Transcript to accompany video

Video: ‘NICE Guidelines: Inpatient Mental Health Care 2000-2023’

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Transcribed by: National Collaborating Centre for Mental Health (NCCMH), Royal College of Psychiatrists

00:05 S.Pilling	So, thank you very much for inviting us to provide the Lampard Inquiry with an introduction to clinical guidelines as developed by the National Institute for Health and Clinical Excellence, otherwise known as NICE.
00:19 S.Pilling	What we want to try and do, over the next 45 minutes or so, is provide you with something about how guidelines are developed, but to focus particularly on their role in the development of best clinical practice, the implications of the guidelines for the way services are delivered.
00:42 S.Pilling	And in doing so, what we want to do is provide a background to the overall clinical guideline programme, we want to focus on the key guidelines of concern to the Inquiry that were developed between 2000 and 2023, and also draw your attention to updates and developments within those guidelines. And finally, we want to provide a broader context, not just relating to specific guidelines, but to the additional resources that were put in place to support the implementation of some guidelines, the challenges that were faced in the introduction of guidelines, and also to spend a little bit of time looking at how we best measure the impact and outcomes of effective guideline implementation.
01:40 S.Pilling	Just to introduce ourselves, so I'm Stephen Pilling, I'm Professor of Clinical Psychology at the University of College London, and I've been involved, for the past 20 years or more, in the development of clinical guidelines. And my current role is a consultant clinical advisor on mental health to NICE.
01:59 T.Kendall	And my name is Professor Tim Kendall. I'm currently the National Clinical Lead for New Models of mental health care. And I'm consultant psychiatrist working with homeless people in Sheffield, where I live. I was, in the past, I was National Clinical Director for Mental Health working at NHS England between 2016 and 2024.

And before that, Steve and I both worked together on NICE guidelines in mental health. We did the very first NICE guideline together and we continued that collaboration through ‘til 2016.

02:46 S.Pilling Just a brief introduction to NICE. NICE is an independent public body of the Department of Health and Social Care. And its key role is to provide independent, rigorous and systematic evaluation of health care evidence. And, on the basis of that, to produce guidelines and recommendations for clinicians, for people using services, their families and carers. And, based on that evaluation, encourage the uptake of best practice with the intention of overall improvement of healthcare outcomes.

03:24 S.Pilling This is achieved, not just by a rigorous examination of the available evidence, but by ensuring widespread professional involvement and support through collaboration with the Royal Colleges and relevant partner organisations, but also, as you will hear later from us, a central role for people who have lived experience of mental health in helping us shape the output of those guidelines.

03:56 T.Kendall Okay, so what are NICE guidelines? Now, NICE have developed a set of methods which have been consulted on, widely, and are now embedded, updated regularly, but those methods govern the way you produce a guideline.

04:13 T.Kendall So first off, you pull together a group of experts, that's broadly including experts by... in clinical work, experts in research, but also crucially experts by experience and they're supported by experts in guideline development. Now, it's their job, as a group, to go out and get all the relevant evidence that they can possibly find that directly relate to that particular guideline area and then, using agreed methodologies, they analyse that, they systematically review it and come up with what you might think of as a very slimmed down set of very reliable evidence for the guideline group to consider.

05:04 T.Kendall Once they've got that, they will then develop a set of recommendations about what treatments work and what treatments don't and in what context you should be using those. So, once that's done, that's there to support clinical decision making, both for the clinician and for the person who uses services.

05:28 T.Kendall Okay, so what exactly is the status of NICE guidance? So, as I've said, NICE guidance is there support the clinician and the service user to make decisions. It's not a substitute for decision making because decision making has to take into account preferences, has to take

into account values that the patient's got and so on. So it's there to support that process.

05:58 T.Kendall Guidelines can't be mandated. We can't just say, look, everyone's got to do this. As I say, it's there to support decision making.

06:09 T.Kendall So, what can NICE guidelines do?
Now, before we had NICE guidelines, generally speaking, you... So, I'd be working in Sheffield and I'd be thinking, well, 'What does the local professor say?' you know, and you might have, come and have a visit from an eminent professor from UCL or somewhere else, who would tell you about what they knew about guidance and that was generally about the best that we had.

