nurse.

TT: According to your CV it is!

KN: I think I did it just because I wasn’t sure what I wanted to do and it would give me an opportunity to experience different things. I didn’t do it for all that long because it wasn’t really what I expected. I joined an agency and the agency would ring up and say there’s a patient needing looking after at such and such a place. So the various hospitals or private people would contact the agency and send the person they thought was suitable. So I went sometimes to people’s home to look after elderly or sick people. Sometimes to, one of the places I enjoyed going to most was King Edward 7th’s hospital, was it Beaumont St? Somewhere just off Marylebone Rd.

TT: You see pictures of the royal family going there.

KN: Yes that’s right. I didn’t meet anybody royal, but I like being there, it was a good atmosphere and good care. But my job there was mainly what we called ‘specialing’, which is being with people after surgery, so the ward nurses could get on with the general duties, and my job was to sit with one person and do whatever was necessary after surgery. Of course in those days it was before intensive care units.

TT: Yes that right, it could be traumatic in lots of ways, could be quite demanding.

KN: It could be quite demanding, but I don’t know, one took for granted one’s job, you knew your job so you
got on with it. But then as part of being a private nurse I went to a nursing home in Highgate that was run by nuns. And I did work with them for quite a few months, again specialing individual people, or there was a ward where they had long term elderly people. But doing that sort of thing for a short period of time is ok but it does become boring. I can't remember, it must have been around that sort of time where I met someone who invited me to become a driving instructor.

**TT:** I noticed that on your CV. You were doing that part time as well as combining that with nursing?

**KN:** I think, oh no wait a minute I've missed out the district nursing.

**TT:** Well as a district nurse as well?

**KN:** Actually the district nursing was after the, after the midwifery wasn't it?

**TT:** Well it seems to be all the same time, so you're a student midwife, you're doing some private nursing, and then you're also doing some district nursing.

**KN:** District nursing, yes I became a district nurse full time with Islington borough council and started off as a sort of general district nurse where you were given an area which was your area, but then the idea of having nurses attached to a GP group practice came in, and I was attached to Dr Rosen's practice in Balls Pond Road I think it was, and I really enjoyed that. There were three doctors, Dr Rosen, another male doctor and a lady doctor whose names I can't remember. Regardless of the areas that their patients lived in, so there would be nurses looking after areas, but if my patients lived in their area I took the patient off their hands, but worked very closely with the doctors and the advantage of that was that they trusted me to make judgements. So if I rang them up and said such and such a person needed to be admitted to hospital they might arrange the transmission without necessarily having to go themselves. Or they might feel, or I might feel, they needed to see the patient to make the decision. So because we had a close liaison, they knew how much to trust me or how much to take my word for things so it relieved them, and I also started up a clinic, I think this happens everywhere now, that doctor surgeries have nurses who run their clinics in the practice, and I did hundreds of ear syringings. They commented on how wonderful it was to be relieved of that job. But I did minor dressings. I would hold a clinic one or two nights a week.

**TT:** One or two nights?

**KN:** Yes, it would be in the evening. So I would do my daytime work and then have an evening clinic. Not till very late, I don't know, I can't remember but it would be for people after work to come and have their dressings changed or their ears syringed, something like that.

**TT:** And this was your initiative to help, to set up this clinic, to actually help?

**KN:** I don't think so, no, I think it was their idea.

**TT:** But you must have been very willing and able.

**KN:** Oh yes, well I was always eager to help, and I think that was what my parents gave me, the understanding that you get on and do your job, and I didn't mind, I never felt that I had to work 9 to 5 and clock off, I would just carry on until I was finished.

**TT:** But you didn't stay in that for very long?

**KN:** No, I did become ill at one point, and then I found that the physical side of nursing was too much, but at the same time I met someone I thought I was going to marry, I didn't in fact marry him, but neither of us had that much money, but he knew someone that ran a pub, and I started as a barmaid in the evenings to save some money to get married. It was there that I met the guys, the man that ran the driving school and
the men he worked with, and one night he said to me ‘I've really drunk too much to drive home, how about you drive me, Kay’ so I said ‘sure no problem, but what about the car?’ and he said ‘well you just bring the car back’. I lived very near there, and I said ‘ok’ and rang him up and told him where the car was parked, I can’t remember what we did with the keys, I suppose he had another set of keys, I can’t remember, but after that when he came into the pub he said to me ‘it’s ridiculous, why are you working in a pub, why don’t you become a driving instructor, you’ll earn lots more money’ because he was quite impressed with the way I’d driven him. I thought that was a wonderful idea, and so I learned how to instruct, passed my test, and then I did, I worked with them for a while, evenings and every other weekend because district nursing was every other Saturday, and then I decided, I left district nursing and worked at the Italian hospital as a private nurse.

TT: Is that the Italian hospital on Queen’s Square?

KN: On Queen’s Square, yes. Which was interesting, again none of it lasted long because none of it really stimulated me. I was always looking, I think I was looking for something that I was interested in and I decided to start looking for another part time job to go alongside the driving instructing which I did enjoy, I loved teaching. And I saw an advertisement for a research nurse working with Dr Michael Hill at – Public Health Laboratory Service, Colindale

TT: Ok well I've got somebody else in my notes, before that. You did something else first. Research assistant to Eve Bendall?

KN: Eve Bendall, yes. Gosh I missed it out, good job you're here! Now wait a minute, so from the Italian hospital I must have seen the advertisement from Eve Bendall. Now Eve Bendall was a wonderful woman, she was a nurse and she was doing a PhD, and she was interested in finding out whether, and she had obviously an idea, she wanted to prove her hypothesis, that nurses who are good at exams are not necessarily the nurses who do the good work on the wards. So she employed three of us part time, so that must have been going alongside the driving instruction at that time, she employed three of us, she chose the hospitals by sticking a pin in the map, and I can’t remember whether it was every week, or whether we did it for more than a week, but we would go I think it was three days a week to a hospital and we would be given a ward and certain nurses to watch, the nurses obviously being recruited prior to us arriving and had agreed to take part in the research, and we had clipboards and we had to watch for certain actions, which she would then of course have on her little written questionnaire. And the questions, the activities had to be things that were done by both 1st year and 3rd year students, so they were simple things such as ‘does she look at and shake down the thermometer before she puts it into the patient’s mouth?’ I mean these were, these things they don’t have to do now, they have disposable ones now. ‘Does she offer the patient a bowl of water after the bedpan’, that kind of pretty basic things. In those days nurses delivered the food to the beds. Again I think that’s done by someone else now, but do they just put the food on the bed table or do they make sure it’s pushed up to the patient and make sure the patient can reach. All of those fairly simple tasks, and all, of course the three of us would always travel in and travel back together in the evening, and we would all agree that we would spend hours watching the nurse and as soon as we turned our eyes away the thermometer would be in the mouth and we would’ve missed whether or not they looked. And she then gave the nurses the written test and a psychological profile, and at the end of the day she proved that actually the good nurses are not so good at writing down what they do. It’s a practical profession really, but I have to say now that I work with nurses that are very well qualified and very specialised. I’m impressed at their knowledge and their professionalism, I think nursing has changed enormously since I was there.

TT: So did you get a flavour, or an interest, in research from that experience? Or were you still a bit undecided?

KN: Well it was a short term job, because obviously she just had to collect the information and then she wrote it up, got a PhD and became Registrar of the General Nursing Council, so when that was coming to an end I had to look for a job to fill its place.

