

AUDIO INTERVIEW TRANSCRIPT

MacLeod, Patrick: transcript of an audio interview (06-Jun-2015)

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Biography: Professor Patrick MacLeod (b. 1940) is a Clinical Professor of Medical Genetics in the Department of Medical Genetics University of British Columbia and an Adjunct Clinical Professor in the Centre for Biomedical Research, Department of Biology, University of Victoria, in Victoria, British Columbia. He trained in Medicine at the University of British Columbia before going on to train in Paediatrics and Medical Genetics at the Montreal Children's Hospital under the direction of the late F Clarke Fraser PhD MD OC. He is a Fellow of the Royal College of Physicians and Surgeons of Canada, and a Fellow of the Canadian College of Medical Genetics. He has initiated research in various paediatric neurological disorders, contributed to the mapping of the gene for what is now known as spinocerebellar ataxia type 3 (Machado Joseph Disease) and the natural history of Rett syndrome in a large cohort of Canadian families.

TT: Tilli Tansey

PM: Patrick MacLeod

PM: Well, I came to consciousness on a beach on a small island on the west coast of Vancouver during the end of the Second World War. My father was an anti-submarine pilot in the [Royal] Canadian Air Force, and Japan had been launching fire balloons from submarines hoping to start forest fires in British Columbia. So he was in the anti-submarine thing. And when they realised that there were 300 forest fires in British Columbia that nobody fights, the Japanese had plan B, then they moved progressively down into the States, and these bases moved onto Vancouver Island. I lived with my family there, at the north end, the middle, Victoria, then my family, my dad mustered up Vancouver. I grew up in Vancouver, went to school there. My mum and dad had three more children, my sister, my middle brother and my younger brother. I went through the traditional, you know, boy scouts, air cadets type of thing, and eventually went into the regular Air Force to fly for a couple of years as a jet navigator.

TT: Was there national service in Canada?

PM: No.

TT: So this was, you weren't conscripted, you volunteered?

PM: No, no, for reasons I don't understand, I skipped Grade 4.

TT: Which is how old?

PM: Let me see. How old am I in Grade 4? Eight or nine? I was a problem child in Grade 3, I know that the nuns had me sit outside the classroom. My mum being a teacher negotiated, next thing I know I go back to school in Grade 5. Skipped Grade 4, I have no idea what my problem was, but that didn't serve me well later on. But I got through it. And then I went to UBC [The University of British Columbia] and I just wasn't ready for it, I was too young, and decided to go aircrew for a couple of years, which served me well

* Interview conducted by Professor Tilli Tansey, for the History of Modern Biomedicine Research Group, 06 June 2015, in Glasgow. Transcribed by Mrs Debra Gee, and edited by Professor Tilli Tansey.

later on. Came back, wanted to go into Medical School - had always wanted to go to Medical School. Went into Medical School at UBC, graduated. As I said earlier, I started off down the road to do neurosurgery, basically because of a patient. I went off to do an internship in the States in New Hampshire, Dartmouth Medical School, because it was a two-year programme that had extensions to the Boston circle of training programme. So that made a lot of sense. Then I got this career path change from neurosurgeon to paediatric something or other. In the United States, in that period of time, the National Foundation for the March of Dimes was collecting dimes to cure polio. And once the Salk and Sabin story was played out, they were going to dismantle this. But somebody, and I don't know who it is, we should try and find that out, convinced them they should keep the momentum going, but raise money for birth defects. And to this day there are birth defects meetings under that rubric. Well, they also made available training scholarships and things like that, so when I got to Montreal I must have qualified for a birth defects fellowship in paediatrics. And again there was no formal curriculum for medical genetics, you just learned on the job and followed your interests, and again serendipity has come to town on many occasions that things have just fallen into my lap without any effort at all, and helped that.

TT: Can I just go back to when you were at school, because you just sort of gave me this throwaway line, you'd always wanted to do medicine. Do you know why?

