

AUDIO INTERVIEW TRANSCRIPT

Tudor Hart, Julian & Thomas, Mary: transcript of an audio interview (14-Jun-2000)

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Biography: Dr Julian Tudor Hart (b. 1927) was an epidemiologist working in the Epidemiology Research Unit in 1960, before moving to general practice in 1961 until 1988. See also Mullan F. (1995) Interview with Julian Tudor Hart, February 1995. Primary Care Oral History Project, 1995–98. Modern Manuscripts Collection, National Library of Medicine, Bethesda, MD, USA. Dr Tudor Hart's practice records from 1965 to 1992 are held as GP/13 in the Wellcome Library, London (for confidentiality, access to these records is subject to embargo).

Biography: Ms Mary Thomas (Mrs Hart) (b. 1940) was a fieldworker at the Medical Research Council Pneumoconiosis Research Unit from 1960 to 1962, and later for the MRC Medical Epidemiology and Medical Care Unit.

AN: Andy Ness

JTH: Julian Tudor Hart

MT: Mary Thomas

AN: Can you tell me about yourself, your early life?

JTH: I was evacuated during the war to Canada, where I got most of my secondary schooling. I was briefly in the army after the war and shipped out again, because I had a fractured spine. [I] went to medical school at Cambridge and St George's Hospital [Tooting, London] and got into epidemiology because I had started as a GP, which was what I had intended to do. I went into practice much too early before I had had enough postgraduate training, mainly because of pressure from my then wife, of my disastrous first marriage, who just wanted me to get earning quickly. When that marriage broke down and I had a sort of dislocation of everything, I had the opportunity to get back to complete my postgraduate training in hospital with a series of house jobs that I should have done earlier. I had thought about being a paediatrician in West Africa, but I soon decided that that wasn't what I really wanted to do. I had been interested in epidemiology as a student and in my five years in practice in London. I had been interested in it because I knew about [George] Pickering's work at St Mary's on distribution of blood pressures, and I could see that his great difficulty in finding a representative population from referred hospital patients that that problem wouldn't have existed if he had been a GP. With registered populations in the NHS, you had just the population.

I had already started measuring blood pressure systematically in my Notting Hill practice. Harry Keen lived in the same street and Geoff Rose was a big friend of Harry Keen's, so I met him. So I was sort of in touch with epidemiologists. And I was a very active member of the Communist Party, and in my local branch of the Communist Party, Richard Doll was another member, and his wife Joan Doll. And in those days epidemiology was actually a very political subject, social medicine was a very political subject. One of the reasons it stopped being called social medicine was because so many social medicine people began to

* Interview conducted by Dr Andy Ness, for the History of Twentieth Century Medicine Research Group, UCL, 14 June 2000. Transcribed by Mrs Jaqui Carter, and edited by Professor Tilli Tansey and Dr Hugh Thomas.

be embarrassed at this close association with socialism. So it slid into the, so to speak, value-free or supposedly value-free methodology that Walter Holland went on about. But we are talking about the 1950s and epidemiology still had its traces of its birth from operations research in the war and giddy expectations of post-war.

AN: Was there a sense of what an epidemiologist was or did at that time? Was there an idea of this is an epidemiologist, this is what they do?

JTH: Yes, there was. I think partly because of the model of operations research in the war, we realized that, looking at how disease behaved in real people, as they really lived, was a model, not limited to infectious disease. In operations research you researched how to do the D-Day landings with maximal success and minimal casualties by looking at every aspect of the Normandy beaches. You looked at aerial photographs of the patterns of sand on the beaches, from which you could calculate what different tides did and what weights of tanks they would support, what people could wade through and what they couldn't, carrying whatever armament. You had to look at every aspect of it. And there weren't areas for scientific research and other areas where you had priests or artists or something, you just looked at everything, seeing whether you could calculate, whether you could make estimates, whether you could quantify. Well that was a background that had been very successful, it had been pushed by scientists like J D Bernal, who looked at the world, as naturally Marxists and socialists. That was something that Churchill and Mountbatten and so on just had to accept. If they wanted imaginative scientists they couldn't limit themselves to establishment figures like Peter Tizard's father [Sir Henry Tizard], so after the war what had already been beginning in the 1930s with [Edward] Mellanby and John Boyd Orr, Major Greenwood and Bradford Hill. Mellanby and his important series of articles on statistics in *The Lancet*, had already begun to prepare the ground. Even that was political, they were associated, particularly with nutritionists like Boyd Orr, who were tied up with the campaigns for doing something about the diets of poor people trying to feed and clothe a child on two shillings a week, the children's allowance for the unemployed, and so on. It was political, looking at things collectively, looking at things in a social context. The essence of Conservative policies before the war was just the same as it was with [Margaret] Thatcher, 'there is no such thing as society'. Well you can't answer very many interesting questions if you don't think society exists.

So anyway, for epidemiology, we saw that infectious disease was just a very small part of it, and actually at that time an apparently diminishing part, because of the success of antibiotics. A lot of people interested in epidemiology came from a background of tuberculosis control, because that was something that had always attracted people with a social view. And we could see that we were getting on top of that very quickly, so it was the non-infectious diseases we could see were going to dominate. That was unusual. If you talked to people in other countries, about epidemiology, they always thought you were talking about epidemics, and by epidemics they always thought you meant infectious disease. They didn't think you meant appendicitis or coronary disease or whatever. Perhaps it was just because we were in England, but we seemed to be ahead of everyone else. We certainly seemed to be ahead of the Americans. I think because of the politics of it. Epidemiology at that time was strong in South Africa, but it was strong in South Africa among Jewish intellectual opponents of the South African white establishment and when [Daniel Francois] Malan was elected in 1947, there was a period when people like Sidney Kark were still trying to carry on doing clinical work in townships, simultaneously very political, and also doing social studies in. They went off in three directions, to Israel, to England, and to the United States, and provided a whole cohort of very important world names in epidemiology. For example, Mervyn Susser, a huge man, who went to San Francisco after his work in Manchester on bedwetting and things. I think in the States it took off later, but for example in the Framingham heart study [Massachusetts], I think the quality of the initial work was greatly inferior to the quality of the work that [Archie] Cochrane was doing in Rhondda Fach. They had 66 per cent response rates in Framingham, and the whole cohort was impaired ever since, because what about the other 35 per cent? And the quality of the measurements! Bill Miall looked at the raw data on blood pressures and it was terrible, the usual business of terminal zeros for systolic and diastolic pressures. The quality of data at Framingham improved as time went on, but at take-off I think it was of a very much inferior quality to ours. They chose Framingham, a middle-America population,

almost entirely white, with very few poor people, and such poor people as there were, were probably in that 35 per cent of non-respondents. That contrasted with the Rhondda Fach population, with response rates around 90 per cent. They went for the Rhondda Fach, because Cochrane was studying pneumoconiosis and you don't have pneumoconiosis in Buckingham Palace, but I think, for the archive, there was also an element that was political and social, also to do with the 1945 election and post-war expectations in Britain, which were very different from America. In America the Cold War was already going on. Very early on, the Cold War stopped the liberal/social programme in America, which never since managed to get round to providing a health service for the whole of the American people. It all got tied up with hostility to social ways of doing things, collective ways of doing things, already collectivism was equated with communism, and they were looking for individual solutions for everything. We weren't like that. So I think that had an effect early on.