06:39 T.Kendall Now we've moved away from that sort of, that kind of evidence into a new era which NICE have championed, which is one that we call evidence-based practice. So, it means that we now have the best evidence available, not just one individual's view of it. So that's been a big and important change, which I think has gone right across the health service.

07:07 T.Kendall Now, second thing is that the generation of knowledge nowadays, there's so much of it that it would be impossible for any clinician, even less so someone who uses services, for them to be able to assimilate all that knowledge and evaluate all that evidence. So what NICE is doing is doing it for the clinician and for the service user. So, it's to synthesize all of that and support them.

07:37 T.Kendall Now, obviously, one aim of this is that you improve clinical practice. We see that as a very important part of all of this.

07:52 T.Kendall Nevertheless, and this is important, an awful lot of NICE guidance is based on randomised controlled trials and so on, which give you a statistical average of differences between a treatment and its comparator. So, you need to bear in mind that it gives you a guide to what's likely to work, but it doesn't tell you what will work. It is a statistical tool. So it steers individual choices but it doesn't give you individual choices. It does give clinicians and patients, it gives them knowledge regarding what is best care. And I think that's quite important that it synthesizes what comes out, so NICE guidelines will give you an idea of what the best care would look like.

08:48 T.Kendall We also do use guidelines to underpin things that we call quality standards. So, we can do audits and we've been doing one at NHS England for more than a decade looking at the treatment of

psychosis. And we use the NICE guideline to see, well, to what extent do services reach those standards. It's also true, and I've been a medical director myself in the past, that you can use NICE guidelines to just see the extent to which individual practitioners are using the best evidence available. So, you can identify perhaps what's not such good practice.

09:32 T.Kendall We also use guidelines to help people improve their practice and we've got a number of quality improvement programmes in different parts of the NHS and at the Royal College, where NICE guidelines are used specifically to do that. And you know, part of that would be training people - training people to do particular kinds of interventions and helping people not do ones which don't work.

10:02 T.Kendall I think, finally, there are two things that you probably won't have thought about unless you've been involved in this. One is when a commissioning body such as an ICB, an integrated care board, commissions a service, they generally speaking will only commission services which deliver NICE care, NICE-concordant care. At least that's their aim. And, finally, governments, and this is true from when I was working as National Clinical Director, the guidance that we give as clinicians to politicians and the advice that we give that influence the spending of money is that we would use NICE guidelines to do that. So they've now got into all levels of the NHS.

10:59 T.Kendall Okay, I'm just going to ask you to take a look at what guidelines can't do. And this isn't an exhaustive list by any means, but it's important. I've already said that NICE guidance underpins clinical decision making, but it does not replace that clinical decision making. It doesn't in particular replace patient choice. So it's not uncommon that I might have, in a NICE guideline, that you'd have a psychological treatment, say for the treatment of depression or for the treatment of schizophrenia, and you might at the same time have a pharmacological treatment. It's not uncommon that patients will have a preference. We would say in the guideline, offer both, but it's important that people using services retain that choice and that we support them in that choice.

12:00 T.Kendall Now, that doesn't mean to say that we don't try and use the guidelines to support all of a patient's needs as far as the guideline would help us. So, it might be, how do we help people get, people with schizophrenia, for example, get back to work with Individual Placement and Support? How would we get them reducing symptoms with both cognitive behavioural therapy and pharmacological treatments, or reduce relapse rates with family interventions. There's a whole range of things that we can offer, but in the end, the patient is the one who has to make the choice.

12:39
T.Kendall

Now, I have to add an important caveat. NICE guidelines are focused on particular individual conditions with a few important exceptions, which we will refer to as we're talking. Many of them, for example, on depression or generalized anxiety disorder or obsessional compulsive disorder, schizophrenia and psychosis, each of these are focused on a particular individual condition. Many of the people that we see will have more than one condition. So, particularly so for people with more severe mental health problems, who I work with, for example, who are on the street across a lot of the time, that they will have physical health problems, they will have perhaps chronic schizophrenia, but they'll also have quite severe anxiety and depression and so on, and drug misuse and so on. So, it's important to bear in mind that most of the research that underpins guidelines doesn't cope that well with how do you tailor this for people with multiple problems. So you just have to bear that in mind. And it's particularly important here because many people who end up on inpatient units will have more than one problem. So, it does, it limits our confidence of what a guideline can do.

