

Alex Clarke Keynote Address

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Diana Harcourt: Right good morning everyone. I'm now going to pass you over to Nicky Rumsey who is the other co-director of The Centre for Appearance Research and Nicky is going to introduce this morning's keynote speaker Professor Alex Clarke.

Nichola Rumsey: Thank you. It gives me great pleasure to introduce to you Alex, it's also been great fun finding out a bit more about her. I thought I knew quite a lot about Alex but its amazing what you find when you dig, so here's some of the digging. It's all nice honestly. Alex started her professional life by training as a nurse, but during her training she realised she was more interested in the way her patients thought than she was, in terms of replacing their bandages at their next dressing change. So the day after she qualified as a nurse she enrolled at university to study psychology with the view to becoming a researcher. There is something about Alex though that you will see if you know her well, which is at the heart of her is a clinician, she is part research part clinician, and during her studies of psychology the clinician won out and she decided to train as a clinical psychologist. Her first job was at The Royal Free Hospital in Hampstead, London, and she went to work with Marie Johnston, who I guess is considered to be the mother of Health Psychology in the UK, and a formidable person to work with, so as a first appointment as a clinical psychologist that must have been quite something. I spoke to Marie and said I was going to introduce Alex, so Alex is now looking really worried, Marie told me that Alex and she wanted to set up a joint academic and NHS department at The Royal Free Hospital in London and that which they succeeded in doing and that was way ahead of its time. I think as a mark of Alex as both a clinician and a researcher she made her stamp on Health and Clinical Psychology very early on.

Alex took some time out from her career to raise her family but when she came back to the working arena, those of us working in the field of visible difference were very fortunate that she decided to focus her interests in this area and she took a key role at the charity Changing Faces which at that time was still quite young and when she was there she developed the basis of their intervention programme and she was very influential in doing that. Alex has now gone full circle and is back at The Royal Free in Hampstead and she is the Consultant Clinical Psychologist and Head of Psychological Services there. She is also a Visiting Professor at UWE so again the clinician and the research hold sway. So in terms of wondering how best to introduce you to Alex and her wealth of experience I decide to pick on four of her attributes I admire the most, there are lots but I have pick four for you.

So firstly and probably most importantly I guess, Alex for me, is the ideal of a practitioner researcher, not only is she an excellent and very intuitive clinician she is very committed to research and the evidence base of what she does. I really admire Alex because she enjoys writing and this is a complete anathema to me, I find writing very hard, but her CV is testament to her eloquence in writing and the extent of her wisdom. The second attribute is Alex is unfailingly generous with this wisdom. She is a fantastic collaborator. For her it is much more important that the well-being and treatment of patients are improved than it is for her to take the credit for any of that improvement.

But often a lot of the credit should go to her, she is really generous in her collaborative efforts and gives people ideas and encouragement all the time.

Thirdly I have to admire that Alex's particular ability to rein in and shape the behaviour of powerful men in particular but women as well. Marie was the first probably but two come to mind particularly, one – I love him dearly so don't take this the wrong way, James Partridge the Chief Executive of Changing Faces has needed a bit of shaping and direction over the years and Alex has been fantastic at doing that and was really influential in the direction that the charity went in. The second has to be Peter Butler, I'll take advantage that he is not here to get cross, but he's the Head of the Face transplant Team at the Royal Free, and Alex has been very influential in shaping the direction that that team has taken and raising the profile of psychology there. And lastly Marie Johnston still remembers that in response to an evaluation of Alex's teaching the most memorable response was 'I like her dress', there wasn't anything about the teaching. But Alex does always manage to always look the part. She has a wardrobe of well cut, stylish, outwardly conventional trouser suits that we all envy. But the magic thing about Alex is you need to check out her shoes. She has a fantastic weakness for shoes and her shoes are completely awesome. I have been in several tense and difficult meetings with Alex over the years, not because of Alex but we've been in a situation where we have been trying to ram a point home and if ever I find the heat rising and myself getting a little irritated I bend down to get something out of my handbag and check out Alex's shoes under the table because I know I'll smile and when I come up from that I will all be fine.

So it's both a pleasure and an honour to introduce Professor Alex Clarke as our keynote today. She is the psychologist's psychologist. She is the quintessential practitioner-researcher, with awesome shoes. Thank you.

Alex Clarke: Well I never knew she did that, it's amazing what you find out. Well actually it's a strategy, so at conferences people can say 'she's the one in the red shoes' and they don't have to say 'well she's quite old and she a little bit over weight' and all of those kinds of things, I commend that to you as an alternative.