TT: And all of this time you were still carrying on the driving instruction.
KN: Still carrying on the driving instruction. Because I needed to earn a full time salary, wage, whatever you call it. So after Eve Bendall that must have been then, was that then Michael Hill?

TT: No, it says I.P. Todd on your CV, 1974-1979.

KN: Do you know I must have got that the wrong way round.

TT: So you went to see Michael Hill first?

KN: Yes I must have started with Michael Hill first because it was the fact that I was working at St Mark's that Mr Todd met me and knew me, and asked me if I would like to do the stoma-care study, so I did.

TT: It was published, one of your first papers, that was 1983 that it was published, the stoma-care, so that would make sense, it was Michael Hill first.

KN: Yes, I must have seen the advertisement for, that’s very odd that I got it the wrong way round. I don’t have a record of all the dates, I don’t have old payslips and things to look back and see who was paying me at the time. So I remember going for the interview with Michael Hill, and first of all I rang up St Mark’s to make sure that I could, because I knew the job would involve me being in the clinics, so I rang up to find out when the clinics were, and they were quite specific that they were certain mornings or certain afternoons, there were no clinics that would go on all day, so I knew that I could fit the driving instruction around that, so when Ian Todd asked me to do the stoma-care study that was the point when I did give up the driving instruction altogether.

TT: So what were you doing there?

KN: He was a biochemist and bacteriologist, he was interested in what goes on inside the gut, gut flora, and one of the things he discovered was that patients with polyposis don’t degrade their bile. My job was collecting stool samples in clinic because in those days, and again it’s different now, every patient who came to clinic had a sigmoidoscopy, with a stainless steel rigid sigmoidoscope. So once the doctor had finished examining the rectum I would be standing waiting with my little pot that had a spoon on the lid, and I would manage to catch a little bit of poo, and then the samples would be labelled and put into a freezer, and I would also have to collect the information about the patient, the basic information and what was wrong with them, and over time I was continuing to update the information, so he was looking at patients with colitis, patients who had had cancer previously, patients with polyposis, and I think that’s probably all. And of course if a patient with colitis developed cancer, which some of the long term colitics did, that was of great interest because he could then match it up to his laboratory findings. So it was quite a basic job but that was where I found that I really enjoyed collecting the data. He allowed me to develop my own record system and labelling system, all the specimens had a ‘K’ number he said ‘why don’t we have a “K” number to distinguish yours from other people?’ Of course I had my car because I was still teaching people to drive, so I would drive to Porton Down, first of all they were based in Colindale for a few years, and then the laboratory moved to Porton Down, and so every Friday afternoon I would drive to Porton Down with my specimens and talk to the guys in the lab, deliver my stuff, and he would take me for a meal in a local pub, and then I would drive home. We got on very well, he got on well with everybody, he was really amiable.

TT: This is Michael Hill we’re talking about? So was he also at St Mark’s?

KN: No, he was first of all based at Colindale, at a laboratory called the Bacterial Metabolism Research Laboratory (BMRL), and it was based in Colindale. And for some reason they had to move out, I don’t know but they had to move. He was offered laboratory facilities at Porton Down, and a lot of the staff went with him because it’s a lovely part of the country, and his wife moved with him, and I know he kept sheep, and when he moved he was sort of a country boy really. He collaborated with St Mark’s
TT: So it became a part of the microbiological research facility?

KN: Well the other part of Porton Down was guarded by men on the gate and you weren’t allowed to go into that part of it, so there was always a very clear distinction between what we called BMRL or CAMAR (Centre for Applied Microbiological Research), that’s right, he became part of that, but the secret part of Porton Down (the chemical defence part) was through a gate further on, but they got used to seeing my car coming, they knew me and I’d give them a wave, a wave to the sheep as I was coming through the fields. So I enjoyed that, it was a good time of my life, long before I met my husband, so it was, yes.

TT: Can you pick out what it was you enjoyed about it, because it seems very different from when you were doing your private nursing?

KN: Not nursing, really, but there was some patient involvement yes, because I had to meet the patients in the clinic, I had to wait around a lot for my patients to have their notes get to the top of the pile, as it were, and I would talk to the patients who were waiting to be seen, and just apologise for the wait, and of course a lot of St Mark’s patients are regulars, the patients with colitis, with polyposis, you see the same people coming back over and over again. Crohn’s disease patients come back regularly. So over the years I got to know a lot of them. But in particular I got to know Dr Bussey who ran the Polyposis Registry, who was a great teacher and loved explaining his work. In those days he wasn’t really involved in the clinics in the way that we as the Registry team became involved in the clinics later, but I wasn’t working with him, I was only at St Marks’ doing a different job, I was only collecting samples from different polyposis patients, so I would talk to them. He had explained to me the importance of screening for the children, and I would be talking to them and ask them about their children, and I would advise them to bring their children to clinic. So it was in the days before contracts, before you had to get a GP referral. And in many ways for the patients with polyposis it made life easier because I think it’s very difficult for parents to suggest to children who are, I mean at the time it was recommended they come to clinic from the age of about 14, to suggest to a 14 year old to come to clinic to have their bottom examined. The reason that the Registry staff at the time chose 14 was because they thought it was an age at which children would obey their parents, rather than at 16 where if they said no there would be no persuading them, and the idea of the medical staff was to be very welcoming to the children, and although they would have a sigmoidoscopy, if they agreed, it would be very limited, so it would prove to them that it didn’t hurt, it might be a bit embarrassing, but it was worth it if it was going to save your life. So I understood all that at the point before I worked in the Registry, and I would talk to the parents and say ‘well look, you know, next time you come, just suggest that they might like to come with you’, and by doing it in that very informal way, I think it was easier for the parents to persuade their children to come, no pressure, come if you want to, don’t if you don’t want to. Whereas when the child has to be taken to the GP to get a formal referral, it kind of makes it psychologically a bit more, makes it too important, I mean it is important but you want the child to feel that it’s normal, natural, rather than something to be frightened of, of course that all changed. But because of my involvement I would leave little notes on Dr Bussey’s desk, you know ‘saw Mr So and So in clinic today, he’s promised to bring his children next time’, that kind of thing. The Registry team got to know me, and the doctor who was in charge of the Registry at the time was Dr Basil Morson, he was head of research, the consultant pathologist, and he was, had apparently said to Dr Bussey that at some point Dr Bussey would go under a bus, because he was beginning to get older, and that he really ought to find somebody to work with him. He worked at the time with a lady called Dr Sheila Ritchie, who was amazing, and taught me a huge amount about what I eventually got to learn about polyposis, but she was a volunteer, she worked free of charge, she just had her petrol costs refunded to her, and I think in Dr Morson’s mind they needed somebody permanently salaried, to know where everything was. He used to say ‘I think it’s all in Dr Bussey’s head’, well of course it wasn’t, it was all documented meticulously, but that takes us back to what we said earlier that the bosses often don’t know what the workers are doing, they just know what comes, we can provide what they want when they want it, but they don’t know how you do that, and of course it wasn’t in his head, it was very meticulously recorded on a card system, no computers at that time. So I was offered that job.