It is, of course, true that if you focus on pneumoconiosis as a topic, then you are going to go to an industrial working-class area with a militant political tradition. For me, I saw in Pickering's work, an opportunity to apply my political ideas to clinical medicine as a medical student, my politics was more important than medicine, and it still is. Politics, in the sense of changing the world, is an overall context within which medicine operates, so in that sense it is more important. I had wanted a way to be a useful person, politically changing the world while actually doing something useful with my hands. I always wanted to be a GP. I assumed I could never to get to be a consultant anyway, because I assumed that you would get shut out from that area of work if you were political. Quite correctly too – people like me who did try to become consultants, for example, Ian Gilliland and Michael Tempest, had a terrible time getting jobs. I had very primitive ideas about being a kind of tribune of the people and all that jazz, and suddenly I realized that epidemiology is really a democratic subject, high response rates means one man one vote, everybody in a community is important. We need everybody's blood pressure, we don't just need the blood pressures of people who have come along to see you about their blood pressure or have coronaries, we need the whole distribution. This wonderful discovery of Pickering's, that blood pressure continuously distributed, so we no longer had to label people as having diseases or not having disease, but could interest ourselves in how much they had and whether it was useful to call high blood pressure a disease. So de-reifying disease, getting distributions and combinations of distributions, was a new thing. I could see straightaway that the debate between Pickering and [Robert] Platt it wasn't a scientific debate, it was a social debate. I think John Swales, in his book about the Pickering-Platt debate, missed the central point. He treated it as an interesting philosophical disagreement, but I think the philosophical disagreement was ultimately social, it's Platt saying medicine cannot operate without labelling. You can't expect doctors to take clinical decisions without putting people in two boxes, the people who have got it and the people who haven't got it. Pickering was saying, 'well I am sorry if it's awkward for the doctors, but this is the way human biology actually operates. We can't have two boxes, just because you want them. At the very least you need three boxes'. He didn't say this actually, but I could see it, because as a GP it is true that you have got to box people, because you do have to take decisions, you can't just observe them, but at least you want three boxes: One box for those with good evidence that doing something is better than not doing something that the gains outweigh the losses; and then another box for those with good evidence that we should leave them alone. But you always need this other box in the middle, of people in whom we don't know, we have got to wait and see, we have got to go on measuring and collecting more evidence. We know all the time that the three boxes are proxy for something that isn't necessarily a unimodal or bimodal distribution but it is continuous. To me it doesn't matter, despite the great battle was whether the distribution was unimodal or bimodal. Actually I think it is almost certainly bimodal, because we have most 'essential' hypertension, which is insulin resistance in fat people, and a much smaller number of other hypertensions with other causes, known and unknown. Incidentally, this means that the maturity onset diabetes clinic should also be a hypertension clinic. The message is the same, the treatment is the same, the education is the same, the variables we measure are the same, so why the hell have two different clinics? GPs, as human biologists, ought to be operating in that way. The bimodality covers undetected contractions, Conn's syndrome and all sorts of itsy-bitsy hypertensions, which are important. I got angry with people like Peter Elwood, for example, who behaved sometimes as if those rare conditions didn't exist. They may not exist to statisticians, but they bloody well do exist for the people who have got them and whose GPs don't detect them. I used to say to an audience 'how many people in this room have got

acute pain in their lower abdomen?'. No hands would go up. And so I would say 'alright that's great, acute appendicitis has been abolished, it doesn't exist and we don't need acute appendectomy'. It was a silly question to ask, of course, but in the same way it is silly to say that because in a random sample of the population you don't turn up anyone with pernicious anaemia, that pernicious anaemia isn't an important thing to find. So anyway, I thought great, this is what I mean by politics changing the world, this is an area of politics where I can see opportunities for useful work. I saw that most people couldn't see that, so this was something I had to do myself. There we are, that's enough of that. That's that bit of the story really.

Richard Doll was not only in my Communist Party branch, he was also my patient and his family were my patients, and as they had just adopted a child, a baby, I actually had quite a lot to do with them as a GP. At one point in the fifties he said, 'you know Julian I think that one way your obsessional tendencies might be useful are in epidemiology'. I think this was because I was an obsessional record keeper. I always wrote something down when I saw patients, I always had their medical records there, and I don't know why, I had always done it. When I was a houseman on tuberculosis wards I wrote pages and pages of histories, because the patients were so interesting. Where my efficient colleagues would write two lines, I would write two or three pages, and I remember thinking, my colleagues think I am mad. So anyway, Doll let that remark fall and a couple of years later, I said I'd like to take him up on it. By then he was based at the Central Middlesex Hospital, for his clinical work. He was doing quite a lot of clinical work then in the gastroenterology department with [Sir Francis] Avery Jones the guy who wrote the standard textbook on gastroenterology. The Central was a really important hospital then. He knew that Archie Cochrane was looking to recruit somebody for his unit, and the extraordinary thing, this is what really mystifies me now, is that without any interviews, or me submitting applications or as far as I remember even filling in any forms, but the whole business of my appointment seemed to be entirely based on an old boy network, or perhaps an old comrades network. So I was taken on with a view to going down to South Wales, but starting off doing sort of dogsbody work for Richard on various projects that he had got going, where I just learnt about epidemiological choring, data gathering. He had been commissioned to do a study on survival in ambulances of patients who had gassed themselves with what then was carbon monoxide-containing domestic gas, and whether it was worth adding carbon dioxide to the oxygen cylinders, because they were worried about depressing respiration with pure oxygen. So I had to go down to South London ambulance station where all the London County Council [LCC] ambulance records were kept, their archives. They were in an attic, which nobody seemed to have entered for years, with piles and piles and piles of counterfoils from the ambulance driver's records. The biggest problem was the dust, it was horrible choking work. I had to go through all these counterfoils looking for people with coal gas poisoning, and then somebody else had to find records of whether they survived. Some units were using these mixed gas cylinders and others weren't, and death rates in the two groups were to be compared. Well, I could see within the first day or two that what was really happening in these ambulances was that, the ambulance drivers were arriving, finding a corpse, which would be quite pink, of course, because of the carbon monoxide poisoning, and rather than say to the family 'I am sorry there is nothing we can do, this person is already dead,' they were giving the benefit of the doubt to the family, and also to themselves because it spared them having to break bad news. They would take them to the hospital and the hospital would say they are dead, and, of course, that would go down as a death in the ambulance. So I decided very early on that this study was completely worthless and there was no way that it could answer the question. I am sure I said that to Richard and I don't know whether he took it on board or not, he probably would have done, but he might not have acted on it, because I think it was commissioned work and something we were paid for, and it had to be completed.

But it was an early introduction to the futility of quite a lot of epidemiology and that it can be an awful lot of no fun if you are not in control of what you are doing, if you are just choring for somebody else. Because I had to go on doing it, I set up my own little study that I could do at the same time. I was interested in firework injuries because I reckoned that we needed legislation to stop people selling fireworks before November 5th. I started by being interested in how many there were, but then I became more interested in juvenile suicides. About once every other day, ploughing through these records, I would come across kids who had hanged themselves, children of ten and nine and so on. There weren't enough of them for a good study, but it made me aware that this problem exists, and I thought how a

study needed to be done of why they did it and so on, as far as one could. Anyway, I suppose I passed this test, which was presumably to see whether I would give up the whole thing. But I did find that being shifted from a position of having to take decisions at a rate of knots, with a continuous stream of very high pathology patients in Notting Dale general practice, to a position where you couldn't take action, I found it very irksome and I went on finding it irksome all the way through. In many ways I did want to get back to decision taking. And then Richard put me onto a statistics course at the [London] School of Hygiene with about 30 other people, almost all of whom were from abroad. The teaching was by [Donald] Bradford Hill, which was very, very good – he was a wonderful teacher. He could see straightaway whether people were keeping up with him or not, and he would adjust his pace accordingly. He was a really nice man. And Peter Armitage, who was a very big name in medical statistics, indeed. He was a hopeless teacher for me, because I hadn't done calculus at school, I was never much good at arithmetic, I could do ordinary algebra all right and quite enjoyed it, but he wasn't starting at my finishing point. He did nothing at all to find out what level we were starting from. At first I thought I was the only one, but then when I started talking to the Greeks and the Yugoslavs and other people who were there, I found that most of them were completely lost, but it wasn't worrying them. They were there to get a diploma or even just to be 'been to's' and so it was quite demoralizing. Day after day we had these classes where we pretended that we understood what was going on but didn't understand it at all.

So again I tried to start doing my own work in the library, finding interesting things. Way before anybody else was drawing attention to it, I found that mortality rates were not converging (as most people then assumed), but social classes were diverging. This is in 1959 or 1960. So after three months of statistics, I decided, that the only way you can learn medical statistics was by using my own data that I had generated myself. It then suddenly becomes very interesting indeed, and you really want to learn the techniques. The other thing I learnt, partly because of that experience in the attic with the LCC, was that it didn't matter how sophisticated your statistical analysis was, if the original input data was not of good quality. I decided the kind of work I wanted to do, was not to do the mathematical handling myself, but to produce data that could be handled mathematically by others. If clinicians can do that, then they have created an immensely important experimental facility. How anything is handled statistically is really quite a trivial question, a question of technique. I have a strong bias in favour of statistics that are comprehensible to non-experienced people who read about them. I think if we get statistics that are so sophisticated that they are intelligible only to other statisticians, it reduces the rest of us to a level of uncritical readers, and that's bad. I have the same feeling about meta-analyses, it's only other meta-analysts that can judge them, so I have to use George as my observer. And I trust him.