So, I feel a tremendous imposter really standing here, a member of the team at CAR, talking to all you who are doing research and thinking about how the two things connect. Nicky is right over the years, I suppose I've just been nosey really or had tremendous curiosity, I think of myself as a clinician, but a clinician who is always asking why. Why does this work? What is the problem? How can we use the information we get from one setting so we can learn more so we can treat other people? So that's where it all comes from originally.

I haven't got a list of people to thank, because I was frightened to death I would lose some people and leave people off. But Nicky and Di at CAR, are at the back of everything I do and particularly the other person I want to pick out is Esther, who is here, Esther Hansen who is my buddy and calm co-worker at The Royal Free. So many many thanks to Esther for a lot of the ideas and a lot of things that we are doing.

So what are the aims, what do I want to talk about today? Well, obviously I'm a clinical psychologist so I want to focus on intervention. I want to think about the challenges and opportunities of the clinical setting, really I want to think about particularly how do we work with our colleagues. You will see later that I have got some illustrations of thinking about how we work with our surgical

companions particularly and that's a new direction and idea of how I'm think. I want to think about how we integrate research in clinical practice. I want to ask what we have achieved, where we have got to, and what are the next challenges.

Now, in thinking about this, obviously when you're putting together a presentation like this I wanted to produce some illustrations to break up the talk to think about illustrate the point I'm making with some visual slides. Great drama when I set out to try and do this as I discovered that most of my images I have shamelessly stolen from other people, and most of the people are sitting in this room. So I thought what can I do instead, and I thought let me have a look and see if I can think about some of the referrals we get in our clinical practise, and see if some of the points I want to make are illustrated in the referrals that we make to each other. Some of them of course when I sat down to read them were very very funny. But that is partly because things go off, I should say just to kind of protect when you see some of these things, that our work it goes off to India digitally and it's typed and it comes back and it sometimes gathers things in translation that would not be ideal, and it isn't necessarily representative of what people send them. But it also, as I went through these things, found that it told me quite a lot about communication and quite a lot of things that we needed to change. So, here's a good example 'would it be possible for you to see this gentleman in your clinic at some point, I have no idea what you do in your clinic, but I generally think it supposed to be a good thing' I'd like to think that there was a letter that came with this perhaps that told be a little bit more. But that's quite often the basis of what we have to work on. This is the masterly first sentence tells you so much more than you really need to know, absolutely clear what the problem is here. Right the way through to some that I perhaps have, the poor Royal Free and what goes on in terms of communication Wouldn't you just love to be a fly on the wall.... But I like to think that actually it's, no, we do better than that on the whole. So from time to time I'll illustrate what I'm doing by giving you an example of a referral letters.

So as Nicky said, I seem to have bookended my life by starting at The Royal Free and finishing at The Royal Free, been working in this particular field as a clinician for fifteen years. First of all in a community setting with Changing Faces, latterly in the NHS at The Royal Free, setting up an embedded service, so putting psychology into a plastic surgery setting, and all the way through as an honorary member of CAR, and that's been tremendous because that's been a way of really backing up what we've been doing with research and for young researchers sitting here what I would say is that is finding a team to work with, one of the real barriers I think to trying to do research which isn't always straight forward particularly when you've got a busy clinical job, is to find the team, don't try and do things on your own, its much better to do it in groups. To take that joint expertise, to build on the strengths of the team, there will be someone in the team that is good at the bits that you're not particularly good at, you are if you are lucky there someone that like writing, someone who like data collect, much better to work in teams. It's been so fruitful working with this group down in CAR, as well as some other collaboration up at The Royal Free and UCL.

So let's start with Changing Faces, this started for me by opening the Guardian and reading an advert and it said Changing Faces were looking for someone to come in and work in social skills, and that was appealing and I went and met James Partridge and that's where it started, at a time when Changing Faces was literally two or three of us working out of Cowper Street. Hardly any equipment, I think James just had a laptop on an orange box at one point. I came in slightly after that, but right from the beginning I worked with Changes Faces and that was a tremendous opportunity and really

when I look back at what we were doing then now in some ways I realise I am trying to get back to some of those models through the work at the NHS and I'll tell you more about that.