TT: The job you were offered was to be, sort of the boss’s apprentice, so ideally you were going to take over?
KN: An assistant. Well not really, at that point they didn’t say to me that I would take over, and I think I’ve missed out the fact that when I was working with Ian Todd, I was also working with Michael Hill, and I gave up the driving instruction to work with Ian Todd. At the same time of course I was having discussions with Dr Bussey because he worked at St Mark’s. I was working with Ian Todd and that job involved designing a questionnaire, which I could take to people’s homes to interview them about what it was like living with a stoma. And we soon realised that none of us knew how to design a questionnaire properly, so Ian Todd got in touch with the department of social sciences at City University, and I was introduced to a lecturer there called Richard Barron and he agreed to help us to design the questionnaire. And it was huge because it covered not only questions about living with a stoma but how do you cope in your normal life. So we had to have a section for housewives, for people who were working, people who were sick and disabled, and for students, so I had, so it was quite a thick book, every time we made alterations I typed it all up on a little portable typewriter, and every time we made alterations I would have to retype however many pages came after the addition. And eventually when we did a pilot study, and when the questionnaire was approved finally, we had it professionally typed up by my sister onto special paper that you put through a Roneo machine which we had at St Mark’s. So I then did the Roneoing, and the aim was to interview 100 people with a colostomy, and 100 people with an ileostomy, so I had to do 200 questionnaires. I can’t remember how many pages were in the questionnaire but it was about half an inch thick, I suppose the paper was quite thick because it wasn’t very good quality paper, or maybe better quality than you get nowadays because now paper is very thin. Then there was the question of getting them bound in some way, and I had a friend who worked in a university, and he got his department to agree to punch the holes and put the, I don’t know what you call it, the plastic binder on it. Of course there were boxes of these things because they were so big, so I was getting help from all over the place, then I went out and interviewed people at home. That was a really, really fascinating job.

TT: So when was this?

KN: That was the Ian Todd period.

TT: Ok so this is early 1980s, something like that.

KN: I started in the Polyposis Registry, I started in St Mark’s in 1974.

TT: So late sort of, early 1980s, that’s fine. Can I just ask, how was this work being funded?

KN: Funded, yes, Cancer Research Campaign who paid my salary was funding well Mike Hill, I don’t know if everybody was paid by them but I was certainly paid by them. The Ian Todd work was funded by voluntary contributions from stoma care companies, appliance companies.

TT: To St Mark’s or to Dr Todd?

KN: I was paid through St Bart’s hospital. The St Mark’s surgeons knew all the stoma-care product company owners, there was Salts and Hollister, and a company that had a green logo, not Clinimed. I did some lecturing with Clinimed at some point, I’m not sure if they were involved in funding that research. And also Surgicare – we were funded through all of them, they all contributed. We had dinner at Ian Todd’s house one evening so I could meet them all. So they could meet me, more importantly

TT: And this big questionnaire, this big stoma research, who funded that?

KN: That was through all of them, funding me to do it. I think the paper, I mean things came out of the NHS in those days which wouldn’t come out of the NHS now. I guess the paper and the Roneo was just run by St Mark’s. All of this hospital work is completely different now. In some ways it made it easier but in some ways it hid the real cost of research. I don’t know which is better. I don’t know how much money was actually wasted by doing that, and the NHS should fund some research because you can’t care for people
properly if you don’t have the evidence for what you’re doing. But things change.

TT: So then you become what I call Dr Bussey’s apprentice.

KN: Yes, well the reason I realised I’d missed out the stoma care, was because at that point I got introduced to Richard Barron who was involved in a new masters/ diploma course at City University called Survey Research Methods. And he advised me to do the course as a diploma student, but I came top of the first exam which was Questionnaire Design, which I knew very well how to do! Although it was on lighting or something so I had to do the research to design my questionnaire, so a request went forward for me to transfer to the master’s course, which was approved, and so that’s how I got onto the degree course.

TT: And you got that in 1985?

KN: I got that in 1985 after I’d started working with the Registry, so when I started working in the Registry they agreed to give me one day a week to go to college.

TT: So when you started working with Dr Bussey, what exactly were you doing? Some of this you already knew from your other work, so you already knew Dr Bussey?

KN: I knew Dr Bussey, I knew Sheila Ritchie, when I started working with them we had an office that was rather like two railway train carriages, one after another, so you had to walk through our office to get to his office. So he was beyond us, I had a desk, face to face with Dr Ritchie and she kept saying to me ‘I don’t know why you’re here, Kay’. So it wasn’t a very happy start, but she really, she taught me the systems. Dr Bussey was already fairly elderly. He taught me a lot about polyposis; I would spend the working day with Dr Ritchie and the mealtimes we would have the three of us together, and Dr Bussey would talk about polyposis and polyposis patients, and stories about patients. And sometimes we would feel ‘gosh can’t we talk about something else’ but when Dr Bussey was no longer there I realised how valuable it was because it is the personal stories that imprint the knowledge on your brain. If somebody just lectures you on facts it’s hard to retain them, but having the personal stories about the patients, we would see the patients in clinics and he would tell us the whole family history. And of course it became imprinted. So I was really helping Dr Ritchie with the paperwork because it was all paper.

TT: So these were all the record cards?

KN: So he kept the cards, Dr Ritchie kept the family files and, now, I think actually things were slightly changed by the time I started with them because there had been a trial called the ascorbic acid trial, when I was collecting samples for Mike Hill, so I got involved in the ascorbic acid trial itself but I had to go to the sessions where the research was taking place. There was an American doctor, professor, called Jerry DeCosse, who developed a theory that vitamin C would reduce the size of the polyps or make the polyps go away, the adenomas, all of this research was in adenomatous polyposis, not the other syndromes. So he was convincing enough that they agreed to do a trial. St Mark’s always was able to produce bigger numbers of patients for trials than any of the American centres because of the NHS. Patients would come to St Mark’s and they could continue to come to St Mark’s because they got very special care and it was free. Whereas in America patients would tend to go to the cheapest doctor and therefore they didn’t have the same call on patients that we had. So it was agreed that Professor DeCosse would come every three months to St Mark’s, to examine a group of patients. So the patients were enrolled by Dr Bussey and Dr Ritchie and the idea was that they would all come during one week because the consultant’s clinics were Monday morning, Monday afternoon, Wednesday morning, Thursday morning and Friday afternoon. So they would come on the same day that they would always come for their consultant, but they would come to a different location in the hospital for their examination. And Sheila Ritchie, a very clever lady, she realised that this was a really good system, having all the polyposis patients that were coming come during one week, because they met each other, and they chatted, and it became sort of a self-help group for them. And they would bring their children, people that were nervous about bringing the children would meet the other children who didn’t mind coming. So it kind of gave her the idea that she should put into place what became known
as polyposis weeks. So when the trial finished, and by the time I joined the Registry the trial had finished, 
but she had put into place what were called polyposis weeks, she and I would go into clinics during the 
polyposis weeks and we would then retrieve the information out of the patient notes as to how many polyps 
were seen and whether the patients had had any other illnesses, and what about other family members, 
whether there were any new babies, and what children were coming of age and needed to come into clinic 
next time. So that was our job and then we would come back to the Registry, and would write it all up by 
hand into the family files. So the record of each patient was stored in their own family file.

TT: And were you constructing pedigrees at the same time?

KN: Dr Bussey constructed the pedigrees by hand, yes.

TT: Based on all the data that you were accumulating?

KN: We would take the family history and draw it out as a rough diagram, and he would then draw the cards, 
tiny little writing, yes.

TT: So this was your introduction to the project.

KN: This was how I learned my job.

TT: Dr Ritchie was still there. How long did Dr Ritchie stay?