Anyway so then I go down to South Wales and spend a year. They gave me a project. Archie gave me a project where I had to look at tuberculin sensitivity in relation to progression of PMF, progressive massive fibrosis, as a sort of final desperate validation or invalidation of Gough's hypothesis that the determinant of PMF, as opposed to simple pneumoconiosis, was tuberculosis. I think this is a very interesting thing historically, because I think it is beyond question that it is not, tuberculosis has nothing to do with it. But it was an extremely attractive hypothesis, it's the sort of hypothesis that seems so self-evidently true that you can hardly believe that you need evidence to prove it, but I watched so many people crash on having a religious belief in their hypothesis, who subsequently bend data to prove what they feel is already proven, but is just from the doltish multitude that you have got to produce some more evidence, because otherwise they won't understand it. That happened with [John] Yudkin and sugar, he was so convinced that sugar was poisonous that he never produced any data at all that supported it, and yet he went on and on and on and on, and even suppressed some data that conflicted with it and so on. But it was a real education, because I originally thought well you know this is bound to be true, I am wasting my time, and then I had to research the literature and first of all I thought well I had better establish whether it's regular sensitivity is tried, it was being used as a proxy for how much tuberculosis people had or had had, was it a good proxy for that? And I came across extraordinary papers like one that had a whole mathematical thing based on if one tubercle bacillus causes 'x' amount of response then three million bacilli will cause whatever response you like. And I remember thinking we mustn't let this approach be quite the centre of research. This is not real.

I found quite a lot of people, not a lot, I found four or five people with quite profound tuberculosis, who were tuberculin negative, this was known, but it was always dismissed, that the reason these people were not tuberculin positive was that they had an overwhelming infection and that they had no host resistance at all. It may well have been true that they had no host resistance, but they certainly weren't in recognizably different states than the other people. They weren't overwhelmed, and I decided that we had got to be quite sceptical about how useful tuberculin sensitivity was for individual decisions. It was a very useful epidemiological tool, and of seeing what was happening in general, but actually the proportion of false negatives would be quite high, 5 per cent or something like that, which was news to me. But I went on using tuberculin testing in my practice because I was still looking for tuberculosis, so it was useful for GPs in general to do this. The other thing I learnt during that study, Ian Aird at Hammersmith had discovered accidentally that blood groups were related to duodenal ulcer and there was suddenly an explosion of interest in the relation of ABO/RH blood groups to every disease under the sun, because all you had to do you went through a Hollerith calculating machine and you would get your answer if you had got a series of anything that also had ABO/RH blood groups. I arrived at the PRU, Archie's unit was separate from the PRU, the Pneumoconiosis Research Unit, but in fact everybody shared the same mess, had tea together, they were in the same building and you couldn't really tell them apart. And it had a terrible effect on the established researchers. Archie was not one of these, but nearly all the others suddenly saw their names in lights, that they were going to make a big breakthrough because they had run one of these things through a Hollerith machine. I remember thinking this is a terrible way to be, I mean they were in a tearing hurry because everybody knew that if there were any answers going to be got this way they were going to be got very quickly, and they had to be first. Well how ridiculous. Sure it would be fun if we found this, but why is it important who gets there first on a silly thing like this. But anyway I did think, I thought well it was damned unlikely that ABO/RH was going to be related to duodenal ulcer, but even if it is, the chances that we were going to find anything else that's related to ABO/RH still seems extremely remote, and most of all pneumoconiosis, progression of PMF, but they got terribly excited that PMF progression might be ABO/RH blood group related. So I was given as an extra job, that's right, they thought though it might have reiterated progression and they thought, 'oh well now that we are into genetic characters, I wonder if there are some other ones that we could throw in that would be easy to do? Oh yes phenylthiocarbamide (PTC) tasting, whether you can taste phenylthiocarbamide, that would be interesting.' I thought he's going round the bend, why should selecting random genes and looking for associated things, so I was given the task of ascertaining PTC tasting in these miners that we were screening. I really was against it from the beginning because it was a fishing expedition, because it was going to confuse the men. The men in the trial understood what we were doing, they could understand Roth's hypothesis too: I mean I had to explain why I am giving them these little injections, they could see that and maybe it made sense, but explain to them that the capacity to detect phenylthiocarbamide might be related to progression of PMF they seemed to find very unconvincing. It may have been because I was completely unconvinced, and so was when I was explaining to them why we were doing it. I decided then and there that I would never accept other people's hypotheses to be tested at the same time as whatever we were doing, just because you can do it. Again I would have had to read the literature and I decided about PTC tasting. Somebody had gone up the Amazon and claimed to have tested PTC tasting in young Amazonian Indians. Well my experience of testing PTC tasting in South Wales miners was that it was extremely difficult to do. It wasn't because I made it difficult, I thought how do we know that the people either taste it or do not taste PTC, what right have we got to assume that there are only two boxes?

Perhaps this is a great characteristic. Perhaps people who are homozygous taste differently from people who are heterozygous. So the only way to find this out is to have different concentrations of PTC. Well, of course, they had to be quite arbitrary, but what I did was to do, I think, 10 little beakers, two or three of them had water in them and the others had different concentrations, quite widely different concentrations of PTC. So the man had to go right down this long rack of things, tasting them and we did indeed find, although I never published anything about it, but we did find that there weren't just tasters and non-tasters, there were, presumably they probably were heterozygous. Anyway I very quickly found that it was almost impossible to do. And for the men? Well they all had the core respiratory function test, and you can imagine the comments, 'now they ask us to do this bloody thing'. It was the last thing that they had to do, and everything about it was sort of end of term, and I am sure my attitude to it was I was really fed up

with it, I was sure that it wasn't going to get anywhere, and I could see that the men didn't understand, I could see what was happening. The first two or three of these jars that they tasted, they were really thinking about it, but after that, they just wanted to get on with it, so I don't know how real their answers were anyway. And so Mary [Thomas], who was another fieldworker in the Unit, and who I had admired from afar, she said 'well would you like us to do it Dr Hart?' She said 'we can see what you are doing, and you know we could do that'. I said 'oh that would be a great help if you could do it.' And from then on it seemed to go swimmingly. They didn't seem to have the difficulties that I had had. So years later, after we were married, I said to Mary 'one thing I have never understood was that bloody PTC tasting thing, I just couldn't get anywhere with it, I thought the whole bloody thing was nonsense and I didn't think the answers the men were giving me were reliable anyway. Actually half way through everybody else seemed to lose interest in it as well, even the people who had made me do it, seemed to fall out of love with the hypothesis, and were beginning to see how silly it was. But you gave us all these figures at the end and everything seemed to have gone very well, of course, they were never analysed, nobody ever looked at the data, but it seemed to go all right. Why was that?' And she said, 'oh of course it did, when I said to you we could see what you are doing, I meant we could see that you weren't really doing it, we could see that nobody believed in it, we knew that this was an element in the study that was of no consequence. So we reckoned that the best thing to do, was just to get on with it, that we could pretend to do things more efficiently than you could.' The data was worthless, but then the whole thing was worthless. I wondered how many other studies were like this. The experience strongly reinforced the feeling that I have had ever since that the main function of medical conferences is simply to assess the reliability of the people. It wasn't just a question of looking at the published work statistically and so on, it was also a question of assessing the integrity of the people involved.

Anyway after a year of that kind of thing I was thoroughly fed up with just being an epidemiologist and not being a clinician. I was doing locums, as a GP in the Rhondda, partly to make money, and partly because I was interested to see what was happening to these men, where you could intervene actively rather than just make very accurate measurements for research. The state of Rhondda general practice was appalling. I was having to see up to 60 people in a morning session and another 60 in an evening session and do 15 or 20 house calls in between. All you could do was pick up, out of ten people consulting, one or two who had got major reversible problems, really big things. I remember seeing a woman with uncontrolled thyrotoxicosis going into heart failure in her twenties who had been referred to the hospital where there was a sort of peripheral outpatients held once a month. She was on a waiting list and was expected to be seen within about a year, and here she was already in heart failure. The GPs didn't try to use anti-thyroid drugs available at the time, and probably quite right too, because they weren't confident in their use, but this was an emergency where something needed to be done urgently. I can't really remember, but I think probably what I did was melt the wires and just make the hospital take her in. But anyway, I would pick up three or four people each session, where I would actually try to be a doctor. For all the others all I did was meet expectations, which was very easily done, just to sign some piece of paper or something, but it was shocking, terrible, there was a lot of gross pathology there. It was terribly demoralizing. The only way you could work there was by gritting your teeth and saying well, we are going to change this, and change it as quickly as we can. We can't do it today, but we can make a start today.