First of all we were able to pick up the phone and speak to people about the things that concerned them right from the outset. So we were really able to explore the information needs including relatives and health professionals and it's tremendous when I think we had an outcome slip, so when we had been speaking to people we filled in just a sort of summary of their address, what we had done and just a sort of contact for our database and one of those boxes said cause of the problem, the condition and actually you'd often get to the phone call or get to the end of what you had been doing with people and you would realise you had not found out what had caused it, you didn't know what the source of a disfigurement condition was because you had been working right from the outset with somebody about what the impact was, about the difficulty they had from the psychological perspective and that contrasts so vastly with what we are doing in the NHS now where we tend to be a tertiary referral right down the line, so people are getting into psychology long after their concern has been framed in terms of a surgical solution, and I really miss that opportunity to work with a psychological formulation from the outset. It's interesting how much people's information needs were framed in terms of what can I do about this, how can I manage this. It was not about looking for more details for the condition it was looking for exactly those sorts of things, about help actually developing and coping with their condition.

At Changing Faces we began to think about the ways in which we were intervening so the beginnings of thinking about what an intervention looked like, I think we can think about that now in terms of what I think you could call a 'target stressors' approach pulling together the commonalities of these sorts of things that people find in difficulty and working out ways in helping people manage them, based really around the fear avoidance model. So it was a very behavioural way of working in those days. But the useful thing about framing that model and setting that out was it also made it very clear what we weren't doing. And it meant that you could incorporate into the organisation a delivery of clinical services, people who weren't necessarily skilled psychologists, some people working there had their own experience of a disfiguring condition and some people had some counselling skills. We were all if you like a range of training and experience, but there was a role for everybody involved in framing this model and putting it there. It was the beginning of a stepped-care approach because once we got this model and we were running it with people we were thinking much more about how we can deliver this more remotely, how we can train health professionals, how other people may be able to develop this kind of working. Ten years ago one of the things I was thinking about head and neck surgery and thinking about how I might resource clinical nurses specialists to deliver the kinds of interventions that I was doing. What I found was that while nurses were not very confident about what they could do, they very much recognised they were in the place, in the setting where they could achieve a lot with a bit of training, and we put together some days where we would use some resources they could use and some training days where those nurses went back to their patients. Then we measured in the patient group the impact of them putting in place the kinds of interventions that we had developed with positive benefits for patients so there we are the beginning of a stepped care approach to how we deliver these things. This was also the beginning of the collaboration with CAR on one of our early research papers which was the audit study which I did with Nicky and the team here at CAR then looking at the prevalence of concerns about disfiguring conditions in clinics in London and in Bristol.

Here is the model which we published in 1999 here, which as you can see now looks very basic, very behavioural, just the very beginning of trying to describe what we are doing in terms of people feelings, we are acknowledging legitimacy of concerns so we are just providing a framework for a more focus approach think about beliefs and behaviours. Very basic target stressors, managing stares, managing coping and questions. It was interesting talking to Michelle yesterday, who is still using some of the booklets that we developed right the way back then at Changing Faces, which was around managing other people's reactions.

As I say, if I summarise the great advantage of working there in the community setting it was being able to think about the biomedical approaches or able to think about a psychosocial approach rather and trying to frame the difference between a biomedical approach and thinking much more about psychological approaches which aim to reduce the impact of altered appearance rather than appearance its self, by modifying cognitions and behaviour. Now that seems, that distinction seems very obvious to psychologists, but it's a very difficult thing for other people to grasp. It's the basis of actually beginning to work somebody clinically, it's the basis of explaining what you are doing to medical professionals. One of the ways in which I have tried to think about this is to draw that out in diagrammatic form. So we have got here then is just a simple grid where we put objective appearance along the horizontal axis and we are moving from the far left from where we call an appearance unremarkable, so that's most of us, up to an altered and more unusual appearance up to the right hand side of the axis, and we put on the other axis if you like our psychological dimension so it may be distress it may be worry. It might be as I say a psychological dimension, the response or impact of visible difference. The stars represent people in different places on this grid. So star 'A' is someone who is very typical of the people who come through into the clinic, so someone with an appearance that is very unusual differs from if you like from the normative point but is also very distressed or worried about their appearance, and the goal if you're working surgically with someone is to move them down this horizontal axis, is to move them towards the left hand pole but with the implication by doing so you also move them down the vertical axis. It isn't just a movement in terms of just aesthetics as its own end point or its own goal its because it has an impact on how we feel and how we think about ourselves. It is about us moving down that vertical axis. If you think about at patient at point 'C' then they are not someone very different in terms of their appearance but their stress around appearance is very high. So I would say in that sense the real aim of treatment is to work immediately down that vertical axis to drop them down so they are less distressed. I think patient 'C' is the person people have been talking about in earlier presentations here at this conference where surgeons have made a significant difference but someone is still not very happy with their appearance because we haven't had an impact, we haven't dealt with the psychological side. And if you look at 'B' then, 'B' is James Partridge, James or Simon Weston or any of the people whose appearance is objectively different from the norm but are absolutely fine in terms of their psychological functioning. So that's actually I think a good way of just drawing out and working and plotting where you think an individual patient sits and talking about goals of treatment, intervention and just thinking about where we are trying to get to, for both surgeons and psychologists the direction of travel is down to that end point. And sometimes we do it surgically and sometimes psychologically, more and more often we work together to do it between us.