14:13
S.Pilling

I'd just now like to provide some background to the guideline development process itself. As you've already heard, guidelines are based on the best available evidence and we bring together people with expertise, both clinical and research expertise, people using services, carers and the broader members of the public to help us understand the process of development.

14:39
S.Pilling

That begins with the identification of a particular topic. As you'll see from the overall suite of NICE guidelines, it covers most of the key mental disorders that present from day to day within the health service. And the decision to choose a particular topic will be dependent on a number of factors. One, what is seen as the current need for further development in the area and what's seen as the level of evidence that's informing best practice. And that's a process of consultation in itself, collaborating with colleagues working in health and social care, within the delivery of healthcare systems, and we've already said with people in receipt of services.

15:29
S.Pilling

Once a topic has been identified, a scope has been produced and that scope is developed and is itself subject to consultation and development, again using that broad range of service users, service providers and service commissioners. When that scope has been developed, it leads on to the development of NICE guidelines. Now, as we've already been saying, there is a very robust process focusing on both clinical and cost effectiveness in the development of NICE guidelines. I think it's right to say, at this point, that NICE is seen as, say, the international leader in the development of clinical guidelines. So there are very robust methods that underpin it and I think one thing that is particularly a strong characteristic of the

NICE process is that emphasis on clinical, on cost effectiveness. It's not just that we want to provide the best treatments, of course we do, but we also want to provide the treatments that provide the best value for money - the best return on the investment.

16:40
S.Pilling

So, after that process, which could take a good 12 months or more, the guideline goes out to consultation. And, again, there's a broad range of consultation from experts in the field, from service providers in the National Health Service, and indeed from wider social, health and government organizations. And there's a clear responsibility on NICE in the development of the guideline and the response to it to provide evidence, to respond to each and every response that comes in. It's a very careful and thoughtful process. And, actually, it's one that almost invariably leads to an improvement in the guideline so that you then see a final revision of the guideline emerging that you've got reasonable confidence is not just based on the best evidence, but you've also learned from the process of consultation something about how it might be most effectively implemented and what the challenges will be, too. So, the guideline is then published and it's up then for colleagues, whether it's in the Department of Health and Social Care, in hospitals, in community settings, to take forward that programme and implement it. We'll say a little bit more shortly about the process of implementation.

17:59
S.Pilling

And finally, I just want to say something about the quality of the evidence. There are some areas of mental health, psychosis being a very good example, where we have really extensive evidence on the effectiveness of pharmacological, psychological, and social interventions. There are other areas, particularly where you move into areas where it might be a less common disorder, it might have more complexities that cover both health and social care, where the evidence, for example, from randomised controlled trials is somewhat less than ideal. But that doesn't mean that you can't make guideline recommendations. And in those circumstances, what we would do is use the expertise of the guideline group, drawing on the available evidence to try and develop recommendations which we think address an important area even though the evidence may not be as strong as it could be in other areas. And often that's a really important thing to do. Under-researched areas should not be neglected. We should be able to say something about what we think is the best available evidence. And, as I said earlier, that process of consultation allows us to have some confidence that the recommendation could still be of benefit. But often in those circumstances, we'd also make a recommendation for further research. And I think that's another important contribution that NICE has made over the past 20 years, is to highlight important areas of clinical practice where research is limited and, in collaboration with colleagues, for example, in the

National Institute for Health Research, to commission research to address those areas of uncertainty.

19:56 S.Pilling
I should also add that NICE run a surveillance programme and the purpose of that programme is to identify new evidence and, in particular, new evidence that may require the updating of a particular guideline. And that surveillance process can be important in deciding when a guideline needs updating. And it also is something where NICE take account, not just of the available evidence, but what information comes back from the NHS and from other colleagues about the current effective implementation of those guidelines.