So towards the end of that year, I suggested to Archie that, as epidemiologists they were always moaning about how they couldn't get access to GP populations because the GPs weren't co-operative, why don't we set up a research practice. I'll be your GP, I won't be an epidemiologist anymore, but I will understand that you need access to my populations. I'll look after the population, we will build up a group of like-minded colleagues, and we will develop a peripheral centre of excellence, which will be a teaching, research, and clinical unit, just like a teaching hospital is. The deal is that if you are a patient in this practice you are taught upon and experimented upon, but in return you get state of the art care, better than other places, just like in teaching hospitals. Archie was very taken with that idea. He said 'yes we will do that, as soon as one of these old GPs retires or something, we will get you into the practice. Then when patients see the care that they are getting in your unit, they will all leave these other terrible old men, and they will all come to you'. And I said, 'you can't do things like that, that isn't how we work, we won't get anywhere with that attitude'. His whole attitude was really that the Rhondda GPs, the quality of their work, was a

kind of moral failure, whereas obviously it was the product of a whole set of circumstances, over which the GPs had almost no control. The little bit of control they might have had, they didn't have because they were not politically aware that if you are in the shit you start shovelling it out, you should do something about it. That's not how we were educated, but we were educated. We were educated in medical schools to find a good place to work, not to find a bad place and make it better, that wasn't the aim. I was quite impatient then, and I think I needed to get out, the pay was terrible, and the MRC has always been an appalling employer.

AN: Tell me more about why it's an awful employer.

JTH: Well the pay for doctors was bad, it never took any account of the fact that doctors have lots of other ways of earning, besides ordinary practice, and certainly I could earn more as a GP than I could earn from the MRC, even in the valleys. I mean I can't remember what the local pays were, but the reason I say it was an appalling employer was not mainly about doctors, but about other staff. It was shocking. When Mary was working for the MRC, which she did for most of our working lives, there was a time when she was the head of our research unit, she was running the team, organizing everything, a very responsible job, and doing it very well indeed. She had got a fearsome reputation in Tom Meade's unit, but she was being paid less per hour than the street crossing lady outside the school. It isn't as bad as that now, but the impression I always had of the MRC was that it still had a tradition of aristocratic dilettantism. There was an assumption that if you went into research you weren't interested in money, because if you had been interested in money you would have gone to Harley Street or something. Why people should be paid less if they are doing more responsible and more socially useful work is beyond me. It's quite true that good researchers are less interested in money, but that doesn't mean they shouldn't have it. The same thing applied to all the other employees, that it was a privilege to work for the MRC. Just like hospital secretaries are paid half of what they would be paid by industry, in the same way if you were in research you were paid even less than that, because of the privilege of being associated with research. So I think it was a bad employer. I learnt that at my mother's knee, because she was a member of the Association of Scientific [Technical, and Managerial Staffs, ASTMS], the original predecessor of the MSF (Manufacturing, Science, and Finance). It was as true of the health service as it was true of all research bodies, was that they were all appalled at the idea of trade unions, how would anybody want to be a member of a trade union? They were appalled at the idea that people should raise such mundane questions as pay and so on.

The MRC was and still is an extremely conservative organization that is, I think, very resistant to any kind of social innovation. For example the warfarin study was piloted by us and by a practice near Bath. Our main job I think was to find out whether it was feasible to do it at all. Whether you could get men between 45 and 65 to agree to be screened and identified as in the top quintile of risk for coronary heart attacks, and then to be randomized to treatment with either low-dose warfarin or placebo, and then to be followed up for five years with venepunctures every three months. At the same time even your own doctor did not know which group you were in. Those are extraordinary things to ask anyone to do. And yet at the end of the first year, we had 85 per cent of the men eligible for the trial participating in it. I think that is an astonishing figure. Even when the trial moved to all the 100 or so practices in the GPRF (General Practice Research Framework), it was over 60 per cent. Now I think that is an amazing achievement. I pressed all the time for the GPRF to be developed politically as a social force. We have now got between 11 and 12 per cent of the UK population in GPRF practices, that is a tremendous potential force. The proportion of practices with patients in teaching practices (trainee practices) is about 15 per cent, a mighty force by innovation. Until the advent of primary care groups and local commissioning, there was no mechanism for systematic innovation in primary care. It was left entirely to the initiative of individual GPs. The only reason we had any sort of organized force for innovation was through the trainee scheme, because there you could set standards, and in fact that did happen, trainee practices did innovate, and that set new norms within some effect on all practices. Now this is a new way innovating it through research practices, but the MRC just didn't want to know. Tom Meade didn't want to know and I am quite sure that he was faithfully echoing the views of other people in the MRC. The whole idea of the MRC being a political force, a force for change, was repugnant to the MRC establishment. Their whole attitude was contemplative, they saw their job as to observe the world, not to

change it. It's somebody else's job to change it, whose, I don't know. I mean it is not the politicians, because the politicians' main objective is to keep it the same, so they had a weapon they refused to use. We had recruited our own men on the basis of five year's study, but we hadn't thought it through, and nobody else had either, that for the pilots it's not going to be five years, they were still recruiting people ten years later to the trial, and we were still in it. Our men served 12 years. What were we supposed to do? After five years of course we said to the men now you contracted for five years, but we don't have an answer, and part of the bargain that I'd given them was that one of the advantages of being in the trial, was that as soon as we had an answer, they would receive the benefit of it, one way or the other. But we couldn't do that, because after five years we didn't have an answer, because we were the advanced troops. So all we could do was to say 'I'm very sorry, we ought to have thought of this, but we didn't, so although you were recruited with some false pretences, they were not conscious false pretences'.

Anyway, after all that, when the trial was finished and we did have an answer, I raised with Tom Meade and with Stan Peart the question of finding out from the participants what they had learnt from the experience of the trial. My guess was that recruitment to randomized control trials was going to be more and more difficult to the extent that people would become better educated, more critical, and more consumerist in their approach. They will be all for research, but done on somebody else, not them. The whole idea that if you benefit from research you have a duty to contribute to it, is having a harder time now than it would have had in the 1950s, for positive and negative reasons. Positive reason that people are less willing to have other people take decisions on their behalf, and they want to think it through themselves. That's an advance, but on the other hand, there are people who think less searchingly now than they did, especially in these sorts of areas. The docility of the population and their gratitude for having free care on the NHS is a waning asset, you can't count on that for the future. So we have got to find out why these people agreed to the trial, why they stayed in it, and how their ideas changed in the course of the trial. I realized that this was going to have to be qualitative research, but qualitative research is better than no research. Originally my idea was that we would have a conference and we would get participants to come along to the conference, obviously it would have been a self-selected minority, and just listen to them. I thought we would have a non-medical chair, perhaps Claire Rayner or someone like that, some big personality, who would encourage them to get off their chests what they had been thinking all this time. I have got a lot of time for Stan Peart, he's a very nice man, just the kind of enlightened epidemiologically minded clinician that I like most. But he just said, 'oh you can't be serious Julian, you know I would love to be able to say that we could learn something from the participants, lovely idea, but you can't be serious'. He turned round to Tom and said, 'look Tom, what can they possibly tell us that we don't know and we haven't thought of,' and Tom said, 'yes, well, of course Stan.' So I was quite angry, I was really shocked, I hadn't anticipated, I didn't think it was possible that anybody would say such a thing. So I spluttered something or other and then Stan added insult to injury by saying 'now come off it Julian, we all know your practice, your patients, if you asked them to take part in a randomized control trial of brain transplants, they would agree.' I said 'Stan you know this is absolutely not true, you don't understand anything about my practice if you think that.' We had very high response rates, much higher response rates than other people did, but that was because we put the work in, because they trusted us, because they knew we never put them through experiences we had not shared ourselves. We were very critical. We had an elected patients' committee, we always discussed the project with them, and got their approval first. Because they had us as hostages because we lived in the practice and would have to live with our mistakes. Most epidemiologists just come to an area, plunder it for all the knowledge they can get, and then disappear and that's it. We weren't in that position and that is very, very important, it is a safeguard against the most irresponsible kinds of studies. I was sure, I knew that these men went home often to wives who would say, 'Oh I don't like this trial you are in, look at so and so, he was in a trial, and he had a heart attack last week, don't you want to know whether he was on the warfarin or the placebo?' Now we had all learnt, including the participants, that that was what we must not know. The first people that fell off their perches during the trial, we knew and the participants knew that had we known which group they belonged to, it would have been impossible for us to carry on with the trial, because the subjective feeling that this person has died because they were in one group or the other, is overwhelming. That's how you feel, even though you know it's nonsensical. So all the people participating, but often not their families, began to share this view, and, of course, the men talked to each other and the stronger ones supported the