Levels of intervention then, again I am thinking about working at Changing Faces, what was nice about working at Changing Faces was that we were not only working at the individual level, we were

working in this red circle here on terms of individual and life style factors, but thinking about social and community networks, thinking about going out and influencing health services and working much more across this great society dimension and that's work that Changing Faces has gone on and on doing and is so active and so effective in doing. Do you know it is interesting there was a time when I worked there when I would start off by describing what Changing Faces was and what it was about and what its aims were and so on and now I don't have to, now I can just talk about Changing Faces and everyone knows what Changing Faces is and it's lovely that that is the case.

Now having achieved some of these things then there in that setting I go back to The Royal Free, what possessed me, with all that Changing Faces had to offer, why did I go back to The Royal Free? I was thinking back into a large complex teaching hospital, to a strongly biomedical setting, where I'd be working very hand in hand with doctors, working with referral systems and working in this tertiary setting where people were coming to me via these routes in through other people first of all. And I've put a picture of The Royal Free there its, the patients sit in the blocks there that's where the wards are, the nice shiny glass along the front here is where our management, administrative offices sit. Esther and I work in the basement, actually that's where most of the good work goes on in the basement or the hut on the roof I've discovered actually. For once environment is not indicative of the quality of what is going on inside it. So at The Royal Free the idea was to develop a proper psychology service in plastic surgery, so there was a real focus on managing patients, but also on managing pathways and one thing that psychologists can bring I think is to actually think about the way in which we take people through a process and the way in which peoples satisfaction with the process they are going through will impact on peoples outcomes. There is some interesting work in surgery showing how important these process factors are in terms of people's satisfaction with the end point that they reach. I was lucky to have a very early success in terms of pathways because one of the problems people had was with people having breast reduction surgery and the fact there was an enormous number of people coming wanting to have breast reduction, a lot of these ladies were, their BMI was too high so they needed to lose some weight before they were eligible to have the surgery, a lot of them were smokers and people had a situation where people would come into the clinic take a long time to explain what breast reduction was from a surgical point of view and patients would come back perhaps three months later having not lost weight, people going round and round and not very achieving very much but taking up a lot of time. What I did was, redesigned that pathway so they came through psychology first of all, so we helped them manage those behavioural goals before they went into the surgical setting. We did an interesting intervention, I discovered most of the women coming into that setting were very preoccupied and concerned about their appearance, they had never had a bra fitting, most of them were not wearing a good bra, so we brought a bra fitter up, we spoke to a company called Bravisimo, and we asked them if they would come up to our clinics and set up like a little mini shop in the outpatient clinic, they were delighted to come and do that. So we cleared one of my treatment rooms and set up a lingerie department and the women would come from seeing me to be fitted for a nice bra. We didn't give them a bra, we didn't try to sell them a bra we just tried to show them what it was like to have one that actually fitted and what they would look like dressed afterwards. So we gave them another way of managing and normalising their concerns and that was actually tremendously helpful for our very young 'refer-ees'. Its shocking actually that the youngest people that were coming up to that clinic were 13 and 14. I don't know who was referring really, people up in to that medical setting, young girls as old as that are not appropriate for surgery anyway, it just gave them a medical problem and made them

worry about things. What we did was take them and show them that they could have a nice pretty bra that fitted them, we pointed out they could have a thong to match and that is very important if your 14 or 15 and we just provided a different way of dealing with it. We also put in a really good education package so everyone came in a group to one education day, that's where we got one surgeon to come and take them through the process, I talked to them about other way of managing appearance related concerns and the nurses talked about coping with and managing their condition when they were post operative. So we had a very different kind of pathway. Many of the people who were not appropriate for surgery were screened out very early on. The surgeons cut the amount of time they spent with people. By the time they came into the clinic they were fully informed, they wanted the operation and were ready for surgery and so we had made a much more efficient pathway. So that is actually a good example of a quality pathway that is actually an efficient pathway, it's a cost saving pathway, that's how we described it to our managers. So it was really a very effective intervention to do first of all and Hannah who isn't here has now actually implemented that pathway in to her service at the Royal London, so that is the way that particular kind of concern is now managed. So managing different patient pathways is also something psychologists can bring to the table.