PM: Oh, sure. Yeah, I can tell you. We lived in central Vancouver and the family doctor did house calls and night calls. I got a job at the local pharmacy being the delivery boy. And one of the deliveries was to deliver things to his office. I got to know he and his wife, who was his nurse. One thing led to another and he started taking me on house calls. Leo Friesen was his name, he had a very profound influence on me, and I looked at this, you know, because another event had happened, I'd forgotten, to sort of dial back a bit, and that was the nuns had me all lined up for the seminary. I still remember Grade 11 I had an interview, and in Canada the large missionary priesthood of the oblates, they do a lot of work in the North, so they, this chap interviewed me and I got this impression, 'Don't call us, we'll call you.' It just was terrible.

TT: But your family doctor, you must have been a...

PM: There was a pastoral component to it, you know?

TT: Yes, but you must have been a bright, inquisitive boy, because family doctors don't take every delivery boy on house calls, do they?

PM: Well, there was an ulterior motive from doing that. He wanted to get to know me so I could babysit for their kids. And I'm in their second family as a consequence. But Leo was quite a good thing. And eventually when I was serious about going to medical he said, 'I don't think you should go to Med School. Medicine is changing so much, it's going to be tough and you're not going to enjoy it.' Certainly I remember that. There was always this pastoral component, I guess, from the nuns and everything else. And medical genetics offered that kind of opportunity.

TT: Far more than, say, neurosurgery?

PM: Absolutely.

TT: Because you engage the patients in a much more direct way.

PM: You identify with, the wonderful benefits of being a medical geneticist in your line over the years, you meet every conceivable belief system or non-belief system on the planet, and you get to learn all kinds of things. And there's the art of medicine, the science of medicine, but there's also the pastoral aspects of being with people.

TT: Do you have any sense, because you're also an educator training future generations of doctors; is there any way you can teach that?

PM: By example, by Clinical Genetics. In our situation at UBC, Vancouver Island, all the paediatric rotations involve a rotation through medical genetics, and they have no idea what you do. Because when I was a boy in first year medicine we had 30 hours of lecture medicine, labs. Now we have a problem-based oriented curriculum, and you get a smattering here and a smattering there, and you really don't know that genetics is even a career until it's too late. And so we give them an opportunity to sit in in anything from, you know, a tough prenatal case or listening to some family struggling with the realities of Huntington's disease. The beautiful thing about being a medical geneticist is that the system gives you 90 minutes. Wonderful chunk, and you can get so much more done in that sense, you know? So it has that opportunity to get involved and I have stories that would go on for a month of people and families and stuff you know, but it's a benefit. So I try and encourage these young students to consider a career in medical genetics. The problem is with the training programme in Canada, they're trying to look to change this now, because you're basically forced in fourth year, early on, to make a career choice. And you haven't done any of these rotations yet, you know? And so one of the things I've really tried to do is get exposure to the pre-med curriculum, and so at the University of Victoria, we have a core programme in human genetics. It's a requirement for honours biology and now a requirement for honours biochemistry and microbiology. And so I do this dog and pony show where one of the basic scientists teaches the course, and have me come in and say, 'Well, why is this relevant?' And it's like a recruiting poster, because every time I do that someone will take me aside at the end and want a career in genetic counselling or in medical genetics, they've never heard about this before. And so time and time again it's a recruiting opportunity to get them involved. And then the medical students, they're so differentiated by the time they get into Medical School that they don't have time to think a lot about these things. So now there's a movement afoot to try and change that to a five-year programme where the fifth year you work and are paid in family practice.

TT: So this is at the end of the training before the internship?