KN: Dr Ritchie stayed until 1991 I think, because, so I joined the Registry in 1984, and in 1985 St Mark’s 
celebrated its sesquicentennial, so doctors from all over the world came to a big meeting at the Barbican 
centre. And Ian Todd, who was the senior surgeon at that point, he might even have been Sir Ian by that 
stage, I don’t know when that happened, he had a patient, a young girl, very pretty girl, a nurse with a very 
big desmoid tumour. Desmoid tumours are myo-fibroblasts, it’s like fibrous tissue that grows, particularly 
in polyposis patients, in the abdomen. Maybe in the abdominal wall but very often they’re intra-abdominal, 
rooted in the mesentery, so they’re very, very difficult to remove without removing the small bowel, or some 
of the small bowel. And at that time doctors or surgeons were warned that if you did cut into them or biopsy 
them it tended to stimulate the growth, and these tumours would, the patients would look pregnant. The 
girls, and some men but it was more girls, it seemed at that time, they looked as if they were about to have 
the baby, they looked nine months pregnant by the time the tumour grew to that size. The tumours were 
very painful, because they were pressing on the gut, but within the tumour itself it seems they would describe 
it like a burning pain. And Ian Todd was absolutely distraught that he couldn’t help this girl. And these 
tumours were very rare, I mean polyposis is rare, or adenomatous polyposis, FAP (familial adenomatous 
polyposis), as it hadn’t yet been named. It was about to be named, we called it adenomatous polyposis coli 
in those days. I’ve lost my train of thought.

TT: You were talking about 1985 and Ian Todd.

KN: Well FAP is rare, the number of people getting a desmoid tumour is about 10% of those people, and only 
about 10% of those are the big ones, so very rare. So Ian Todd decided that he would hold a polyposis 
meeting just after the 1985, 150th St Mark’s meeting, because all the people around the world who had 
knowledge and specialised in polyposis would be at the Barbican meeting, and with Sir Walter Bodmer from 
what became CRUK (Cancer Research UK), I think it was still ICRF (Imperial Cancer Research Fund) at 
that point, they arranged to have a meeting at Leeds castle, in Kent, and it was quite limited because there’s 
only space for about 30 people to stay overnight at Leeds castle. And so I was not invited because I was 
very much the baby, I’d only been there a year, and Sheila Ritchie said to Ian Todd ‘if you expect Kay to 
understand, really become involved in polyposis, she has to come to this important meeting’. And I have to 
say I’ve worked with some amazing people, because it was through their foresight that things eventually 
happened the way they happened, because by being at that meeting I met all the important people and I 
 began to understand through the feedback from Sheila Ritchie and by seeing what happened at that meeting
I understood how knowledgeable the St Mark’s team were compared to some of the people around the world who were so-called experts, and really didn’t understand a lot about what the diseases were. Basil Morson (St Mark’s Consultant Pathologist) was at the meeting and there was a slide put up by a leading professor and he said ‘this is an adenoma’, and Basil Morson banged on the table and said ‘Mr Chairman that is not an adenoma’ and he said ‘oh I’m so sorry my pathologist must have got muddled up’, and put up his next slide, ‘This is an adenoma’, ‘Mr Chairman that is not an adenoma’ I mean, to somebody like me who’s learning it was an eye-opener that you have to be very careful about who you believe. There was another gentlemen there that I spoke to, I’d only worked in the Registry for a year, but I knew what juvenile polyposis was, and it was very clear, talking to another senior guy from another American university that he thought that juvenile polyposis was adenomatous polyposis in children, the histology of a juvenile polyp is completely different from an adenoma. So it was invaluable for me to see those things because it made me very careful about what I believed, what I read, after that. So at that meeting APC became renamed, familial adenomatous polyposis because it’s not only the colon that’s affected. Dr Bussey was there of course, all the important people were there. And from that meeting, it was suggested that, well first of all nobody else knew how to treat desmoid tumours, that this was an unknown, and so it was decided that we should do a piece of research, Sheila Ritchie and I would do a piece of research whereby we sent questionnaires to any hospital where we knew there was a registry, or suspected there was a registry, to collect information about how many patients did they have, and how many patients did they have in the different groups, like with desmoid tumours, upper GI (gastrointestinal) disease, and other cancers. So when we got back we designed a series of questionnaires and we sent them out to the different hospitals ready for the next meeting. And Professor DeCosse, that was 1985, Professor DeCosse from New York, or was it Washington because he held the meeting in Washington, he had a very, very rich patient who agreed to fund all of us and our husbands and wives to come to Washington in 1987 for a follow-up meeting for Sheila Ritchie and I to present what we had learned from our questionnaires, and again it was a limited group of people who were invited. The idea was to just have the experts invited, it wasn’t meant to be a meeting to teach people, which is what it evolved into ultimately. And from there we decided to have the next meeting back in England in 1989 which was, so that was 1985, 1987, 1989, and that 1989 meeting was Sheila Ritchie’s last meeting, and after that she retired.

TT: And did this group have a name?

KN: So it became known as the Leeds Castle polyposis group - LCPG.

TT: And does it continue to the present day?

KN: Yes, in a way. Another group formed to, because we in the LCPG at the beginning it was mainly surgeons because it was mainly a surgical disease, but of course by the early 1990s the gene that caused FAP had been discovered so a lot more geneticists began to be interested, and we were very seriously accused of being, what’s the word, when you keep other people out? Exclusive, and we didn’t want to be exclusive just wanted to find out the truth about things but we realised that we had to open it up, open the meeting up, so after 1989 the meetings became open to anybody to come. And we encouraged people who had started new registers to come. But we were only looking at that time at FAP. In the meantime Lynch syndrome, or what it was called, hereditary non-polyposis colorectal cancer (HNPCC) had evolved, come onto the map, and another group including Henry Lynch himself started up a group called the international collaborative group for, so they were holding their meetings every year and the LCPG were holding their meetings every two years. And of course we in the Polyposis Registry didn’t go to the Lynch HNPCC meetings because at St Mark’s we have two separate departments because we have too many of these patients, and they are managed in a completely different way, so we have a family cancer clinic, and the people from the family cancer clinic would go to the HNPCC meetings and we would go to the LCPG meetings. I was the honorary secretary more or less from the beginning, and in 1989 Sheila Ritchie had retired anyway, so I didn’t really, I hadn’t understood of course that all the polyposis people were going to the HNPCC meeting, but they all understood it and said ‘this is pointless, we’re all going to three meetings where we should just be going to one a year or one every two years, so we should join’. So it started gradually but by 2005, when Professor John Burn held the joint meeting, it was about the second or third joint meeting in Newcastle, we formally
evolved as InSiGHT, he decided it should be known as InSiGHT as it made a nice name. The International Society for Gastrointestinal Hereditary Tumours. It’s a bit of a mouthful but he chose the name, or he suggested the name and we all agreed that it was a good idea, which it is because it’s a good name for a group. So we became formal in 2005 and in 2010 we actually became a formally registered company, incorporated, and a registered charity. So that’s where we’re at now, and it, I think as a society it does need to, it needs to become more active, we do very little apart from our biennial meetings, every two years, but we’re in the process of designing a new website, and the idea ultimately would be to be able to expand the knowledge of the group to the whole world, because going to an international meeting is hugely expensive, and a lot of people involved in something which is quite a rare condition, they can’t afford to go, so to open up the expertise to everyone around the world through the website, I think, will be the future.

TT: Do patients get involved?