We were required to operationalise the cosmetic surgery guidelines, now I spoke a bit about this in the session this morning. There is a restricted access to cosmetic procedures in the NHS and you can have a long discussion and a long debate over why some things are aesthetic and some are reconstructive and certainly what we do know is that these guidelines are dreadful. They are not particularly well evidenced based but they are the best we have got at the moment, and the reason I got the post was to try and operationalise those and to put together something that was a bit more structured in terms of how we put it together. I'll tell you a bit more about that in a minute.

So I want to go back to Tagliacozzi, I want to talk a bit about surgery, who is one of the earliest plastic surgeons, and here is Tagliacozzi's technique for reconstructing a nose after people have had their nose cut off, which is what people, if people were villainous in some way, after theft or something of that kind that sort of stigmatising procedure would be done to mark them out so Tagliacozzi started to develop a way of reconstructing noses, very much in the same way people still use now. But look at the definition of why he was doing it. Isn't that interesting to see, that a sixteenth century surgeon understood the psychosocial model. He understood that actually it was not purely creating an aesthetic situation, it was actually about peoples thoughts and feelings. Then if you look at what happened in the second World War which is again much where we tend to think about plastic surgery happening, again a very very effective team Gillies and McIndo were working down in East Grinstead, not only very wonderful surgeons but fantastic psychologists, really understanding that they needed to rehabilitate people with these devastating injuries together, actually that there was a group process that was going to support them, that the goal for surgery was that they would be reintegrated in society and actually if you read about what happened in East Grinstead and there is a lovely book called the rehabilitation of warriors, which actually tells you about what happened there and you can read about what was a really good programme those plastic surgeons put together.

So what is happening in plastic surgery today, so here is a good example of the kind of referral we would get into our clinic and see in putting together these kind of referral letters there is a real sort of belief that somehow the physical appearance is matched, correlated clearly with how people

think and behave. So if we go back to my model then there is some idea that the amount of distress should be proportionate to some one's objective appearance and that there is something wrong with somebody whose appearance is not very different from the norm but is distressed and that is a very very prevailing belief. What is interesting is that I was going through referral letters of the last six months and I could put on one side in a huge pile letters that are framed in this kind of way. And here is another one then, "I think his distress is out of all proportion to the scars themselves". Why would they be proportionate? Where does that belief come from? That actually as psychologists what we know that across the whole of disability is that it is actually psychological processes that predict response to disability, to disfigurement, to health change. But there is still very much a prevailing belief that it is related to the physical condition, I think that very interesting and we've got lots to do to challenge that. Here's a "patient seems to find difficulties to adjust himself" so it's some who is at the beginnings perhaps of a psychological formulation.

So the cosmetic surgery guidelines then, beginning at The Royal Free, our opportunity to actually get in there and build a service are built around this problem that they stress the objective rather than the perceived criteria so they look at what someone has looked like and build around this idea just as these surgeons letters do, that somehow the people's distress should be proportionate to the disfigurement or the problem that they have. So if something that is very marked and obvious that they are somehow more deserving of surgery than other people are, it can be justified in that setting. The corollary of that of course is that smaller things are trivial in their impact or manageable without intervention. They have a very weak evidence base, they vary across trusts, they are inconsistently applied. There is a whole research basis now which Sharon Cook and colleagues have put together, there is a lot in the literature about just how difficult these sets of guidelines are, how to apply and just how unfair they are. And how they kind of highlight this idea that surgery is available on psychological grounds and recruit into the pathway just the people who are going to be able to benefit from them. But that was a way in, to actually working in this unit and what I did was to try and think about how we can assess people in a different kind of way because what was happening until we got there was that people would be referred for a psychiatric assessment and our psychiatrist colleagues would be asked for their opinion, a good example of a poor communication really, if you ask a psychiatrist for their opinion they will give you a psychiatric report a psychiatric history, of course they will, because that's apparently what they are being asked. But actually that wasn't what the surgeons wanted to know they didn't want to know about risk, they want to know about the utility of the procedure they could offer. So they didn't want to know that somebody didn't have any psychiatric illness therefore there was no reason why they may not have a breast augmentation. They wanted to know why the patient was thinking about a breast augmentation, what benefits it might provide. So that was the way in which we framed a completely different way of thinking about this and tried to assess on this basis. So we looked at the appearance related concern, we focused on the specific concern that people have, we looked for a direct impact on behaviour. We also looked for a realist understanding of the procedure and the expected outcome and active participation in treatment so we began to build the idea that this was a partnership from the outset, that people should turn up to appointments, that they would be given information to read that they would need to read and take in, that's what I mean by that kind of dimension. I know you can't read the detail of that, but by framing it that way we were able to look for the psychological indications for surgery, amass the evidence, how were we going to measure the evidence, so put some psychometrics in there, produce some post operative aims, so what's the