PM: Yeah, before your internship. So that you get out and see some things. And I've had more people over the years that never heard of this career in genetics and are now one of my, two of my colleagues that I work with, are both from that, heard me talking and here they are side by side, colleagues. The other thing about this, and I don't know where this fits in, but for 10 years I was a founding member of the Department at this big academic centre in Vancouver, which is right smack dab in the middle of pretty expensive real estate. Then I moved to Kingston to do this linkage project, and they had two hospitals - but one is really primarily an administrative building and outpatient, the other is a full ocean-going hospital. And I began to look at the fact that every time you went up on the ward there was some mother who was caring for a baby with croup or something, and she herself was just a little marginal. You could interact with, you could just know that she just struggles a bit. And then over labour and delivery you'd always go up, there was some mum you would interact with, or the family members, and you knew these were struggling families. So I asked a question about this after I was there for a year and I was given this typical 'It's the north of Highway 7 syndrome.' In the old days the road went from Toronto to Ottawa along Highway 7, which is Canadian Shield, and there's about half an inch of topsoil and then there's the Canadian Shield. So these families north of [Highway] 7 eek out an existence that's sort of Appalachian sort of thing. So I said, 'Okay, well, there's something I want to...'. So I dug around and I came across a white paper in 1961 - this is now in the mid-1980s - where they did a national survey of children's needs and they used Frontenac county, where the Kingston General Hospital is, one of the bellwethers, and they collected all this information from this county. And the consanguinity rate was no different than anywhere else in the country. So I wondered, 'What's going on here?' So it finally dawned on me. At the British Columbia Children's Hospital, you don't see whoop and croup, because they're in the community hospital. Yeah, there are some in the very expensive part of Vancouver but not many. What you see are fourth level rare complicated cases of everything, you know? In Kingston you see them all. So you get a much better feel for the burden of genetic disease in a community, right? So when I came back, that's why I didn't want to go back to Vancouver because it was, 'I am the consultant, here's what the GP [General Practitioner] will do for you.'

TT: A different level?

PM: A totally different level. And so I adopted this community genetics approach. So we did house calls and we did outreach, we did all these things, you know, and you get a much better take on genetics in a community, and what it says than spending your life in a really academic centre where you're just seeing the rarest of the rare. Like this one chap, his whole life was around 14 patients.

TT: Was that easy to set up because that sounds like quite a big step, in the Vancouver situation to start doing house calls?

PM: Yes and no. Historically, let's dial back 20 years, when a corn cytogeneticist was recruited to the University in biology to teach genetics. His wife, also a corn cytogeneticist, didn't have a job, so she persuaded the pathologist in this hospital that he should have a chromosome lab. Now in those days historically there was a national survey of needs of Medical Schools, and decided we needed five more Medical Schools. Well, four of them were built, the fifth one in Victoria, was resisted by the people in the community. They didn't want any of this town and gown stuff - 'We have this nice community here, forget the Med School, we don't want University people telling us what to do.' So they resisted this. So there was this friction dynamic between Victoria and Vancouver Island, and the chromosome lab was started up there.

TT: The chromosome lab was on Vancouver Island?

PM: They set one, there was a big one in Vancouver but there was nothing on Vancouver Island so she set it up and I began to go over every three months. And eventually that just fell apart and I moved to Kingston and it lost its accreditation and nobody would go near it because there was no medical school. So coming home and taking that on like that, there was nobody there doing anything. The first thing I did was went up five hours north of the city to a community to establish an outreach and so we would commute, you know, three times a year up the island to see patients, and it just grew from there. So that was quite easy. But the problem was that the person who recruited me is a pathologist and the manager is looking at 29 units on the island, one of which is medical genetics and it doesn't fit, right? And so over the last 15 years we've been the low-hanging fruit for any cuts and things, okay? So that's been the downside. And we struggled to exist, we've had a couple of real serious attempts to shut us down and send everything to Vancouver.

TT: And is that a very local situation there or is that mirrored across Canada? Is this a sign of the times or is this a confluence or both?

PM: It's a bit of both. So for example in the province next door they followed the British Columbia example.

TT: Is this Alberta?

PM: Sorry, Alberta. They had I forget how many, 52 Health Hospital Boards in British Columbia, so that's a terribly large number of Vice Presidents and whatever. So they eventually amalgamated it down into six Health Authorities. And Alberta, taking that, they did the same thing. And they downsized and took down that hospital, and three years later they made a mistake, they were going to build the hospital up again. So it just stumble bums on after another, and these people come roaring in with great ideas.

TT: It happens all over, doesn't it?

PM: Exactly. That's why these newspaper headlines are the same, exactly the same problems, you know. Wait times, and bureaucracy, and red tape, and stuff.

TT: You mentioned the word "accreditation". Something that has come up in some of our Witness Seminars about the recognition of where medical genetics fits and particularly getting, in this country, recognition as a specialty in the Royal College of Physicians, for example. What's the situation in Canada?