KN: Not at the moment, there’s a suggestion to have a patients’ session at the next meeting in Florence next year, in 2017, but how far they’ve got with that I don’t know. I think one of the main problems with that would be language. You know if the meeting’s held in Florence, presumably the majority of people attending would be the Italians, because they’re close by, or the neighbouring countries, but I don’t know, a lot of people do speak English, the meeting’s held in English, but we try, things evolve, things change but up until now we’ve tried to ensure that the meeting move around, so they will be in Europe, in America or the Americas, Australasia, and they sort of rotate round, so everyone gets a chance for it to be near to home.

TT: And what is your involvement?

KN: I’m the honorary secretary, so I do the minutes and the agenda, I draw up a draft agenda, send it to the chairman and the secretary for their comments, I do the minutes, get them approved by the secretary and chairman and send them to the council. There’s a council which is elected by the members, I keep the membership database, send out the invoices, receive the money, manage the bank account, that sort of things. Again it’s the sort of thing I enjoy doing, the organisational side, it’s good.

TT: Can we go back a little, Kay, to when you are charged at the Leeds Castle meeting with doing the questionnaire, and doing more research. And you and Dr Ritchie write to other registries. How many other registries were there and how did you find the m?

KN: People like Dr Morson and Sir Ian, they would go to meetings all over the world, they would be invited to speak on their special subjects. So they would know people, people would frequently correspond with the pathologists from around the world, asking for advice, you know, ‘do you think this is a case of Peutz-Jegher’s disease, syndrome, or not?’ We always had a good exchange programme, so there would always be somebody from a hospital somewhere around the world working in the path lab, to learn how St Mark’s did the pathology. Visiting doctors, there would always be an exchange at registrar level, they would come to learn endoscopy with Christopher Williams who was a world leader in endoscopy. In the gastrointestinal, the lower gut, the colorectal world, people knew each other, and people were always writing to Dr Bussey for advice. Obviously we only involved the people we knew, and hopefully with the website, and the internet, more and more people will become involved. It does surprise me now when I see a paper written about a polyposis syndrome, and I see that they’re not members of InSiGHT, why would they not want to be? Maybe they don’t know about it.

TT: I’m just thinking back to you in 1987, it was a very different world then?

KN: It was a very different world but you know the people who were really interested would have been in touch, we were always getting people come to talk to Dr Bussey, and even after Dr Bussey died in 1993 I think it was, people would come and talk to me and Sheila Ritchie, she had retired by then, me and the person I was working with, Judith Landgrebe, and they would say to us ‘we’ve learned more today than we’ve ever heard’. By 1993 I’d been working there for nearly 10 years, and I’d learned not only from Dr Bussey and Dr Ritchie but from all the surgeons because we regularly attended the clinics, and from the patients because you learn
a lot from your patients.

**TT:** When did Dr Bussey retire?

**KN:** Dr Bussey died in 1993, he actually became ill, he came to work one day, he walked through our office, he would always tell us what was in the Daily Telegraph as he walked through the office, and he went into his office, and by this time I was sitting opposite Judith and I said ‘he looks not well’, and so I went in to see him and I said ‘Dr Bussey I don’t think you look very well’, and he said, he always speaks very slowly, ‘well Kay, I don’t feel very well but I thought I’d wait and see if anyone noticed’ So lovely. So I went over, it must have been a Monday, to James Thomson’s clinic and I went over and said to him ‘I think Dr Bussey is not well’, and he went over to see and James Thomson arranged for him to see someone, and he gradually went downhill. He was a wonderful man, I remember walking over the garden with him one day through the garden at St Mark’s, our office looked out onto the garden, and I put my arm around his shoulders and I said ‘oh, Dr Bussey’, and his skin was very, very dry and flaky, I said ‘Dr Bussey you're flaking away’ and he said ‘yes Kay, and one day I'll be just dust’ - he always had that wonderful humour.

**TT:** Did he teach groups of students?

**KN:** He taught the post-grads, we run regular post-graduate courses at St Mark’s, and as a young man he was in charge of the museum, of all the specimens, because he was an expert colorectal pathologist. He actually did the pathology of all the polyposis specimens, and when he worked with Dr Dukes before Basil Morson’s time, Dr Dukes retired in the 1950s, Dr Bussey had worked at St Mark’s since the 1920s, and he worked with Dr Dukes on his ‘Dukes’ classification of cancer’ papers, and Dr Bussey could draw you the most wonderful diagrams, and he did draw all the diagrams for the cancers and any of the polyposis patients who got cancer, he would draw the lymphatic spread as well as he would take photos, he was the hospital photographer. He had a very interesting life.

**TT:** The reason I asked was that I was interested whether his expertise was throughout the hospital, or whether it was just a small group. Whether he had a wider impact?

**KN:** He would lecture abroad if he was invited, he did become at the time one of only three honorary members of the American Society of Colorectal Surgeons. He’s not a surgeon of course but they had such respect for him, so every now and then if there was a meeting where they wanted someone to talk about polyposis it would either be one of the surgeons or Basil Morson or it might be Dr Bussey who was invited. People who came to St Mark’s and met him absolutely loved him, there was Professor Tetsu Muto in Japan who would always come and talk to Dr Bussey if he was in London, and come to St Mark’s. He taught people from all over, yes, all the pathologists that came to learn from Dr Morson would get a teaching session with Dr Bussey, and any registrar or clinical research fellow who wanted to do some research with cancer or polyposis, because in the early days he was more involved with cancer as well as polyposis, but in his later life he settled on polyposis.

**TT:** It sounds as if you had joined quite an exciting hub, there were lots of different things going on, lots of possibilities.

**KN:** Well when I first started at St Mark’s with Michael Hill I remember talking to him one day and I said ‘well I’ll probably stay for a couple of years’ I said ‘I normally stay in a job for about two years’ thinking to myself ‘well by then I’ll be bored’ and of course I didn’t get bored. I think it was the first hospital that I’d worked in where I met doctors who seemed, I mean I’m sure the others did as well, I just didn’t see it, but they had a genuine interest in finding out why people were ill, and why people weren’t getting better, and you know they wanted to get to the nub of it, and I had huge respect for them, and I enjoyed working with them, I enjoy doing a job that’s worth doing, and I don’t like wasting time, and at St Mark’s I felt that I could contribute to things that were worthwhile.

**TT:** So after Dr Bussey died you then became the registrar, the manager?
KN: Yes, it was always very loose, when I first joined the Registry nobody had any titles, and Dr Morson was the head of research, and the Registry existed, you know he would wander in and say ‘I’ve had a letter from here or there and this is interesting’ and we just kind of worked together. Obviously I was the baby, and Dr Ritchie by this time was doing most of the sort of, the hard work, and then I was assisting her, and Dr Bussey was keeping his records from the information we gave him. And then Dr Morson realised that he was going to retire, and he wasn’t sure about the future, he said ‘I’ve got to protect the Registry, so I need to make it formal’ it had always been part of the wider research department. So he said ‘you need to become a formal hospital department and you need to have a director’, and it was agreed that Mr James Thomson would be our director, I think it was 1985 that this all happened. I remember writing a little poem at the time about it, because we had a meeting to discuss it with James Thomson who’s a very precise, formal sort of person, and he said ‘we must have headed paper, and we must have our names on it’, and so it was agreed and I think we designed it with the St Mark’s lion and the Polyposis Registry, and our names went at the bottom, and we decided we would have a red lion although I don’t think that lasted very long because of course we didn’t have printers with red ink in those days, and maybe we did get it printed for a while, I don’t really remember but we had our names on the bottom with our degrees and Sheila Ritchie said to me ‘well Kay, now that we’ve got headed paper with our names on it we can sign our own letters’, because up until that time we’d been told that the patients were not our patients, they belonged to the consultants, and we were just research workers so we weren’t allowed, if we were writing to a GP to say ‘we recommend, you know, we haven’t seen this patient for a while’ or ‘we recommend that this child gets screened’, we had to get a doctor to sign it, but from that moment on we signed our own letters. So that’s when it became formal, and so we had to have titles, and Dr Ritchie said ‘well we register births, marriages and deaths, so I’ll be the Registrar and Kay can be the Assistant Registrar’ which was a terrible title because people immediately thought that I was a doctor, and that I was a surgical registrar in some way. Sometimes it had its advantages because it gave me a bit more clout, but I never misled anyone deliberately, and then, so I don’t know what Dr Bussey’s title was, I can’t remember, he was probably research fellow or something. But that remained my title right up until when, I think right up until when my funding moved to Imperial College, I don’t think I even had a contract in those days, when I actually got a contract, maybe I did, oh yes I would have had a contract from CRUK, but I think it said research nurse actually.