goals of surgery and then think how we were measuring the outcomes. So that was a different way of doing this and gradually that has provided us with a lot of data and we were able to publish that. I am a very strong believer that we should try and share all this information, that we should try and publish as much as we can, try and make available the ways we are working to other people, other people may disagree with us. They generally improve what you've done, we do much more by kind of sharing this information and that might be through the peer review journals, but it might be through newsletters, it might be through talking to journalists, perish the thought, but we are working in an area that is tremendously interesting to other people. We get a huge amount of opportunity to share what we are doing and I think too often we shy away from it. We should be using those opportunities to disseminate our practise and think more about what we are doing.

This again is trying to develop what we are doing now and what we know from the data, that I was talking about in this morning's session, to try and move to a point where people, when they are talking to someone about appearance in the message that the patient gives which might be something like "I'm worried about the appearance of my breasts". Instead of hearing 'breasts' and pushing people down a surgical pathway, hear the words 'I'm worried'. So what we are actually finding I think more and more that these are problems around anxiety and distress and that's how they are appropriately treated. I use the analogy this morning of trying to treat people with an obsessional compulsive disorder, a fear of contamination, by sending in a steam cleaner to make sure that their house was immaculate. Sometimes I think that actually a surgical procedure is a bit of a steam cleaning devise and we know that you treat these things by understanding more the anxiety process and reducing the rumination. I am actually now seeing people coming through the clinic, a lady the other day of 70, worrying about having her breast implants changed, it's a tragedy that actually someone is going through their life using a way of coping with anxiety that isn't actually going to be a lasting way of working, that it is actually requires coming back and leaves them think in the way in which they rely or for a psychosocial functioning is something to do with a surgical procedure. I haven't put that very well but you understand what I am saying, that these aren't fix it solutions, you run out of road. If you learn very early on the way which you manage your psychological concerns is through a surgical procedure you will go on seeking surgical procedures and these are the people we are seeing just go on doing it to the point at which it's just not helpful for them.

I'm hoping that we can start to think about then, direct access to psychological services in this setting but we will have to educate our GP's. GP's don't do plastic surgery training, GP's don't have any knowledge in this area. It's nonsense for the Department of Health guidelines to ask people to go and discuss things with their GP's when they are drawing their information from the very sources of misinformation that the patients are. There is a lot we need to do about educating people.

Here's an example of a piece of research, because when we are working side by side with our medical colleagues we sometimes see opportunities for psychological thinking in something that appears first of all a very very straight forward surgical question. So Ju Ling is a plastic surgeon who was doing his PhD at The Royal Free and he was doing a prospective study over 2 years looking at the impact of New-Fill in treating facial wasting associated with the anti retro virals that you use to treat HIV. So he was interested really in just a pre and a post study, does New-Fill make a difference to the facial volume for this facial wasting and he was treating people over a period of six months then following them up for a period of two years. And at the outset we discussed this together and

said actually it would be very interesting to have some psychological information in there as well, so let's use our psychological measures to see what impact it has from the subjective perspective. So what we measured was the clinical grading, we asked a subjective question 'how noticeable do you think this is to other people?' so there was a subjective measure. There was a measure of volumetric change and they were using laser scanners for this study so we actually had a very precise measure of cheek projection so unlike studies where we are measuring severity usually by observers to rate how severe how something is and getting inter-rater agreement, here we had a very hard measure of just how much the volumetric change was moving. And we also measured psychological change, our scales in those days being the DAS 59, this was before the DAS 24 was really used, the HADS and the Rosenberg's Self Esteem scale which we no longer use, we have found things we think are more useful. However, here's the results then if we look just at one scale, I'm just showing a little bit of this data, but you can see this is looking at social anxiety or social self consciousness and at six months after treatment it's dropped enormously but it begins to creep back. People are becoming more socially anxious at the end of treatment and what is happening is at six months is they have stopped, they know what I actually going to happen now is the facial wasting is gradually going to return as the effects of the New-Fill wear off. But if you look at the volumetric change, unexpectedly what was happening was there was some infiltration of some of the tissue into the New-Fill and although the patients were expecting the volumetric change to stop at six months it actually increased, it goes better before it came down again. So you've got a dissociation between the physical improvement and people perceptions of improvement. So actually the subjective noticeability, the expectation that things were going to change was enough to increase the social anxiety even when it was actually improving. And that was a very interesting way of almost piggy backing on the back of someone else's research to say something very interesting psychologically is happening here, let's think about this from the psychological perspective as well as just whether or not New-Fill works. And that's another way actually of getting across to our surgical colleagues or the people we are working with some psychological ideas and how these things work together.