PM: Well, we have a long history there, because the Royal College accredits these training programmes in paediatrics and neurosurgery and internal medicine. And we petitioned them for many years to allow us as medical geneticists to join the Royal College and bring our PhD colleagues with us. And that was anathema, we don't give PhDs. So we established our own college in 1975, the Canadian College of Medical Geneticists, which at that time was two-thirds basic science and one-third MDs.

TT: How interesting.

PM: And it led the way, it was the first in North America to do that. It accredited individual persons to the exams, and it accredited the training programmes.

TT: Can I ask you, because you say, 'we established it' - I mean who, how did you negotiate that and who did it, where did you get the funding?

PM: Well, I can tell you. I wasn't, I was junior to this but my department head, his mentor, who was my mentor, John Hamerton, who has been featured at this meeting in the cytogenetic story that Peter Harper's doing, they were key players in that, in petitioning, I'm not sure how they went through the process to get a thing called a "College". But I was on the Credentials Committee for 10 years and there were the cytogeneticists, the medical geneticists, and then there was the biochemical geneticists, and then there was the molecular geneticists. And so now we have these robust training programmes, and so if you're a young person interested in human genetics you can do your PhD and a two year post-doc in one of these training programmes in molecular or cyto, or both now, molecular cytogenetics. Less and less for clinical geneticists, because although the people who established the College were primarily PhD counsellors, there is the whole issue of funding. So if you're a physician they can bill the programme, your Department can bill for physician service, you can't bill for PhD services. So Dorothy Thompson, whose *Thompson & Thompson [Genetics in Medicine]* textbook was universally used across Canada, was a PhD who began genetic counselling at Sick Kids in Toronto. Irene Uchida was the same: a cytogeneticist in Hamilton. But, eventually, it became lab sciences for PhDs. And then clinical geneticists for the rest. And it's a pretty rigorous process to sit your exams and, you know it's not an easy thing, you really have to be top of the game. So much so that you get reciprocity with the American Board of Medical Genetics, because that's the standard, you know, against which we compare them.

TT: So you get Board-certified?

PM: Yeah. And then some of my colleagues in programmes who were involved with the Royal College petitioned them and eventually in 1992 the Royal College gave in and recognised medical genetics had long ago outgrown its traditional home in paediatrics and yes, it's a freestanding specialty. So I've written every exam that was offered along the way to be qualified, including the Royal College exam and I have a dual qualification, paediatrics and medical genetics. For reasons I don't understand we have not been able to persuade the genetic counsellors to follow suit. And I'm not quite sure what the problem is. But I see they're trying to get provincial recognition for genetic counselling as a, all these people have Masters degrees.

TT: Same in this country.

PM: And so they should be able to get accredited for counsellors. So I remember in Vancouver I have a colleague of mine who runs the marriage and family therapy credentialing process, and in some respects genetic counselling is marriage and family therapy, you know so it would fit, but nobody seemed to really go after that. So we find ourselves in this funny situation with a new, as I stood down a new person came, and I have to sign all the letters of my genetic counsellors, which I, you know, because when I went to Victoria I recruited two people, a cytogeneticist to build up the lab and a senior genetic counsellor, who was a Canadian living in the States, and she came in. And she had a clinic. Once and a while she'd come and ask me for advice or what I think she should do, but I didn't see her patients, I didn't read her letters, she just went on with it, you know, got on with it. In fact I kept telling people the most knowledgeable person on this island when it comes to hereditary cancer is Myra Micek, okay? Because she was. And then new people come in,

‘Well, we’re concerned about liability and stuff,’ and I said, ‘I’ve been practicing 35 years and I’ve had no problems, I’m not about to start now.’ But, oh no, it’s creeping credentialism...

TT: Yes, and all this bureaucracy, getting the right stamps.