weaker ones. Of course we lost some, but in general the ones we lost were exactly those people, with the least faith in logic and science and reason. The men were being pushed one way and another by events, by their families, by kinship experience, but eventually we built up a kind of cohort loyalty for everyone, they were proud of being in the trial. Now all these different things, I wanted them to talk about them and get them documented, because I thought this is important for the design of trials in the future. I felt that we had reached a point where the population should be involved at the design stage. We should say to them this is what we are planning to do, what do you think about it? They would have spotted straight away that the five-year pilot wasn't going to be a five-year pilot, they would have seen that. We didn't see it, because we didn't want to and it wasn't that important to us I suppose, but anyway I went quite a long way with this. I tried to enlist Iain Chalmers, the Cochrane Collaboration guy, and he was all for it, he was very keen on it, so I had a second go at Tom Meade and Stan Peart, and Tom said you are being very unfair to Stan, he quite sees your point of view but and so on, and he's having a hard time with his wife with Alzheimer's (which was quite true). But I stuck to it, and I said 'well, look, if we can't have a conference, can't we have a questionnaire at least, do something or other to try and not let all this go?' Because we had to hurry, if we didn't do it within six months of the end of the trial, I reckoned that everything would have fallen apart. And so Tom agreed to that. He said, 'Well, you design a questionnaire and we will use it.' So I designed a questionnaire. Then Tom didn't like some parts of the questionnaire. I mean I had to invite the men to be critical, because if we didn't invite them to be critical, they wouldn't be. We didn't want lots of people writing in and saying how marvellous the MRC was. So I said things like 'did you ever feel that you were just being a guinea-pig?' I can't remember everything, but there were things like that. Tom didn't want that. He said to me 'we will pass it onto some other group of experts'. Well that was the last I ever heard of it, it never happened. It just died the death.

I think that speaks volumes for the MRC as a whole. They know perfectly well that they are having a difficult time recruiting people. On the HRT (hormone replacement therapy) study, no wonder that is a very difficult, very, very important study. It is disgraceful that we have been prescribing oestrogen for the menopause for 60 years still without a sound evidence base. I was a child when oestrogens began to be used on a big scale for HRT. It came with the birth of sulphonamides and effective antibacterial treatment, it's so old, yet in the whole of that time we haven't had a good evidence base for doing it. We've caused terrible damage, with oestrogens we were causing deep vein thrombosis and pulmonary embolism, through routine use of oestrogens post partum, routine use of oestrogens in all sorts of circumstances, now are obviously dangerous circumstances, so we certainly know that harm can be done, and that all this wishful thinking about positive effects on coronary heart disease doesn't have any secure basis. So it is a terribly important trial and is politically very important that we establish that it's wrong to work blindly through it for 60 years. It has been very profitable for the companies. If any group really must be taken on board as participants, it's menopausal women. But they are not. If we had a Labour government that was really a Labour government, this is the kind of thing that one would be able to discuss some serious political input into the MRC, to get the MRC to understand itself as a social agency.

AN: So going back to you, you did a year at the MRC unit and then you moved on to your own practice.

JTH: So then I looked for a practice in which it would be possible to do research, because at that time I thought I was not suited to research. Archie told me I was not suited to research, he said you have got to choose to be either an impartial observer or an activist and evangelist, that these are two different career paths, two different mentalities. I said I didn't think that was so, though I didn't say it with as much confidence as I would say it now. I did feel that I wasn't suited to being an epidemiologist and I still think that. I mean my maths isn't good enough and altogether I am in too much of a hurry about things. But I did think that I had a role to play in a research unit. I hadn't had any positive experience of research yet, at that time, it made me a bit less keen about it. But even then, my line with Archie was that he was wrong. I felt that there should be no such thing as completely inactive observers, nobody should do that. It's not a moral stance to be measuring things very well in a population, but not offering them better treatment. There is a tension between observing and doing for every clinician. Do you wait and get more information or do you act on the incomplete information you have? That is inherent in the job, it is a terrible tension,

and potentially disastrous, but there isn't any other way to go. So I think you don't avoid that dilemma by choosing one path or the other. The thoughtless, unthinking interventions that you get with a few surgeons, that is disastrous and total observers are disastrous. Anyhow, I thought if I developed a practice in the valleys somewhere, preferably in the Rhondda, that's where I was hoping to get it. I would develop a practice that was, so to speak, purpose built to be a research department, and then I thought Archie and Ian Higgins, Peter Elwood could come along and they would use my population. So I got Glyncoerrwg, which was an isolated population easily defined. I found gross pathology there, and a shambolic state of the practice. I couldn't contemplate any kind of research for at least five years, I had to shake things up and get it organized. So that was what I did.

About the third year I was there Peter Elwood had been doing haemoglobin studies on anaemia prevalence and so on. I had been very struck by each time I had taken over a new practice, in London and then in Glyncoerrwg, I found a clutch of women with really severe anaemia, haemoglobins of 3 or 4 grams, for whom it was a deliverance, you topped them up with iron and corrected it, and then the effect was fantastic, they looked so well. So I bought myself a haemoglobinometer, a proper one, well fairly proper, not like the MRC haemoglobinometer because I couldn't afford it. And I started systematically collecting data, aiming at eventually a 100 per cent coverage. After I had got about half way to that target, I went down to Richmond Road with it, and talked to Peter Elwood about it, hoping to get some help from him. He was very scathing about what I was doing, he obviously thought it was terrible half-arsed stuff, which it was. But he didn't seem to have any idea of the circumstances I was working in. He went on at me about whether I had weighed people's menstrual loss, whether I had collected sanitary towels and weighed them to assess their menstrual flow, (which we now know to be a grossly inaccurate way of measuring menstrual loss.) But the effect on me was just, I thought 'Oh Christ, you know, I think I deserve some Brownie points just for measuring the haemoglobin'. If I was measuring menstrual loss that's a different thing, but shoving that at me! I was really upset about it. And then, he said 'are you sure that your measuring instrument is accurate?' Well I hadn't done anything to it, I had just assumed that it was. When I did, I found that it was absolutely awful, and I didn't know whether it had always been awful from the beginning or whether it had become awful. So there was just no way I could depend on it. I had to throw away all the data. I lost everything. But it was a good elementary lesson, which I needed. I mean I had learnt all about this before, but you don't really learn it if you are not doing it, it has to be your own work. I was good at criticizing other people's work, but I needed to feel responsible myself for the failure, anyway that's how I learn.

About two years after that I began to be in a position to be able to do something. By then I realized that researchers who went on moaning about not having cooperative GPs, didn't really mean it. They wanted populations, but they didn't want what would have to go with the population, an *in situ* head of the clinical unit who would have a say in how the population was used. I didn't believe in giving epidemiologists a free hand with my population. 'My population' is a very paternalist expression, but, I am afraid that was the real situation. I thought patients were better off having me as a paternal guardian, than having nobody to defend them. I knew what these buggers get up to. I did not want my population ruined by somebody coming along with some project that left us with arid soil for subsequent projects. We needed a kind of crop rotation on studies, so the soil gradually got richer and richer. We needed to plan a series of projects, each of which would contribute to the next and so on. So that we had a bigger and bigger whole population database. And I found that whereas before I had felt very much inferior to my epidemiological colleagues, I gradually found that I was actually ahead of a lot of them on those sort of things. I understood the patients and they didn't. Then quite by chance, I found a lot of gross untreated or lapsed treated, very severe hypertension. I am talking about diastolic pressures of 120, 130, 140. That was an appalling mess. And I found that we were having an awful lot of early coronary disease in a population that shouldn't have been having it, because the orthodox teaching at that time was that the quintessential typical patient with coronary disease was a bank manager, or doctor, or whatever, and we didn't have any. Colliers at that time were doing very hard physical work. Though they smoked, they smoked less than most populations, partly because while they were on shift they couldn't smoke. They did chew tobacco (which has not been investigated by anybody as far as I know) so they were quite big nicotine addicts, but they weren't smoking. Yet it looked as though they had an awful lot of coronary disease. So I got hold of