20:41 S.Pilling
I just want to say a little bit now about the application of NICE guidelines to inpatient mental health care. Now, as may seem obvious from what we've been saying so far, people who receive inpatient care can have a wide range of disorders and, as we've also noted, can have multiple comorbidities. So much of what has been developed by NICE in terms of clinical guidelines will have application to people who are admitted for inpatient care.
What we've tried to do, and you can see in a slide shortly that gives you some idea of the range of guidelines from 2000 through to 2023 that we think have particular relevance to inpatient care. We've also included reference to guidelines across all ages - children and young people, adults and older people. And what we also would be looking at in the guidelines is not just the process of care itself, but in, but the assessments that lead to decisions about effective care, and crucially also those decisions that support the process of effective discharge from inpatient care and the subsequent care in the community that people will receive.

22:11 S.Pilling
And it's just worth perhaps noting that in the development of guidelines, broadly that was very much kept in mind, and so guidelines tend not to be setting specific. And again, it goes back to that point we made earlier, that you do need to exercise clinical judgment when you're deciding where a guideline might be most appropriately provided.

22:36 S.Pilling
The next slide is, I think, rather dense. And I don't propose to go through it in detail, but it's there to give you an idea of what we think are, in terms of the Inquiry, the most relevant guidelines.

22:52 S.Pilling
And I just want to make a couple of points about that. And it's as follows, that the guidelines not only cover a broad range of areas, but the guidelines within themselves change and develop. And you can just see, if you look at the titles of the guidelines, we've actually adjusted them. And I think those adjustments reflect the fact that

we wanted to look and see whether or not the initial implementation and its subsequent impact on practice has had the impact it did. So, very often in the updating of a guideline, we'll be looking at areas where we think, this has not quite had the impact that it wanted, that we would have wanted it to do, and that the changes that emerge in the guidelines reflect both the impact we want to have had and actually new evidence that emerges. And we'll say a little bit in a moment about how that might specifically apply to self-harm.

23:58 S.Pilling Although I've just acknowledged that this slide can be quite complex to look at and potentially to navigate your way through, where we think it could be of particular value to the Inquiry is it gives a timeline for you to be able to look at which version of which guideline was in place at a particular time.

24:23 S.Pilling And, as I noted earlier, the nature and content of the recommendations will change with new guidelines. And so when looking at care in 2005 compared to, say, care in 2015, I think what this diagram will help you to do is determine which particular version of what guideline was in place at that time.

24:47 S.Pilling Now, again, a couple more slides that are just to give you an idea of what, if you wanted to go on to the NICE website, which is publicly available, it'll give you a way of looking at it. And, just you can see from the slide there, there's access to the full guideline that'll also allow you to link into the underpinning evidence. But there are also sections which, for many people, might be the place to start to just look at what the key recommendations in the guideline were. And you can see the guidelines probably significant, for adults at least, the most common cause of people being admitted to hospital in need of care are people with psychosis, schizophrenia and related disorders. So that might be one place, it'd be a good place to start to look at.

25:38 S.Pilling This is an important slide because it demonstrates three things that we think are important about the care of people with psychosis and schizophrenia. And the first is that one needs to take into account a range of factors, as you can see in the top right-hand corner of the slide there, there's reference made to race, culture, and ethnicity. And we know, for example, that people from minoritised communities very often have poorer outcomes than their white British compatriots. And so we try and take into those factors into account.

26:20 S.Pilling And the other factor that is also really important is we know that if you have a serious mental disorder, like schizophrenia, it reduces

about 17 years in life expectancy. That's a really very, very significant burden. And so what we wanted to do in the development of these guidelines is not just pay attention to people's mental health, but also to pay attention to people's physical health, particularly for people who might find it difficult to access physical healthcare. So, being very clear that services have a responsibility, particularly in inpatient care, to take account of an individual's physical health.

27:05 T.Kendall Okay, so we've shown you all the guidelines that we think might be relevant to inpatient settings and you'll notice that over time there's more of them as we've done more and during that time the evidence base that they consider has grown, sometimes differentially, less in some areas than others.