PM: Exactly, yeah exactly. So Vancouver has this training programme and they have, I don’t know, 15 genetic counsellors. One of them decided that her husband had got a job and they’d come and work with us. So she worked with us for a couple of years, three years, and his job changed and had to go back. So when she went back into the old job, she couldn’t stand it anymore, because she had no authority and no autonomy where was in Victoria; these were her patients and she ran with it, you know? So I wasn’t much appreciated around the Department for sort of seducing away some of their key partners. But part of my strategy was, ‘Come on! If my daughter has a Bachelor’s degree in physiotherapy and bills for it through the system, but also privately, she examines people, she prescribes, what is the problem?’

TT: She has professional standing.

PM: Exactly, you know. Anyway it’s not a battle I’m going to win.

TT: So your life, certainly you were back in Vancouver, so you were doing private work, you’re in the hospital, you’re teaching, are you doing all of these at the same time?

PM: Let me just correct that. So, as I mentioned yesterday, it’s almost impossible to make a living as a medical geneticist in private practice, because there are no billing codes. So you can bill as a GP for extensive counselling or as a paediatrician with extensive counselling, but there’s no fee for service for medical genetics in Canada yet. So you’re pretty much in a programme. So as a paediatrician and medical geneticist I was recruited into a pathology group where I was a pathologist, sort of thing. Another billing number, and I surrendered the billing number, the Department bills on behalf of me and the hospital tops it up sort of thing. So I never had a private office on my own, so it was always in an institutional setting in a hospital setting, and I was teaching, had a big teaching load at Queen’s and then I came back to Victoria and there was no Medical School, and the only teaching I would do was these dog and pony show things in biology about three or four times a year, but not much, to the medical students who came over for their paediatric rotation. But now beginning in September we’re going to have two slots funded for paediatric residency, and that means a big teaching commitment, and we don’t have the resources to do that. So as I’m winding down they would like me to gear up to teaching.

TT: Winding up again?

PM: Which is fine, I’d be happy to take that on.

TT: That’s a very sensible use of retired people’s time and experience.

PM: You see the laboratory managers don’t understand that. Because those lab techs, then they retire, they retire. They don’t retread. And so what is this? What are you seeing patients for in the Department of Paediatrics? I mean adults’ work. Why are you seeing adults? Cancer? That’s not a paediatric thing. So across the board there’s this, what we do is just completely misunderstood. And other people will get into trouble because, ‘Ah, genetics is easy, I’ll start a Cardiogenetics Clinic,’ you know, and then run up afoul of how complicated it is to deal with, a patient is one thing, but it’s the rest of the family. And they’re not used to doing that.

TT: Is there anything particularly special about Canada in terms of medical genetics, because of the immigration and people, or because of the longstanding families. I’m thinking here of Jane Green’s work up in Newfoundland of very old families, quite isolated families.

PM: Well, Jane Green was my lab partner in UBC zoology.

TT: Was she really?

PM: Yes.

TT: I didn't know that.

PM: So we're old friends. She went off and married a marine biologist from UBC and he went to St John's and she had her family. Meanwhile I went to Medical School, one thing or another, caught up with Jane many years later. She was in Newfoundland, fascinating story. I mean she was invited as part of the colorectal cancer story. And her contribution has been recognised. She won the Founders Award for the Canadian College of Medical Geneticists just recently at our insistence. The National Research Council, or the CIHR, Canadian Institutes of Health Research, gave her a one year stipend to travel back home just to give seminars at these outreach hospitals. But you don't know that story very much. She has her children and they're out the door, she has a bit of an empty nest during the day, what am I going to do? So she wanders around the hospital and she sees this sign about rounds this week, and this chap is an ophthalmologist and he's giving a talk on some aspect of some form of retinitis pigmentosa, hereditary thing, so she went and listened and said, 'Oh, that's pretty interesting,' introduced herself to him and Pryse-Phillips, and she started work together. And he had the responsibility for organising some of the - what's the word - not accounting, but essentially making sure that the blind individuals who were getting Canadian National Institute for the Blind pensions were actually getting the money. So they had a boat that pulled into all these little outports, you know. So Jane went along with him and started collecting family histories and one thing led to another and her pedigrees and her pedigrees and pedigrees. And then, while she's there up these other places, there's this, it's not an eye thing, it's a cancer thing. Caboom! Just at the right time when we wanted to map, we being the collective, wanted to map the genes for breast and colon cancers, she had these large well-developed pedigrees and stuff, you know. So she rocketed up through that, but she's such a quiet, unassuming person, you know, that she - not the kind of person that goes to meetings and makes a big name. Dragged up to the podium sometimes.