the rawest data that you can get, the death rolls by Local Authority areas. None of these were published, published rates did not correspond to the actual social units in South Wales. Deaths by cause were only reported from much bigger areas, which mixed valley areas with vale areas. So I had to go back to unpublished data as it was received by the Registrar General. The Registrar General's Chief Medical Officer at that time was Abe Adelstein. He was a former South African, in that group that I was talking to you about earlier. He was a lovely man, a very enlightened liberal, socially minded medical statistician, and he really helped me. He did loads of work for me and sent me all these photocopies, without charging me anything. It was wonderful the way you could do things in those days. I wrote a paper, which was published in the College journal. I took death rates in three age groups, under 50, 50-64 and 65-plus and I categorized South Wales populations into three groups: the valleys, which really were the current coal-mining area, the Vale of Glamorgan coastal areas, and the coastal cities, (Port Talbot, Swansea, Cardiff, and Newport). There was a lovely step-wise progression. We had about 50 per cent higher coronary death rates in the under fifties in the valleys than in England, or the UK, and the coastal cities were more than England, and the Vale of Glamorgan was about the same as England. I looked at cancer of the lung deaths. They were just as I would have predicted, they were less in the valleys, so it didn't look as though it was smoking. There was a big thing going on then about hardness of water, and so we looked at that and there was no story. And I looked at stroke mortality, which showed the same pattern but with less disparity between these. At that time that really was unexpected and original, since then, everyone knows that poorer people get more coronary disease. It remains true that in poor countries, it's the rich people who get coronary disease, (I mean Third World poor countries), and in rich countries it's the poor people who get coronary disease. So there's still a complex story going on. Nobody paid any attention to this paper, because the College journal wasn't taken seriously by researchers, but I was terribly excited. The fact that you could actually discover something, you could find something new, it's lasted me all my life, it's intoxicating to actually think that you're on the leading edge, advancing into darkness, bringing light. It's wonderful and it was something that I suppose I thought that was going to happen when I first worked for the MRC with Archie, but the reality had been a terrible disappointment. My son Ben now is working in the East End, and is beginning to do research. He's very browned off with academic medicine and academic research, and I can see he feels exactly the same as I did when I was at the PRU, that it was boring activity, carried out by boring people, and this was no way to spend your life. But he hasn't had this feeling yet of finding something that wasn't known, but a lot of that was luck. I didn't have any help to speak of from anyone at PRU, but I did have help from Hubert Campbell, a medical statistician at Cardiff University, who is a lovely man, very reactionary, big Catholic, very much opposed to most of my ideas. I applied Pickering's St Mary's study to my installation, I got everybody's blood pressure and did the measurements properly, using a random zero machine, and published that in *The Lancet*. That was the first whole population as it lived and worked that ever had everybody's blood pressure recorded in the world as far as I know. That made me suddenly respectable. I tried to persuade my local postgraduate medical centre at Neath Hospital, to invite Jerry Morris down to speak to the doctors about the epidemiology of coronary disease, so I suggested that we get my own hero. He couldn't come down, so he sent his second in command, Tom Meade. Tom came down, having just left Jerry Morris's unit and was just about to set up this new MRC unit, at Northwick Park. He talked to us about the epidemiology of coronary heart disease, I drove him back to the station. We had plenty of time, so I told him the story about how disappointed I had been, that I had wanted originally not to do research myself, but to provide a population for other people to do it, but that I still thought that what we needed was a network of general practices throughout the UK that were of that nature, that is that the clinicians should be epidemiologically minded, but not be themselves statisticians or designers of trials and so on, and that people like him should come along and use those populations, but with real respect for the clinicians, which we had not really had from Archie. He was on that wavelength. I think it was about 1972, and at that time suddenly money had become available for that kind of project. It was partly I think that the MRC had gone on for such a long time with a sacred rule that they didn't do work in general practice, it was because general practice was such an Augean stable, and they didn't think an Augean stable was a good place to do research. They had suddenly realized I think that that was a silly rule, and Tom was starting a new unit and wanted to be different. At that time we thought that if our practice was taken on that way, it would be the forerunner of lots of other similar research practices, that was the original idea. In fact it was what later became the GPRF idea, but the GPRF idea with much more participant GPs.

Some of the doctors in the GPRF were very much involved, but most of them were not very much involved. Anyway, he said 'I think it's a good idea'. And so he implemented it. He provided us with a registrar whose job it was a mixture of helping out in the practice to give me more time so that I could give some time to research, and learning research techniques themselves in the field. The snag was that they were going to be very badly paid compared with their coevals in hospitals, because they weren't having any overtime. Graham Watt worked it out that in the two years that he worked for us he lost about £5000 in earnings, and this was in 1982 or '83, so it was a lot of money. So we were operating against that gradient and actually for the first year I couldn't recruit anybody. But from then on we always had somebody, though sometimes not the kind of people that we wanted, but from then our group was an augmented team from the MRC, and later from the fact that I became a trainer, we had a trainee, as well as a registrar. Altogether we had a lot of hands on deck.

AN: It's interesting. So you ended having a working relationship with an MRC unit in London, that was the epidemiology unit, and very little [to do] with the one that was over the hill.

JTH: Well I always had the impression from Peter Elwood that he felt that I was competing with him. I think it is partly because, Archie went on and on, he never gave up. After he retired he still came in to the Cardiff MRC unit all the time. I think that was a very bad thing for Peter. Archie had behaved to me in many ways as though I was a sort of son that he had never had, and I think Peter Elwood for a long time was afraid that I might be coming back again. Anyway I just got the feeling that he was a bit fraught. The other thing that must have been a problem, he was a Seventh-Day Adventist [Plymouth Brethren]. I don't think he allowed this to interfere with his work, but I couldn't forget that he was a Seventh-Day Adventist. It was a pretty bizarre thing to be, and from his point of view I was a former communist and a Marxist, which was also pretty difficult for him. And I certainly did allow that to interfere with my work, I regarded that as an asset for my work, so it contaminated all my work. We weren't obvious bed fellows. And this spat I had with him when he accused me of not having collected sanitary towels, did really rankle with me. I felt that he was very unfair in his expectations. I think in fact he was just defensive. So it never really worked out.

I had an invitation to apply for the Chair in General Practice, at Cardiff. Previously there had been no Chair in General Practice at Cardiff Medical School, there was a Senior Registrar in General Practice, Robert [Harvard] Davies. He was one of the very few people that I know who was able to make primary care a fearfully boring subject. In British medical schools I think without any other exception, the department of general practice is the most popular among students, and epidemiology, or public health, is the least popular. Considering that the two ought to be overlapping and converging specialities, it is ironic that should be the case. But he managed to make general practice boring and when they made it into a Chair, he naturally was the primary candidate. In desperation the then Professor of Medicine, William Asscher, invited me to apply for it. I was only willing to consider it if I could keep the Glyncorrwg practice, which was not easy, because it's about an hour away by car. When I visited the unit and was taken round it by Robert, I realized that if I was appointed, he would still be there. We then decided privately, Mary and I, that I wasn't going to apply for it because we didn't think it would work out, but I didn't tell him that. Then he sat us down just before leaving and said, with his stammer, 'of ccccourse Julian you do know that there will be two posts of senior leccccturer, which will be my ggggggift'. Silence. I thought well this seems a pretty clear indication, I said 'well that would be a very attractive proposal, it doesn't bother me whether I am called professor or not'. And obviously Robert was going to be a lot happier if he was professor than if I was professor. So I said 'yeah that's OK, do that'. So we departed on that positive note. Then about a year later when these posts actually were created, it turned out that they entailed working full-time as a GP in the practice in Llanedeyrn in Cardiff not in Glyncorrwg, as usual to raise money for the department, because the department was funded through the NHS earnings. So he had swindled me, but I didn't really want to go anyway and it's great that I didn't go.