Here is Olivia Giles, who is one of the ambassadors for the Healing Foundation and who is such a powerful advocate of this idea that it's not about the disability, it's not about the severity, it's about the psychological processes and how you manage that disability. And who has been so helpful in delivering our research here at CAR. But we are not getting it across so look, here is another of my referral letters, I'll read bits of this that are important "she has unrealistic expectations of what's possible surgically, I think she is likely to be disappointed with the outcome, however I think it's impossible to improve the aesthetic appearance from the objective perspective and therefore I have placed her on my waiting list." Now what might you expect is going to happen to this patient, I can tell you what happened, she complained she didn't like the outcome. It's absolutely clear isn't it from that kind of first referral and this person was going to be or can easily then be framed as a problem patient. Here is a good example of us not hearing not thinking about things early enough to really understand just how we might manage somebody like this. And here is another, this one is my worst example, this one makes me want to put my head in my hands really, here is surgery right "she's made such good progress in her sessions with you, she is much less concerned with her unusual aesthetics, I think she's made such good progress that she has earned this surgery. I'd really value your opinion." Surgery as a reward? What ever is that about? Now that is my responsibility, that is somebody I work with really closely, how am I not managing to convey to them the goals of what we are trying to achieve.

So what I think we need to do is, well, is several things. Here is our ARC work, here is our model we are using here. It is very interesting to us as psychologists, but that doesn't make any sense to surgeons. We've got to have a much better way of describing what it is that we do with people and we have got to have much more evidence that what we are doing works. We talk all the time about using a more psychological approach but actually we are really at the beginning of having knowledge about what is effective in terms of interventions, we know something about the computerised interventions and those of you who haven't seen the flyer out at the front about Aly Bessell's work on computerised interventions, please pick one up because she has provided not only evidence that we can computerise and deliver some of these things in a computerised form but it's very expectable for patients and she has got very good outcomes and I'm pleased to say it's not quite as good as working face to face with people which is exactly what we want but it certainly makes very very good changes. We've got, she has done as part of that, she's had a control group, so here is a controlled study and the control group are having CBT as usual and they are also benefiting so here's again some good evidence of the effectiveness of CBT. I'm pushing CBT and I know not everybody works that way or thinks that is the sort of panacea and the answer to things but it's something that's all very well worked up in terms of research strategy a way of approach, it's a systematic approach, it allows us a beginning. Once we have evidence of something working we can standardise it work to produce some good outcomes and then we can look at what other things we might want to do but we can't test all the different ways we are working all at once, right from the start, we've got to start somewhere, let's start here. We have to think about stepped care, we need to evaluate some of the stepped care some of the ideas that we are putting in place and we have to think much more about dissemination and public engagement.

What Nicky didn't say about me, that in a younger lifestyle I used to play the double base in a band, I don't want to tell you about that, but the nice thing about playing double base is everyone is always pleased to see you, they are always short of double bases, you don't have to be very good to play the double base and get in you can sort of thump and put a ground base in and everyone thinks it sounds great and you're not doing anything very complicated at all. It's the same when you work in body image people are very very pleased to talk to us you know if people ask you at a dinner party what you do you soon hog all the lime light. This is something that people are really really interested in. When we were doing our work on facial transplantation the irony was that we would actually be sending things off to the journal at tea time, they would be back by breakfast with people saying not of general interest no one is interested in this work and there would be a queue of people who wanted to speak to you from all the major papers and what have you. This is actually an area that people are fascinated by and we really do need to get our message back out to them because there are an awful lot of vulnerable people being misinformed by the media who are coming into our clinics and are ending up being treated really very inappropriately. So that's a real drive, that's something we really need to do.

Here is our stepped care model, here's the, we actually need to be thinking about delivering education to a huge number of people so we need to have those sort of programmes in place. I realise as I am putting together and thinking about what are the priorities now that actually they are exactly the same as when I first started at Changing Faces. We are making progress, we have come a long way but we've still got quite a lot to do.