TT: She was lovely.

PM: She's a great friend of mine. And then my mentor, Clarke Fraser, when he retired from McGill, went and took over the programme at St John's, and encouraged her to get her PhD. Which was great.

TT: And she brought us a copy of her PhD.

PM: Isn't that lovely?

TT: Which is great for us doing the footnotes for polycystic cancer.

PM: Just, just wonderful. And when Clarke died, I asked his wife if she had a copy of it, because I would love to have a copy of Jane's Thesis, just as sentimental value.

TT: Now coming back to the idea of professionalization of medical genetics, and a number of things in professionalization like accreditation, recognition, societies, journals, what about societies? Because here you are as a European Society, which I hadn't expected to find.

PM: Oh, there's a secret to that. No, for 25 years going to the American Society meetings and you know interesting places like Philadelphia. But you know four times in Philadelphia is enough already. I was bemoaning something to somebody one day about, 'Oh, not in Philadelphia again.' Wherever it was. And they said, 'Well, you know, you should look into the European Society meetings.' So I looked this up and gee, they're going to have this meeting in Prague. Yes! So off I went to Prague. And next year off we went to Amsterdam. Ross and my cousin, and niece.

TT: So you make these a family occasion?

PM: And he'd never been to Ireland before and neither one of us to Scotland, but it's a smaller meeting, it has these neat, much more interpersonal mixers. Last count the American Society was 7,500, you know. So we had all our connections lined up before we even got here in terms of meeting up with Sequeiros and his wife, one of the genetic counsellors from Cuba that started this whole collaboration thing. So I much prefer these meetings.

TT: So the American Society for Human Genetics?

PM: It spun off from the American Eugenics Society and I think it was 1950 that they changed the name. And I was just thinking about this, you know, every year they have several awards. There's the Allan award, which is the most prestigious and their picture and their talk is published in the journal, but I don't think they're ever recorded in the sense of an actual video recording of the presentation. Kind of too bad. And I thought the same about the Canadian College of Medical Genetics Founder Award, there's lots of pictures and things but I don't think the remarks are recorded. So Jane and I are going to change that. Uh, so there are the Genetics Society of Canada is there but it's sort of dwindled away to some extent.

TT: What do you consider your major professional society?

PM: The College of Medical Geneticists. The Royal College hasn't really sponsored anything particularly along that way, because we're a small number of people, you know.

TT: How many?

PM: I'm going to say there's 100 Royal College people. So we're sort of lost. So the Canadian College meetings are well attended and they are well supported through donors and things and really good science. And every second year they meet conjointly with the Canadian Association of Genetic Counsellors, so they have a big dual meeting, which is a proper way to do it, because you're working with these people one day and you can't be at the same meetings.

TT: How big is their membership? The genetic counsellors?

PM: I should know off the top of my head, I'm going to say probably 150.

TT: And what about publication, Patrick? What main journals are we talking about, *JAMA* or places like that?

PM: No, I think most of my colleagues in clinical genetics try and get into the journal *Clinical Genetics* or to the *American Journal of Medical Genetics*. Some goes into some of the other, well the lab stuff goes into the high-end stuff like *Cell* and *Nature, Genetics*. But those are the main clinically-oriented journals that we participate in. I've tried to get published and I haven't had any trouble getting published in the *Canadian Medical Association Journal*, because it's got a broad readership, particularly with someone with an interest in genetics. In fact Alasdair Hunter, my cohort from Ottawa, has published a series of *How to's* for physicians for family doctors. In fact the young lady who talked at the conference yesterday (Elisa Houwink), the GP; she and I had a long conversation because I know someone, I don't know her name anymore, who is a family practitioner in the Ottawa area who is doing the same, so I've been trying to get them hooked up. A lot of Canadians will go to the American Society meetings, because it's the most prestigious and particularly from the training programmes you want to get your abstract into that. The Society for the Inborn Errors of Metabolism has probably six or 10 Canadians who participate in that.