27:27 T.Kendall But there are changes that we've noticed over that time, for example, we've put a greater emphasis on the availability and usability of psychological interventions. Pretty much every guideline we've done has emphasised that there is a role for psychological therapies. And I think that's become more so, and it's been taken up little by little within services, certainly in the community. I think we've also recognised that the physical health of people with mental health problems has become much more obviously an issue. And I think we've already said about people with schizophrenia dying, for men, nearly 20 years younger than their counterparts in society. Or if you're talking about people with serious mental health problems on the street who are now dying, average age 43. So, the physical health has become an increasingly important issue. And I think thirdly, that we've gradually realized that pharmacological treatments need to be delivered in a careful way, not using high doses because it didn't work when we use low doses. So, I think there've been a number of important changes. And you will see that over time, we've redone some of these guidelines to reflect those changes in emphasis.

29:09 T.Kendall One area that is directly relevant to the subject of this Inquiry is the area of self-harm and suicide. We produced NICE guidance on self-harm and, in particular, we had a focus as a result of a fairly detailed study of the National Confidential Inquiry into suicide. We came to the view that we were doing this wrong. And we recommended that the people working in mental health services should no longer use risk scales and risk scores and so on. Less still should they start classifying people as medium risk, low risk, high risk, etc. And, on top of that, that they should stop deciding who should get treatment and who shouldn't on the basis of risk. All of this has led people to, I think, an illusion that somehow they can predict the future using these risk tools. And it was our conclusion that this should move towards what we called the development of safety culture and to move away from risk assessments altogether.

30:35 T.Kendall Okay, so it's important to recognise that NICE guidance doesn't just sit on a shelf, although I'm sure in some offices that's just what does happen. NICE has been picked up by pretty much all national organisations, both within the NHS and those who've got direct relevance for the NHS. I'll now explain a little. So in my role as National Clinical Director, we produce quite a lot of policy documents around perinatal mental health services or early intervention in psychosis services or mother and baby units, etc. Now, all of those policy documents refer and support the delivery of NICE guidance. So I would say it's the routine, not the exception, that NICE guidance is supported throughout the NHS, in policy terms.

31:35 T.Kendall Now, there are some specific documents, for example, implementation guides around the Community Mental Health Framework or around the delivery of early intervention in psychosis services, and those will actually spell out exactly what should be delivered. So in the early intervention in psychosis investment that we produced and implementation guides that went with it, it specifically says that we need to have people trained up to do CBT [cognitive behavioural therapy] for psychosis, we had to have people who were able to do family interventions for psychosis and that we should be delivering on getting people back into work using the evidence-based interventions for that. Now, that has also been turned by NICE into what they call quality standards. So, to help in, say for example, dementia services, we produced a quality standard for dementia. And that again, sort of, it slims down the guidance down to what really is essential to be delivered. And then, of course, with each of these things, you can then identify what should be delivered and then do what national audits or national surveys to see what actually is delivered. And for some years we've now had a national clinical audit of early intervention in psychosis. And we now can say, well, what's the extent to which we're offering people CBT for psychosis? And that has gone up over the years. So, NICE has got into the fabric of the NHS, whether that's policy documents or all the way through to national audits. That's just what the NHS does.

33:38 T.Kendall Now, at the Royal College of Psychiatrists, for at least 20 years, they have developed what they would call quality networks. And the sort of distillation of that is that they have now accreditation standards. So what that means is that a ward or a community team can apply to become accredited, and part of that accreditation process looks at the extent to which they use, they use NICE guidance. So it's even got into that kind of work outside of the NHS.

34:19 T.Kendall We have been very good at implementing NICE guidance in some settings much, much better than we have in others. So, for example, in NHS Talking Therapies, we have implemented NICE guidance in a

whole range of different disorders, depression, anxiety, and so on. And, not only that, we are now getting outcomes that are as good as the trials on which these interventions were based. And the same applies to early intervention in psychosis. We've seen a gradual improvement over time of the implementation of NICE guidance in those settings.

35:02
T.Kendall
Now, having said that, one of the problems, one of the problem areas that I recognise, we've made a number of recommendations around teams, for example, assertive outreach teams or crisis resolution and home treatment teams or community mental health framework teams or community mental health teams. In fact, this area I think is probably our weakest part within NICE. There is some evidence, but the evidence isn't that strong and in some cases it's contradictory. But a consequence of us recommending all these different teams has ended with us having, in some areas, at least 13 different teams for a geographical patch, to the point where, “we have a team for everything but a place for no one.” That's a quote from Steve, my colleague.