There are other reasons why that happened. In general what happened to me all my working life was that I always had some friends at court. The fact that I knew people who were at the centre of things like Richard Doll was important. Occasionally they may have influenced things in my favour, but much more important was it gave me enormous confidence to do things. But I found that the further away people

were, the more supportive they were. So although I would know the Presidents of the Royal College of Physicians and be on friendly terms with people like them, the closer I came to home the less friendly people were, and most of my local hospital consultants were frankly hostile, I only met one or two real friendly sorts there. Most seemed very threatened. I think the whole point about epidemiology is that because it actually applies science, scientific observation to everyday reality, it is very threatening to people who want life to be lived with a reasonable amount of concealment and privacy, letting people pick their noses and do other unpermitted things without being exposed. That's the way most things are done most of the time and that includes medicine. I don't think epidemiology is saying at all that if what you find, if the reality you find is intolerable, that you immediately denounce it as being illegal and so on. That mustn't happen, because that is the world, there is no other world, and whenever you look at things with an epidemiological eye what you first find is a shambles. It really is awful, nothing is functioning at anything like the level we were taught in our medical schools. I was taught perfection, that nothing short of perfection was tolerable. If you found something short of perfection, you got out of it as quickly as you could, to get to somewhere where things were perfect. But actually there was no such place, of course, so what they really meant was that in places nearer to the gap between perfection and reality was made up with hypocrisy. One of the loveliest things I ever saw was a paper by Colin Dollery at Hammersmith who was, in general, much disliked by his contemporaries and colleagues. He has an awful manner and was famous, when I was at Hammersmith, for kicking out rungs as he rose up the ladder. He was a very ruthlessly ambitious person, but he published this paper about his department, his hypertension unit, which included data about what proportion of people attending the department for follow-up of hypertension had their blood pressures measured, and this included the proportion who did not have their blood pressure measured. Now you would think that every time patients went to a hypertension clinic somebody would measure their blood pressure. But that 6 or 8 per cent or something didn't have their blood pressure measured, and he published that. I thought that was bloody marvellous, because that is really what you find, if you arrive without notice, I did a locum at the National Heart Hospital, and some elements of the National Heart Hospital were a bloody shambles. There was a pile that high [gesticulates] of discharge reports, going back for six or eight months. GPs had never had a discharge letter and going through those things, some of those patients I couldn't make out why they had come into hospital, what the hell had been done, what conclusion had been reached, you couldn't work it out. And what could you do? Well write in the discharge letter that it is terrible.

MT: Probably wouldn't happen now.

JTH: Yes, but I bet people were saying that then too. I mean there is some equivalent. Look what are the newspapers full of now? Suddenly people are discovering, that all these things have been going on all along. I mean I am not saying that [Harold] Shipman has been, but if you run a project, an organization, in this ropey kind of way, then of course you will get ghastly mistakes. What's suddenly happening is that we are being made responsible for all our mistakes and they are talking about us as though we were failed engineers, as though we had built a bridge, which fell down. I think it's in the nature of epidemiology that it is an extremely threatening subject, so it operates with one hand tied behind its back, it voluntarily averts its eyes from all sorts of things that cannot really be looked at honestly without taking some action. If you look at it, and if you measure it, then you have to do something about it. You don't have to do something about it in the sense of transforming the situation today, or even within the next year, but you have got to have a plan to make things different, and not everybody going into epidemiology goes into it with that social and political commitment. Most of them are going into it thinking research is fun, it's interesting, it's nice, but they are not really crusading. It is a crusading subject, that's what it is, and your local consultants in your nearby hospital don't want crusaders, they want reasonable people, and preferably far, far away in London or New York or something like that. I have supporters all over the world, who are a long, long way off. If I make waves, they never reach them. And there was a sentimental aspect to it, they wanted to have a GP somewhere who was being what they called a real doctor, you know this all-round, doing everything in a population, including public health and research, because it's a lovely idea. But it is an absurd idea, it's actually obsolete, it's one-man doing everything, it's ridiculous. I pandered to that to some extent, because that was the way to get support and to get money and avoid being crushed, but I don't believe in it. I think the future lies in teamwork, in large organizations, in multi-centred trials. We

had terrible problems in Glyncoerrwg from having too small a population and the temptation to argue too much from virtually anecdotal cases. You can argue a lot from anecdotal cases, I am not against it, but you know what I mean. The possibilities with the GPRF, or with something like the whole Cynon Valley population, are simply tremendous. That's what we want, we need a whole health service that's geared to using routinely collected data for research. It should be of high enough quality. One of the first questions I met was why is it important to have one obsessively accurate measurement on 10,000 people for Cochrane's studies, but not important to have obsessively accurate measurements for 1,000 observations on one person for improved personal care. Not for 1,000 observations, for one or two observations, measuring blood pressure for one person, should be obsessively accurate. Measuring it for 10,000 people you can afford to do it in quite a rough-and-ready Framingham sort of way and you will still get the right answer, but you won't for an individual person. And don't tell me it has changed. Mary went and had her blood pressure recorded this morning, 130 over 90 was it? Well that is rubbish – 0 digit preference and readings to plus or minus 10.

AN: Can I ask you Mary a bit about what you remember about the epidemiology unit, because I don't think your memories are particularly warm.

MT: Well first of all I was inconsequential in what I was doing there. First of all I was only going there as a temporary worker in the Rhondda Fach study between two other plans that I had. And I stayed for a year and a half, I can't remember, it wasn't that long. Probably two years. It was not a happy place to work if you weren't in the scientific staff room. I don't know how happy it was in the scientific staff room, but it was terrible, infighting, backbiting, you know professional jealousies, I presume they were professional jealousies. I was very much younger than I am now, I was an innocent in most of that. It taught me a lot though. Archie was very nice to me, good to me. I was in the peace movement at the time and he defended me when the personnel manager wanted to get rid of me, because I was arrested in London, and was back a couple of days late for work. Mr Cory was quite ready to say that my services were to be dispensed with, but Archie wouldn't have that and he said 'oh just leave it to me, there's no question'. And there was no more heard of it, and there wasn't. We were extremely badly paid, very badly paid, so badly paid that that's the real reason that I left frankly. I just was not making ends meet, transport costs, and living costs. I was alright while we were in the Rhondda Fach when we were getting, you know what do you call it? Overnight subsistence. When we were out surveying. Most of the time we were on the survey, but when we were back in Llandough or in Cardiff in Richmond Road, then the money was absolutely pitiful. And I just couldn't afford to live. And Archie was so generous, because he was a rich man, I mean the rumours were going around all the time, that he was paying for so and so's house and paying for this and paying for that, and I just didn't want to be part of that. I did tell him that I couldn't afford to stay there. I learnt all the skills of fieldwork in Rhondda with Fred Moore and the team, the obsessional nature of data collection, I will be eternally grateful. I'm grateful for those skills that I learnt and have never forgotten. I didn't realize, I didn't know anything about research in those days.

AN: So where were you from originally?

MT: I am from near Porthcawl. My parents had a caravan site, so the valley people came to the caravan site and I did know valley people and that was fine. But I had never been to the valleys to live, it was like going with a passport somewhere, but I really enjoyed it, I must admit. And we did all work hard together. But I can't remember anybody being a sort of team leader. I mean Fred Moore was ostensibly the team leader, and you went to Fred who was the oracle about everything. You know Fred knew everything, and if he didn't know it, he would say he knew it. I am sure he was a wonderful person for Archie to have around, I am sure he was wonderful, but Archie didn't have a team leader. And subsequently I worked, after getting married to Julian, I started work doing all the nitty gritty around the practice, for nothing. Well then I got taken on just to do that little bit of survey work for Tom Meade in Northwick Park about early morning urines and genetic testing wasn't it? That was my first foray going into being at people's doors when they got up early in the morning, to collect their urines within twenty minutes. I was getting up at four or something like that for the men who were on the five o'clock shift. So that was my first foray. I kept them in the freezer. Once a week I went.

JTH: You had to go to Pontypridd. You had to go down there to make carbon dioxide snow. Pontypridd wasn't it?

MT: That was different.

JTH: Oh that was the shit wasn't it? You have forgotten. It was collecting urine first and then the shit.

MT: No it wasn't. Going to Pontypridd in the morning, that was four or five so that I would be ready with carbon dioxide at nine. So my first survey alone was that one.

JTH: No that was Richard, what was his name?

MT: Richard Watts.

JTH: But typically he used our practice. I did virtually no work on that at all, she really worked her guts out. All men were working on shifts in those days and you had to be there whatever shift they worked, and as you say getting up at four o'clock in the morning.

MT: But it was the afternoon shifts as well. I always worked part-time, because of the range of time, well you know yourself, is so awful, that to combine that work with being a mother and a GP's wife where it was pre-digital phones and all that sort of answering machines, where I had to be at home in the afternoon to answer the phone, it was very, very difficult, very hard work.

JTH: But the point we were making is that when he published it, there was my name in there as a co-author, and I had contributed nothing.

MT: I had done all the work.

JTH: And Mary's work he didn't even acknowledge it in the paper, he didn't even say thank you. So we were talking earlier about having people's names on the published papers, the ones who had really done the work.

MT: Well we did say bloody hell, typical, because it was a hard job. I think it was one of our test beds.

JTH: Because we got a very, very high response and Tom was able to show the MRC that he could get a much higher response rate with us than they would somewhere else. He sold the idea of taking on our practice as a permanent feature, it was sold to the MRC on the basis of that.