TT: You really are a very small group, aren't you?

PM: But we have clinics in St John's, in Halifax, Quebec City, Montreal, Chicoutimi, Winnipeg, Edmonton, Calgary, Vancouver and Victoria. We cover the whole country in that sense, but there are long distances

between. But that's how we try and maximise our outreach abilities and outreach is talking to someone about how the advent of telemedicine...

TT: I was just going to ask you whether you do telemedicine consultations.

PM: Very much so. And it started because we used to have, for 14 years, the Hereditary Cancer Programme, and we went out of our way to educate the family doctors on the island about what constitutes a referral for hereditary cancer. And we had educational pieces for them, and my genetic counsellor would come up to these outreaches with me, pretty much exclusively to do the hereditary cancer piece. There was some autosomal, recessive things once in a while. Mine was all hands on, because these people had to be examined. And then, in their wisdom, the Cancer Agency decided 'Cancer control is our thing and we're going to move it all to Vancouver.' So they moved everything to Vancouver and now the new manager says, 'No, that wasn't a good idea, we'll move back.'

TT: These things all go in cycles, don't they?

PM: So with the advent of telehealth, I had done something for one of the IT people, I don't know what it was, but she seemed to think she owed me a favour and the favour came in the form of a, 'We've got this extra telehealth suite we need to site somewhere. Would you like it?' Bring it on. So we have a conference room, a small conference room, and it has a big screen and the health authority, because it's such a remote population, has orchestrated 232 telehealth sites, and booking is child's play and you get up the index and hit the button, and boom, you're ready to go. So we do over 200 a year. And what's really interesting is to see the aboriginal community buy into this.

TT: Do tell me more.

PM: Well, five per cent of the population is aboriginal, there's a large population of aboriginal communities on the island, and for all kinds of reasons, political and historical reasons, they've really not gotten the healthcare they deserve. And they've tried to generate their own health authorities within each reserve and things like that, but it struggles and struggles. But you know for example this one family lives seven hours away from Victoria that involves six hours by car and one hour by boat to get to the mainland. And so they think nothing of it of sitting down in their local health clinic, and there's telehealth and us. And so it started primarily around the breast cancer stuff, because you don't have to see anybody, but it's more now to presymptomatic testing for Huntington's. The initial assessments and things, the first couple of sessions, can easily be done by telehealth. I have always had this thing, when that young lady we were talking about got up, the general practitioner, what's so special about DNA? Now physicians order up lab tests every day of the week and the bioethicists are not breathing down their necks about all the things that might go wrong, and you know. You order up haemoglobin, for crying out loud, you know? What is this, I think they have sort of hijacked the whole thing. Well, there's a formal article in *Nature* some 10 or 15 years ago talking about the, what are they called, ELSE, Ethical Legal and Social Issues component, the five percent of the Centre's budget, Chris [Donohoe] was telling you about at the conference. But the largest make-work programme in America or some terrible headline about this, and then when this young lady was talking about the, 'Oh, it was you!' Ninety pages of consent form. I'd love to get a copy of that, because you know...

TT: Well, fortunately we don't have that now, 90 pages and 12 copies.

PM: But that means 12 people. And so somebody's done an economic analysis in the States that minimally invasive ethics review costs \$300,000. So you start counting the number of people and their hourly rate, okay, so a simple little thing costs \$300,000. So I would think of going back to the people who pay for these 90 page things and say, 'You know, this is what it's costing each time.' It's just crazy.

TT: Roger Strasser?

PM: Don't know that name.

TT: Well, it came out of an idea of doing a meeting on rural medicine so we've got people in Canada, in Australia, Wales, all sitting by their machines and we're going to be holding a Witness Seminar.

PM: That will be great, that will be great.

TT: Which is a very new thread. And it's very interesting you talking about the aboriginals, because you know the Wellcome Trust, and the Burroughs Wellcome company, all originated from Henry Wellcome. Well, his, the very first thing he started supporting and the first book he ever supported publishing, was actually, it was Mr Duncan who was the vicar in Metlakatla, it's up north in, it's north of Vancouver Island.