Facial transplantation, so I'd not been at The Royal Free very long before Peter Butler said to me 'I'm interested in facial transplantation' and I thought just my luck, here I am in a setting doing just the sort of work I want to do, how ever am I going to think about this? And its' very interesting, there was two choices really, I want nothing to do with facial transplantation or to think let's try and understand what it is you are wanting to achieve through this and that is why I've used this slide because this slide has so many different dimensions to it from the whole idea of using a disfiguring condition as a marketing message to try and manage other peoples risk behaviour and what does that do for the people who do have disfiguring conditions, but you can see that when somebody does look at, somebody like Ian with all his passion and excitement about the work he did that, this is Ian Hutchison that spoke yesterday. When you look at Jaqui Saburido and what she looks like now and passionately want to make some change for her. So actually there is an awful lot of good will behind this programme. What my role was in this was to help the team stand back and think about all the different, I can remember making a list and think right okay what do we know about this that we can use, and that was a very short list, compared to the very long list of the things we'd need to find out and the work we need to do and what is good is that we managed to frame that as a research programme and begin to do the studies to find out the kind of evidence we would need to know and the kinds of ways we would manage patients once we got ethical permission to go out and sort of bring people into this pathway. And that pathway is now a very good example of people who have joined in working with psychology very clearly there from the outset and patients coming through that programme don't progress any further until they completed a full psychological, worked up psychological intervention. Always asking the question, what are the problems, what are the problems for someone like this? We have no idea from looking at a photograph, we don't know until we have spoken to someone and understand what their life is like what we are trying to achieve what it is we need to treat and we can go an awful long way treating that psychologically and everyone who comes in through the programme goes down that pathway first of all. Looking unusual is not a reason for having a facial transplantation.

So what have we achieved? Where have we got to? We have got a better understanding of factors associated with adjustment and the new Healing Foundation data gives us a real rich reserve of exploring that further. We've got good first step interventions, it's really heartening to hear how the booklets and things that we wrote at Changing Faces, how the programmes there are now being used all over the world. We've got the development of computerised interventions. So the real key now is to promote access for people, we are beginning to amass evidence of effectiveness and we have established a role for psychologists in clinical settings.

And what are our priorities, education, education, I sound like Mr Blair but very much for the people we work with for the general public, direct access to psychology for patients. I want to take the best of what we do at Changing Faces and embed it in the best of what we do in the NHS. We need to pull together our step models of intervention and we need this evaluation of interventions including joint working. We need to acknowledge the context of intervention and how that is changing through all these programmes that people watch, we think about people and were they draw their evidence. This is actually, I had to scan this in, this is my husband's accountancy magazine, accountancy one thinks of quite a dry profession, look at the cover of his, it must have change I think since he started doing it. But we are delivering interventions in a shifting context in terms of makeover programmes. Just recently we've had a whole run of women coming in requesting labiaplasty. These are women with a completely normal appearance, whose doctors I think half the time don't bother to examine

them, and send them into our plastic surgery clinics where the doctors say 'yes, this is the process this is what the operation is, go away and think about it for three months.' And actually if you get them into our clinics the treatment for someone who is thinking about a labiaplasty is not to watch embarrassing bodies, it isn't to have an operation we are also working in the context now of looking for cost savings in the NHS certainly that is one opportunity when you have got your back to the wall you can change things, that's how the NHS started, this gives us a real opportunity to start thinking about the kinds of things we can do because they are efficient things, they are often cheaper things and actually as we amass the evidence they are better ways of working with patients.

Communication, I don't want to give the impression that all these things are one way so here is me writing back to Peter Butler, 'Thank you for referring AB, I have seen him for 10 sessions' what am I telling my colleague, I am telling him the patient turned up I'm not telling anything more to a colleague what we actually did in the session, I can do much better than that if I want to actually encourage people to think psychologically. So if I write back more in these terms right, 'we have rehearsed an answer to questions about his appearance, which he is much more comfortable about. We have disproved the hypothesis everybody is staring about this is what we did. His eye contact is much improved since he stopped wearing his baseball cap.' I have a particular thing about baseball caps. But it is a very nice thing that I can feed back to someone who gets an idea about what we are actually doing. 'by focusing on his musical skills he has been able to determine the meaning of self worth' or whatever. Something much more about the content of what we are doing will give people a much better idea about why it is important. And these are then the kinds of things we want to end up in terms of response. This is a lovely letter that come back to Elizabeth Robinson who is one of the psychologists working in our team from our breast surgeon, so 'very grateful for your help, your consultation with AB yesterday made the decision making on the surgical part of the treatment much more comfortable. AB is also very grateful for your help.' And AB is a doctor, so here are two doctors who are facilitated by a psychologist to make a comfortable choice about a treatment decision. Actually I reread that and thought wouldn't it be nice if those two doctors had the skills to do that between them. There is a bit of intervention that we may want to think about.

And finally, this letter back to me 'I think together we have achieved far more for this lady than either of us could have done independently.' Now that is a result. Thank you very much.