TT: Could you just say a little bit now about your funding?

KN: Yes, it shifts enormously throughout the time. So once I became funded to work in the Registry which was 1984, formally, in the Registry, I was funded by I think it was the Imperial Cancer Research fund, which then became Cancer Research UK. And they continued to fund me right up until after we moved from City Rd St Mark’s to Northwick Park in 1995, and the whole of the CRUK St Mark’s laboratory staff all moved to Northwick Park, and then at some point, and I cannot remember the date, the CRUK decided they wouldn’t have research workers within hospitals, and the research staff moved to other centres, and I stayed in the Registry, and my funding was moved, or my contract was moved to Imperial College, but the funding, I believe, was still from CRUK, but I was employed by Imperial College. And then Imperial College decided that they didn’t have any value for the Registry, I must admit they didn’t use me, at one point there was a suggestion that we would have a tissue bank at St Mark’s, when the tissue banks went on to a very formal footing, and had to be properly licensed, there was talk about us having one at St Mark’s, and one of my jobs, I spoke with professor Jerry Thomas from Wales, Cardiff I think, and my understanding was that one of my jobs would become collecting cancer tissue, or tissue from cancer patients, cancer from polyposis patients and making sure that it was all banked properly. But the idea never came to fruition, and so Imperial College decided to make me redundant, and that’s a few years back, and so I took one month off, had a lovely month at home, and St Mark’s in the meantime, were negotiating with the NHS to fund me through the NHS, so I went back to work funded by the NHS.

TT: Doing the same job?

KN: Doing exactly the same job, yes. And then I had to have a St Mark’s, well Northwick Park hospital it is, contract, no it was then Northwest London Hospitals Trust, and it’s now London Northwest Hospitals
Trust, these things change and change and change. So I became a trust employee, and my title now is ‘manager of the department of inherited intestinal cancer syndromes’ which is DIICS for short.

TT: How has your job changed over the years? It’s now computerised?

KN: Enormously. When I first worked with Sheila Ritchie, we would go to clinic during the polyposis weeks and we would busily write down what the doctors had written in the notes onto our clip pads and we could come back to the office and write it all in the family files. When I started working with Judith we decided that was a waste of time, we would have the notes, we would collect the notes from the clinic, we would bring them to the office and write it directly from the notes into them. I mean it was still the same job, talking to the patients, getting the family histories. The most important part of the job really for me was taking the family histories, and teaching the patients about their conditions, encouraging them to attend, ringing people up when they didn’t attend. Really cancer prevention has always been the main aim of the Registry, and Dr Dukes when he started the Registry said ‘care of a polyposis patient means care of the whole family.’ The collecting of data for research was very important because I was funded to do the research, but you could only do the research if you had the patients, so the patient care was vital. When we moved to Northwick Park things did change. Although we took our old computer, the computer came in the late 1980s with Sheila Ritchie, and she helped to design what data should be collected. But the truth of the matter is, Dr Bussey could find the answer quicker using his cards than we could, because the computer kind of clicked over one patient at a time, very very slowly, and we used to have little competitions, who could find things out first. He always used to beat us. But when we moved to Northwick Park we set about finding a company to give us a new computer system because by this time our director was Robin Philips and he had a communication with the company who wanted to do research to test out a drug, and they agreed, or we said to them ‘we can only do it if we get a new computer system.’ They agreed as part of the payment for helping to do the trial that we would have a certain amount of money for a new computer system. And so we then appointed a man to design a database for us, we were very, very lucky to find Mike Clarke, who with very little information from us managed to understand what it was that we wanted, and continues to update it even now, because we’re always adding new fields and wanting new information. So the big change from those early days to now, is the fact that we now do far more clinical, we have far more clinical responsibility, from the days in the beginning where we weren’t even allowed to sign our own letters. Robin Philips said to me one day ‘I think we need a nurse practitioner’ and I thought ‘why does he want a nurse practitioner, what can a nurse practitioner do that I can’t do?’ and I sat and thought about it and I thought what we really need is a nurse endoscopist because we need someone in the endoscopy department who really gets to know what they’re looking for, and to have an interest in it. And we did manage to get NHS funding for a nurse endoscopist, and he actually, it was a he to begin with, it’s now a she, is an absolute expert in understanding the rectum of a patient with polyposis. That was the first, no, the first NHS funded nurse was a nurse that helped me with family histories, then the nurse practitioner, we’ve now got two nurse practitioners, the nurse endoscopist, a paediatric nurse practitioner specialising in polyposis, and a nurse specialist taking the family histories. And we’ve got two administrators helping me. The database has changed because it doesn’t just collect research, information, it keeps records of when people attended, when people are due to attend, we’re forever running off lists, chasing people up, tracing people. When a baby is born we can make a note to say ‘this baby is due to be examined in 12 years’ time’, we can put the year ‘12 years hence’ in, so each year we can pull up the people who are due that year, and we can pull up the people who are due to have their endoscopies this month, or next month, or the following month, so it’s changed in that way but we still keep the research data.

TT: Have you included, have you done retrospective digitisation for all your records?

KN: No. That’s something we did talk about at one point and we were going to do. I suppose it didn’t happen because we employed somebody who was going to help us at the same point that our own administrator became sick, so the person who was going to help with that kind of thing became our administrator, and somehow we never then employed anybody to do the digitisation. I think it is something that probably should be done, because the paper records are quite vulnerable. A lot of the information, it depends I think what the researcher would want to know. So much research now is laboratory based, and what the
researchers want is information about the patients from whom they've got blood or tissue, and so the old information I don't think is used nearly as much as it used to be. I think one of the big changes is that we've moved from retrospective, looking back, how many people got duodenal cancer, to saying 'can we have the tissue of the polyps', and ‘why were these polyps forming’, and ‘what will get rid of the polyps’, and ‘in getting rid of the polyps, is there any point’ because we have done chemo prevention trials, where the drugs do get rid of the polyps, but then patients develop the cancer without the polyps being there. So there's something that goes on that's much more, we need to learn much more about the way that the cells are working.

**TT:** There's whole genomic profiling, obviously.

**KN:** Exactly.

**TT:** Coming back to these questions that I want you to think about. In terms of achievements, I just wondered if you would reflect a little on that?