PM: But let me say this on the aboriginals, they are getting involved. We're getting them to participate more and more and they're just so interesting. I mean you have to, you have a young couple with a congenital malformation. We now learn from our ethicist at the University who, anthropologist, the importance of bringing the elders to the meeting. Fine, that's great. So we bring the elders in and talk to them first and say, 'This is what we're talking about, this woman.' And this is a young lady who has a baby with spina bifida, prenatally detected by maternal serum screen. And it's a real push among the aboriginal communities to have lots of babies. So things like marriage is not necessarily a requirement, so there's a real push to have the next generation explode. You didn't embarrass me did you? So she's going to have a termination of pregnancy, that's fine. She goes back to her remote part of the island and a week later the public health nurse calls me up. She says, 'I want to congratulate you guys on what a wonderful job you do, but there's a little sidebar here that you should be aware of. The local word out here is that we're trying to address this teenage pregnancy issue by providing Depo-Provera, and the word is out that Depo-Provera causes spina bifida.' Now just sort of an interesting wrinkle on these kinds of...

TT: Yes, absolutely, yes. Unexpected consequence you have to deal with.

PM: And if you want to do research in Canada with federal money you have to jump through so many hoops now to get approvals and things. There, you know, forget it, sort of thing. Now there's an interesting story for some of this thing and that takes me back to my early days in Vancouver where they recruited a population geneticist from New Zealand, and he had been working in the high planes of the Amazon with Jim Neo, one of the physicians that was mentioned, looking at the Yanomami Indian community, which was so isolated from the rest of the planet, so that their DNA would be pristine. And they were comparing that to the bloods they got from Hiroshima survivors to see the impact of genetic mutations. So Rick was part of that and they came to UBC, population geneticist, and among the aboriginal community there's this chronic problem of cold-induced arthritis, and arthralgias and stuff. So he decided he was going to map the gene for this. And so he had great cooperation with rheumatologists and with the public health officers and with the native communities and rounding up a whole bunch of these families, and got all this DNA stuff. And then decamped to Utah because there were much bigger resources in the human genome group in Utah, and he took all his samples with him. Then they began to see publications by him on the origins of the aboriginal community of British Columbia based on mitochondrial DNA. Now, they hadn't approved that at all. They were in to find out why they got this terribly arthritis gene. And away you went. Well, that wasn't very happy and so he disappeared - nobody knew where he went to. So shortly after arriving on Vancouver Island, I called up; no, I got a call by one of the medical officers of health, telling me about this problem and could I help move this ahead? So I said, 'I don't know much about it but I'll certainly try.' So I called the rheumatologist. He just tore a strip off of me and slammed the phone down. He was so angry. So I let the thing cool off a bit and I phoned him back and said, 'Wait, I'm innocent here. I had nothing to do with that thing.' So he listened and talked to me about, the problem was he'd done all this work and the pedigrees and the DNA had disappeared, and was just left holding the bag. Well, justice comes in the form of a pub. So that medical officer of health is in a pub in London on BBC 2 news, interviewing the new Professor of Biological Anthropology at Oxford, who is our chap from British Columbia. Gotcha! So they tracked him down and it made it into *Nature* about this idea of doing research with samples without consent.

TT: What date is this?

PM: Oh, this is four or five years ago. So it's just, with this modern communication, you don't want to go too far into the public domain. Somebody will catch you.

[END OF TRANSCRIPT]

Further related resources:

1. 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.
2. Jones E M, Tansey E M (eds) (2015) *Human Gene Mapping Workshops c.1973-c.1991*. Wellcome Witnesses to Contemporary Medicine, vol. 54. London: Queen Mary University of London.
3. Jones E M, Tansey E M (eds) (2016) *Medical Genetics: Development of Ethical Dimensions in Clinical Practice and Research*. Wellcome Witnesses to Contemporary Medicine, vol. 57. London: Queen Mary University of London.
4. Tansey E M (intvr); Tansey E M, Yabsley A (eds) (2017) *MacLeod, Patrick: transcript of a video interview (06-Jun-2015)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017101. London: Queen Mary University of London.