36:03
T.Kendall
So, now this isn't directly to do with NICE Guidance but it's part and parcel of the same problem that I see, which is we have developed specialist inpatient teams led by a consultant running one particular ward and that they've become detached from all the other teams that are in the community. Long gone are the days where you had one team that covered the inpatient unit and a part of the community. This, think, has led to inpatients becoming very detached from the community base that supports them when they're not inpatients.

36:42
S.Pilling
In the development of NICE guidelines, there is a considerable challenge. And that considerable challenge is developing interventions that recognise the inequality in outcomes for people from minoritised groups. That's been the case across much of healthcare, and mental health's no different.

37:06
T.Kendall
And it hasn't changed, has it?

37:08
S.Pilling
No.

37:09
T.Kendall
In the whole time that we've been doing this, the unequal delivery of healthcare to, for example, African Caribbean men, that persists in spite of all the recommendations we've made.

37:21
S.Pilling
But there is some cause for optimism. If you look, for example, at the NHS Talking Therapies for anxiety and depression, you do see overall poorer outcomes, now around about 3 % for most minoritised groups. But there are groups of individuals, particularly from the South Asian community, where you see much poorer outcomes. And you can see a virtual replication of that when you look at first episode services.

37:59
T.Kendall
Absolutely true. Having said that, I'm also aware that many NICE guidelines are dominated by particular ethnic groups and there tends to be far fewer people from black and minority ethnic groups on NICE guidance and I think that is a problem that NICE will need to solve.

38:21
S.Pilling
I think it's a problem NICE will need to solve and NICE are resolving. And Tim can give us an example of work with that on the Schizophrenia guideline.

38:28
T.Kendall
Absolutely, when we did the Schizophrenia guideline, I think it was the second version for adults, we decided to set up a small group of researchers and clinicians and people at youth services to look at evidence around black and minority ethnic groups, particularly young black men who were getting a diagnosis of schizophrenia five to six times more than they should be and ending up being under the Mental Health Act at least five or six times more than they should be. And you'll see at the beginning of that guideline that all of the recommendations around race and mental health are from that group. So, there is a way of doing it, we just haven't gone far enough.

39:16
S.Pilling
No, and indeed here at the College [the Royal College of Psychiatrists] we've worked with the Race and Health Observatory, again going back to NHS Talking Therapies, to look at what can be done to improve outcomes and there's some interesting things that emerge. It's often not just the nature of the treatment that's provided, but it's what those services do to reach out to communities and build those links with them that make for a better outcomes. And the second thing is how do you involve people from those communities in the guidelines. And I think this is as important, not just for the health professionals involved in the guidelines, it's ensuring that in terms of the service users, their families and carers, that there's representation of people from a broad range of different communities. I think that's the way we can see guidelines improving.

40:07
T.Kendall
I think there's one thing I'd like to finally add, which is, and I've inferred this before, which is that the weakest part of NICE recommendations is around what you might think of as service-level interventions. So recommendations around early intervention in psychosis teams, not the interventions, or assertive outreach teams or community mental health teams, etc. Now, I think these are the weakest part based on the weakest evidence. And it has such dire consequences to have all these specialist teams in mental health that people now say that they're bounce from one place to another refused from as many teams that, probably many more teams than they ever get accepted by. So it's my view that where NICE is really good is looking at the interventions, psychological, pharmacological and so on. And that's where NICE should focus.

41:11
S.Pilling
So, I'd hope in this lecture we've been able to convey to you that we think NICE guidelines offer the best available evidence for healthcare and, in particular, in mental healthcare. That the developmental process underpinning them is rigorous, it's based on high quality evidence and it stands as a national, international example in the generation of evidence for better healthcare.

41:41
T.Kendall
And following on from that, we've got to bear in mind that, it's certainly my expectation, that healthcare practitioners should, as a result of that, consider NICE guidance in their work with people who use services, with patients. And that should be a routine. There shouldn't really be an exception to that. But the last thing we want is for people to slavishly follow guidelines as if they were a rule and they're not a rule they are simply guidelines. And that means that when you know when they're considered by inquiries like this, or indeed by courts and so on, we're not asking people to be judged do they implement these guidelines, it's do they use them in routine practice.