**KN:** Yes, well I think the achievement really is that the Polyposis Registry, started by Dr Bussey in 1924, and almost stopped by the surgeons in the 1950s, when they started to be able to take out the colon of patients with FAP, and they said ‘right well we’ve cured it’. You know, by 1958, the first colectomy with ileorectal anastomosis was 1948, and by 1958 Dr Dukes said ‘you know, it’s the perfect model of a disease that can be, people can be saved from getting cancer, because you diagnose it in the pre-cancerous stage, and you treat it’. And Dr Bussey carried on keeping the information on all the patients, so that when the ICRF/CRUK wanted to, wanted blood samples for genetic research, the families were still coming and we could get the bloods. And all of that formed a basis which I’ve continued to build on in my work, and I think just the fact that I stayed there so long meant that there is continuation, and people don’t stay (in the same job) so long any more. And it has been a continual worry to me, I’ve had so many people come to work with me that I would think ‘this is the person who is going to take over from me when I retire’ and I expected to retire when I was 65, and this year I’ll be 70. So I now have a team that I do believe is capable to run the Registry without me, but it does worry me. I’m trying to put into place lots of systems that I didn’t use to bother about because I would just check it all myself, I’m trying to put the systems into place, so that when I’m not there, if the systems are engrained in the routines of the staff, as long as they pass on those routines to new staff, the Registry should survive. Of course, now that it's an NHS registry it’s not a research department, although we still collect the information for research, and the consultants are still very keen to do research, and we do still do a lot of research. If the Registry went through a period of research not being done, at least the information would still be collected because it should still go into the database as an automatic process by the nurses, so when somebody else comes along who wants to do some research, the information should still be there, and hopefully the patients will keep coming, because they do get good care, I’m not saying that other hospitals don't, or aren't capable of caring for a patient with polyposis, but there aren’t many places where they’ve got all of these nurse specialists who give the extra time. They can actually ring up the telephone number, and if they don’t get an answer they’ll get a call back if they leave a message, and you know, we’re very, very good at following things up.

**TT:** What do you think the main contribution has been of the Polyposis Registry?

**KN:** Saving people from getting cancer, without a doubt. The average age of colorectal cancer in a person who carries a mutation in the APC gene, which causes FAP, is 39. And by just doing a colectomy with ileorectal anastomosis we extend their life by 30 years. Without the register, and the Registry, a lot of people wouldn’t get traced in the first place. We spend hours and hours and hours trying to get hold of people, and now that we have access to what's called the national database, which is a nationally held database of patients registered with GPs, what we’ve started to do now is to write to the GPs when we can’t actually get hold of the people themselves. Sheila Ritchie and I of course would try to get hold of people through other family members, and that carried on until fairly recently, that we would have to rely on family members, ask continually, ‘well can you try to get your brother’s address, tell him again that he needs to come’ you don’t really know that relatives are telling their relatives. Some people that I’ve met are frightened that because
they’ve got an inherited condition themselves, if they tell their brothers and sisters that they’re also at risk of the same condition that they’re responsible for it, and parents, the same, that they don’t want to tell their children that they might have inherited something from them. So if we, if parents are refusing to bring the children for screening, we can write to the GP and tell the GP and we can write to the GPs particularly when the child becomes an adult, and say ‘this person is at risk’, and then there has to come an end to our responsibility for chasing people, but it’s a lot easier now that we’ve got the access to the GPs.

TT: Have you seen a change in patients’ responses to you over your time, particularly with the polyposis register? The reason I’m asking is a lot of people, particularly people who are GPs for example, talk a lot about changes in patients’ expectations, and when they come into a clinical encounter, the information they have, their clinical expectations. I wonder if you’ve seen any shifts and changes?

KN: There have always been people who would do anything to help, because they know their children and their other relatives are at risk, so with regard to research projects they’re only too keen to take part because they know they’re going to help future generations. With regard to attending hospital, there have always been people who are poor attenders. There’s been a shift in the way the hospitals deal with patients: if a patient fails to attend an endoscopy appointment, they are not sent another one, they’re not sent a follow-up appointment. And for patients with a lifelong condition, and they’re at risk of malignancy, it’s not just that they might be frightened of what the examination shows so they back out at the last minute, but when it’s lifelong, there are going to be times when they forget, and I feel it’s a bit mean to only give them one chance. But of course the NHS is suffering, it’s hugely in debt, all the hospitals are in debt, and each endoscopy appointment, if it’s missed, the hospital loses the money. So going back to the days when I worked with Sheila Ritchie where we could say ‘just bring your child up if you want to’, we’re now at the stage where every single appointment is paid for and has to be funded by somebody, it’s a different system. It’s a good system in some ways, but it doesn’t accommodate ordinary people with all the difficulties that one has in life. We had a system in the department whereby we’d say ‘if they missed one appointment, we will send them another’ but now we’re not allowed to send them another endoscopy appointment, we have to send them a clinic appointment. If they miss that second appointment we send them a 3rd clinic appointment with a letter saying ‘if you miss this one we’re not sending any more, you need to get a new referral letter’. So we try our best but you can’t go on and on and on. But it happened just recently that I was saying ‘well, you know, he’s never missed, he’s missed three now and we can’t just keep sending him appointments’, and then discovered that he was in hospital very ill with something else. So people have good reasons to miss their appointments, and if you’re very ill you’re not thinking about the hospital appointment somewhere else that you ought to cancel.

TT: No, it won’t be on your mind.

KN: So that kind of thing has changed. The people themselves, yes I do think people have more expectations. When I first started working at City Rd, when I was collecting samples of faeces, patients, although they got very good care, the doctors really didn’t expect to have long discussions with them, and the patients didn’t expect to have long discussions. It was ‘ok, how are you, oh you’ve been poorly, so tell me about it, ok turn over, let’s do the sigmoidoscopy and we’ll see you again in three months’. And now patients want long discussions, about what’s wrong, what’s likely to happen, and then sometimes people expect to come back and have the same discussion all over again. And we’d say that is their right, and that’s why the Registry with the nursing staff can accommodate quite a lot of that. Doctors working on their own don’t have the time to accommodate long discussions about things. I know one of our clinics finished at half past eight one evening last week because it was just so busy. People are sick, people need to be seen, people want to be seen, and people want to talk about what’s wrong with them. And that is different.

TT: It would be lovely if you could put that on video what particularly you said about, where the nurses come in, the nurse practitioners. I think it would be a really nice contrast.

KN: I’m always saying to the nurses, ‘you mustn’t spend so long on the phone, that’s why you can’t get all your work done.’ It’s hard to get that balance, how do you get that balance?
TT: Is there anything else you want to tell me, Kay, for this part of the interview? We skimmed over quite a lot, and you've got some really nice stories about people, about your experiences. Is there anything else you'd like on this bit?

KN: I feel sort of a bit confused, because you’re right, that middle bit of my career where I did a lot of things all at once, and they chopped and changed. I feel a bit confused about what order it came in. I think we’ve sorted it out.

TT: I think we’ve sorted it out, I think you put it in the wrong order in your CV.

KN: I think I did put it in the wrong order, yes.

TT: From the way you talk about it, it has a logical flow. And just looking at some of the things you’ve written. I’d like to ask you perhaps about some of these publications. How did some of these come about? You included in those, do you get involved because you’re sort of the gatekeeper because of all your experience?

KN: I did want to say to you that in a lot of those scientific papers I’m named because I provided the material, I provided the patients, they would come to me to ask me for the clinical information to back things up, but actually the science I don’t really understand. It’s not my area of expertise.

TT: But a scientist might not understand the other side of the project?