MT: But I also think that it won the respect of the patients, that we did excellent work, at funny times, and of course they all knew, they had children, and you had to balance things finely. But I learnt all those techniques in the Rhondda in that very short time. The exceptional nature of what you do. I suppose I was still like that at the end really, but I must admit at the end when I retired, I think you do reach burnout and I did not want to see a door knob again, I don't want to knock on anybody's door. I have done enough. I had done enough knocking on doors and exhorting people and having to go for a high response rate, which you are responsible to do. You get so you don't want to ask them again, have they changed their mind and things like that, or looking for the people we knew were hiding from us, because you knew everything about everything. It was very worthwhile, but I know that when I had finished I had done enough knocking at doors. But I do think, we had, I hope we had, a very healthy team atmosphere, it was one of the things I learnt in the MRC, is that there should be no backbiting, none of that, we didn't allow it, I didn't allow it and I suppose it's one of the management things I learnt.

JTH: Well we kept the place going. All our staff knew that we were getting the most pay that we could for them, and there wasn't a rivalry over earnings. At the MRC at Archie's unit, he recruited ex-miners or local

people anyway, and whenever I was on my own with one of them they would start talking about pay differentials and I had never had any idea that relatively small differences in money were so important to people, if they are made to be important. That was really unpleasant. Archie may not have realized that he was doing it, but he kept control over people because he was the one who could always bail them out. Some of them accepted bailing out and some didn't, but actually the ones that did and the ones that didn't hated each other. It really was nasty. The relevance of all this now is purely that the circumstances of recruiting people to trials now, and keeping them in trials are quite different than they were then. What we are asking people to do nowadays is actually much more than what we asked people to do in those days. It's much more potentially threatening and much more complicated and involves a lot more active participation than anything that we asked people to do. Perhaps this subject is discussed and there are publications about it of which I am not aware, but in general I am amazed that so little attention appears to be paid to this. The big companies must discuss this, and where do the hell they think they are going? Where are the future trial participants going to come from? Those companies that don't really care about this kind of research, who are quite willing to sell their products without knowing whether they really do harm or not are irrelevant to this discussion, because in the long run even the worst companies know perfectly well that they have got to deliver something, but a lot of what we have been talking about rides on the back of penicillin. It was because penicillin swept all before it, it changed the world, several generations of doctors and researchers have just sailed along on that wave of good will. If you read what people wrote about doctors in the 1920s, before all this, or even earlier, before insulin and so on, they were scathing about them, they expected virtually nothing from doctors and that was what they got. Now it's a much, much more fraught environment for researchers and I think they really do need to start talking about how they are going to shape up populations. The issue of whether you pay people to take part in research is very, very important. What was said at that meeting about the half a crown for participating miners, was actually true. I didn't know it was then, but I have looked it all up since then, but the inference he drew from it was not true. The argument of the miners' union was that if any men were paid to participate, then all men should be paid to participate, because that was always the attitude of the union, and in fact this half crown it was something to do with defrayment of expenses and so on. But the principle that for participants in research, it should be a voluntary act and should be unpaid, is very, very important. I think the moment people start doing something for a living, whether it is giving blood, or taking part in research or whatever, you introduce yet another source of corruption of data, it is unpredictable and destructive. I don't have documentation on it, but apparently in America it is now very difficult to get research subjects without paying them. It has certainly become very difficult to get students to participate in research without paying them. Well the salt studies that they were doing in Birmingham, the students, when we were doing our salt studies, I remember having a discussion with them about this, they all thought that it was incredible that we could get people without paying. It is horrible having a low-salt diet. Graham MacGregor insisted that everyone was absolutely delighted with his low-salt diets at Charing Cross, and all came back for more, but we never found such people. We in our family tolerated it for a week, because we felt it was important to have some experience of it, our patients had to do it for eight bloody weeks. It was dreadful. The only people you could imagine who would like it, would be those that didn't appreciate food at all. And you know such people do exist. But I do think we need some kind of conference about this topic of how do you recruit and how do you retain participants in research, we could get some people who were participants in our trials probably to come along to that kind of thing, and get an all-round discussion of it.

MT: They are dying off.

JTH: Yes they are. But it's precious material this and it involves a whole question of making the whole population scientifically literate, which is eventually a realizable objective. I was just listening to the wireless this morning, they were talking about getting a higher proportion of young people to stay on after school for higher education and how you do it. Well it was interesting there was a spokesman for the employers, at least as far as I could make out that's what he was, he was the one that was not satisfied with anything, saying that a lot of people doing university courses, things like cinema studies and things like that, and that wasn't what employers wanted, and that employers didn't see things getting better, they thought they were getting even worse, but all the time he is talking about a specification for human beings

that is suitable for employers. What they want. We know what they want. They want infinitely elastic people who will be rocket scientists if that's what they want, but on the other hand if they suddenly decide 'oh no we are not building rockets any more, we don't need you guys', then they just drop them and they will go off and be happy and they will read Shakespeare or something to occupy the time. Well people aren't like that. And it's the same thing with these research subjects: we are not really saying we just want the use of you for a while and then we will stop paying you or we will drop you. If they come in at all, they will actually participate, they will bring their ideas, they will bring their bodies for the experiments and so on, but that's the least of it. We must treat them like that and it will entail a completely different frame of mind than the Cochrane era and my era was completely paternalistic.

MT: Both paternalistic and arrogant.

JTH: Of course it was arrogant and the only thing that can be said in its defence is that there wasn't anything else, that the patients actually cast you in that role even if you didn't want it. The real choice in those days was between a benevolent paternalist and somebody who just used people as though they were laboratory animals. Archie was not guilty of that and nor was I, but what he did isn't the future. The future will be much, much more participative and far more equal. That does need to be discussed and it has got to be discussed in terms of the logistics, we have got to get some figures into it, about what is this actually going to mean. Particularly the exclusion of paying people is a really important decision in principle. You know there has been a lot of abstract discussion about whether people should or should not lose Brownie points for being smokers or whatever, it's nonsense. That kind of discussion leads nowhere, and shouldn't take place, but the other way round, that is to say to people, 'look if you are benefitting from research, then you do have a duty to contribute to it,' I think that is reasonable. If you have a National Health Service that is free to everybody, then everybody should support it. Really I think it is something whose time has come and it has got to happen. And it could also be a way to get the MRC to become more socially conscious, the very fact that the MRC has resisted doing this so long, may mean that when they accept it, there'll be a chance to begin to pull the MRC forward a bit. It's been a patrician, gentlemen's organization.

MT: And I think you know it wasn't easy. We did mostly, as time went round, not in the beginning, but certainly in the end, we did have our village meetings to launch every new project. We did give feedback, but we had to remind ourselves, you know at the end of a session, you are tired, you work all the time, you are doing all sorts of things, you have been given the next thing to start. You have to remember that you have to be there and available, not to just give the personal feedback to patients, but to give general feedback because those who didn't take part, because they were against it, have a right to come in and look. You have to give that general feedback. When we did the salt work we always asked the wives, they weren't going to be patients, but we asked them in so that they knew what the philosophy was and I think that families should be involved in that initial giving over of what was scientific reasoning for the trial.

AN: Thank you both very much.

[END OF TRANSCRIPT]

Further related resources:

1. Ness A R, Reynolds L A, Tansey, E M (eds) (2002) *Population-Based Research in South Wales: The MRC Pneumoconiosis Research Unit and the MRC Epidemiology Unit* Wellcome Witnesses to Twentieth Century Medicine, vol. 13. London: The Wellcome Trust Centre for the History of Medicine at UCL.
2. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Bainton, David: transcript of an audio interview (11-Jul-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017044. London: Queen Mary University of London.
3. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Elwood, Peter: transcript of an audio interview (14-Apr-2000; 28-Feb-2001)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017045. London: Queen Mary University of London.

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5. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Hughes, Janie: transcript of an audio interview (28-Mar-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017047. London: Queen Mary University of London.
6. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Jones, Marion: transcript of an audio interview (10-May-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017048. London: Queen Mary University of London.
7. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Kilpatrick, Stewart: transcript of an audio interview (23-May-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017049. London: Queen Mary University of London.
8. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Miall, William: transcript of an audio interview (13-Aug-2001)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017050. London: Queen Mary University of London.
9. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *St Leger, Selwyn: transcript of an audio interview (27-Jul-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017051. London: Queen Mary University of London.
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11. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Waters, Estlin: transcript of an audio interview (14-Jul-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017054. London: Queen Mary University of London.
12. Ness A R (intvr); Tansey E M, Thomas H (eds) (2017) *Yarnell, John: transcript of an audio interview (18-Apr-2000)*. History of Modern Biomedicine Interviews (Digital Collection), item e2017055. London: Queen Mary University of London.