KN: No, they don’t. I remember giving a lecture to the Kennedy-Galton’s clinical laboratory, to the people that do the genetic, the actual gene testing, the scientists in the laboratory. I gave them a lecture about what it was like to live with polyposis, the fact that they actually, at the age of 14/15 have to have major surgery to remove their large bowel. They were absolutely horrified, and yet they’re sending back these reports saying, you know, ‘positive’ without knowing what that means to the patient. Now that’s not their fault, but it kind of shocked me that they must be doing all sorts of tests for all sorts of disease, and they can’t be expected to understand the implications of all of them.

TT: Patrick MacLeod, on the interview I did with him, he’s a geneticist from Canada, he was talking about Rett Syndrome. He met a young PhD candidate in Montreal, who had never met a Rett patient or their families until he took her round his clinic. Two months later her lab walls were covered with pictures of Rett children, and she felt highly motivated. (See MacLeod – video clip and transcript.) As a scientist, I worked on multiple sclerosis, and the first thing I would do is meet people with multiple sclerosis. So can I ask you, have you ever got very close to some of these patients, some of these families, because you were talking about Dr Bussey who obviously knew them all. What about your personal interactions with the people?

KN: Well I haven’t worked in the clinic now for quite a long time, but in the early days I knew the families very, very well. I remember Dr Bussey saying to me ‘oh I knew him when he was in his pushchair’ and I thought ‘gosh, I'll never be like that’. But of course I came out of the hospital one day to go home, came out of the front door to go to the car park, and there was a lady standing there, wonderful lady with a wonderful accent. ‘Hello gal’ she’d say, ‘hello gal!’ And she’d got this teenager with her, and she said ‘oh now, this is Kay, you need to remember Kay because if you’re ever in trouble you just ring up and you ask for Kay’. Now I knew her very well because I’d met her on lots of occasions but I had no inkling that that was how she saw me. That for her I was a port of call, you know, someone to call if she was in trouble. And that for her to pass that information on to her boys, because they had inherited, well this particular one had inherited the disease from her, that it was important for her to make sure that they also knew that this was the person to go to if you need help, and if she wasn’t around.

TT: How did that make you feel?
KN: It felt great, it felt great. It just, there was somebody else who was, when I introduced a new member of staff to them and they said ‘in those early days when I used to have to come for my check ups and Kay would always be there’, because if I went into the cubicle when they were having their sigmoidoscopy in clinic, I would always stand at their head, so that they knew I wasn’t looking at their bottom, and I could talk to them, to reassure them. I didn’t even remember being in the cubicle with this particular person, and yet it had had a huge impact on her. It is nice, but then on the other side of it there are people that I knew very well who died young as a result of their disease, and that’s very upsetting. Some of the most upsetting work I did was the stoma-care research actually, when I was interviewing people at home, because the interviews would take a couple of hours, I was in their own home, they’d make me tea or coffee, they would often give me a tour of the house. They would say ‘nobody’s ever talked to us about it’, ‘nobody’s ever been interested’. And so they again, I think they felt in a way, the way they would feel if they were counselled, although I wasn’t there to counsel them, I was there to find out their feelings. They were incredibly grateful. But the people who had colostomies of course they’d all had cancer, and I remember driving along one day and just feeling guilty because I smiled at something, because it was just, it was so depressing, and I hadn’t thought about it being depressing actually. I was just doing my job, getting on with it, day by day, of course I wasn’t doing it with anybody, it was just me, and it’s only since looking back on it, I think how awful that is. Because it’s wrong that you should do a job that makes you that depressed that you actually feel guilty about being happy.

TT: But that’s probably just the nature of the job.

KN: Yes, but it must be like that for people that do similar jobs.

TT: We’ve interviewed people who have always done that kind of thing and, well some of them burn out.

KN: Yes, they burn out, I only did it for a couple of years.

TT: But you yourself, actually going and talking to people, was that a therapeutic intervention?

KN: Therapeutic for them, yes. But with the people with polyposis, there are some absolutely tragic stories because there are some people who die young, but then on the other hand, there are the families, there’s one particular family that comes to mind, where they inherited from one of the parents. There were four children, three of them that inherited the polyposis, the one that didn’t get polyposis died young from a heart condition. And so there’s always that question about prenatal testing, not that we would give any advice that you should or shouldn’t have it, we just tell people it’s available, if they want. If they’re interested in prenatal testing we always refer them to the geneticists, because we’ve never been trained to deal with that kind of counselling. We’re trained to talk about polyposis, the meaning of polyposis, the advantages and disadvantages. But prenatal testing, I do sometimes think to myself ‘well polyposis can be awful, but choosing a foetus that hasn’t got it doesn’t actually guarantee a healthy child.’

TT: No absolutely not.

KN: Life is very, very tough.

TT: I’ve had somebody sitting in that chair a couple of years ago, talking to me about starting off in obs and gynae, and the expectations of every child a perfect child. Which is a very modern concept compared with Victorian families of 15 children, two or three of which might make it to adulthood.

KN: And the thought that someone who’s not perfect is in some way not valuable. If we had destroyed the foetuses of all of those people who grew into some of the most amazing people in the world, it would be a very less rich place. Some of our famous musicians and scientists and artists and musicians, they do become ill in some way which perhaps could’ve been predicted when they were, before they were born, and then
TT: This is getting a very difficult interview! Such deep philosophy.

KN: We used to work with a psychologist called Patricia McHugh, and I can’t say she’s the only psychologist I’ve ever met but I certainly had the most admiration for her, because she had a terrific ability for giving you a balanced view of the problem you were presenting to her. I remember once saying to her that people who belong to a family in which there is an inherited condition, in my case it would be polyposis, one of the syndromes, for that family is normal. And she said that I was wrong, and I’d love to have that conversation with her again, but I don’t know where she is now. She left St Mark’s. Because I think sometimes the problems we have is that, like you say, people expect to be perfect, and none of us are perfect, we’ve all got bits of us that we wish were different, and for some of us those things don’t really impact on our life, but if you grow up believing that you shouldn’t have what you’ve got, and that it’s wrong and not normal, I would’ve thought you’d feel a lot worse than if you said ‘well this is normal for my family, this is what happens in my family, some people get polyposis, some people don’t’.

TT: We all think as children, what happens in our family is what everybody does. I think I agree with you.

KN: And those parents that bring their children up knowing that this is what happens in this family, like the lady I mentioned with her son on the front doorstep of St Mark’s. She used to bring the boys to clinic in their pushchairs with their little books. And very often the father of the children, her husband would come as well. They would come as a family, and mummy would get examined and then they’d all go off to do whatever they were going to do. And so by the time it was time for them to get examined it was a normal part of life for them. It’s not normal for some people to go to hospital twice a year, and it’s difficult if they’re at school, and that sort of thing. But if it’s talked about in the house as though it is a normal thing, the children, when it is their turn, they find it much easier. For the families where the parent keeps it a secret and suddenly one day ‘well we’ve got to go to hospital today for a check-up’ and then the check-up is somebody, of course nowadays it’s blood testing, we don’t have to do the sigmoidoscopy any more unless they’ve actually come back gene positive. So it’s a lot easier. But for some children even having a blood test is difficult.

TT: And then it’s the knowledge, what do you do with the knowledge?

KN: And suddenly the knowledge is, you know, it’s something that, how can they understand it when suddenly it’s a strange person in a strange place with strange smells, telling them ‘you might get this thing that mummy’s got’ and they haven’t got a clue what it is. It makes it, I think much more traumatic. Sheila Ritchie would say ‘parents know what’s best for their children’, she had five so she was quite a good mum I think.

TT: I was just thinking about stopping there, Kay. Thank you so much for your time.

[END OF TRANSCRIPT]