

Landing MLTC-M research in the health and social care system

Webinar Transcript, 22 November 2022

[Landing Multiple Long-Term Conditions \(MLTC\) Research in the Health & Care System | Event - YouTube](#)

Chris Salisbury (Chair)

00:00:01

Living with multiple long-term conditions (MLTC) is one of the biggest challenges facing the health and social care system. But whenever there's a challenge, that's also an exciting opportunity for researchers. And there are lots of important research questions. But any of us who've done research on multiple long-term conditions will know it's complex. It's difficult to do, and it's particularly difficult to gain traction in the world where medicine is so dominated by single disease structures, journals, colleges - everything single disease or system. It's so difficult for multiple long-term conditions research to really make a difference in the real world, and to gain traction.

So, our aims are to identify pathways to impact and to implementation of multiple long-term conditions research, to share best practice for engaging and influencing policymakers, and to understand some of the challenges in achieving impact from this research. How we can overcome them as a research community and as funders and as policymakers, and particularly to facilitate networking between different research groups working on MLTC research.

So, we're going to start in a moment with a keynote talk from Professor Lucy Chappell, who's Chief Executive of NIHR (National Institute for Health and Care Research) and Chief Scientific Adviser to the Department of Health and Social Care.

And then we're going to have two panel discussions, one with researchers who have experience of conducting and trying to apply MLTC research, and then another with policymakers who can talk about their experience of being on the receiving end of research, and how it influences health and social care.

We hope there'll be lots of opportunities for discussion. So as people are talking, and in those panels, please join in with your questions and also your ideas and your tips.

And then, in the second half of the event, after a short break, we're going to go into breakout rooms where we're going to ask you to identify your top three facilitators and one main challenge in achieving implementation in MLTC research.

Now, thanks everyone who's been putting their name and role and institution in the chat, and I encourage you to keep doing that - those of you who've recently joined us, that'd be really helpful.

And before we go to the next agenda item, Sophie from NIHR, is going to do a quick poll of attendees.

Sophie Lewis (DHSC/NIHR)

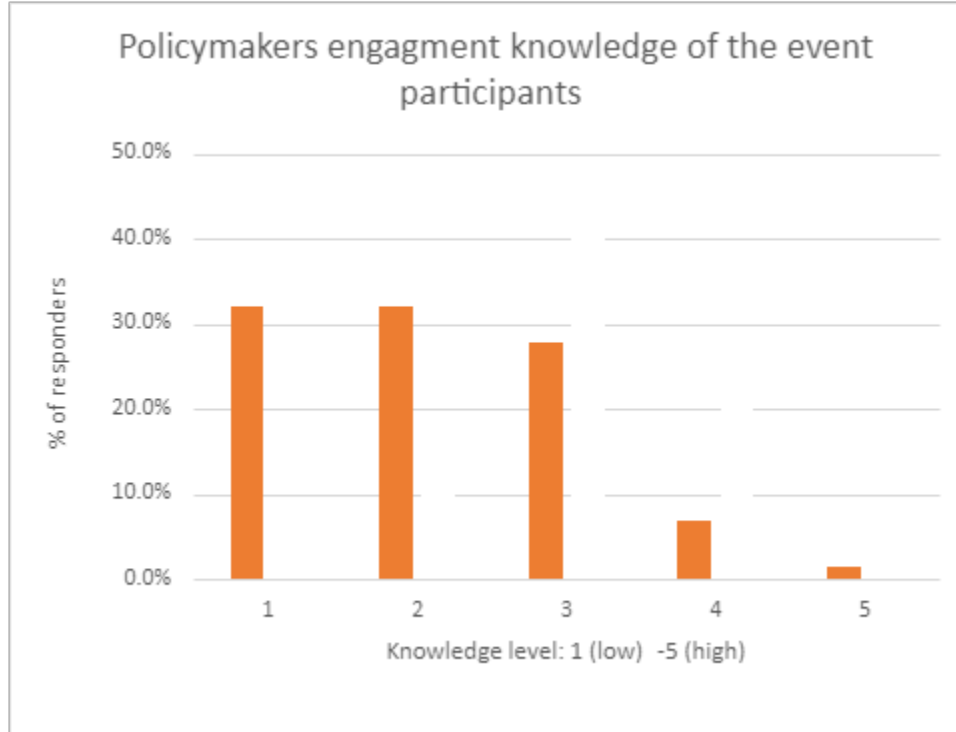
00:02:20

Yeah, the polls should just pop up on your screen. So please just take a few moments to answer that [question]. Thank you.

What is your current level of knowledge of engaging with policymakers? scale 1-5: 1 (low level) – 5 (high level)

00:02:29

Sophie Lewis (DHSC/NIHR)



00:02:39

The poll is just to help us to understand how useful the event has been today, and we'll be asking the same question again a bit later on.

Chris Salisbury

00:02:49

Excellent. Thank you. Let's move on.

So, it's my real pleasure to introduce Lucy Chappell, Professor Lucy Chappell, as I said, Chief Executive of NIHR and Chief Scientific Adviser to the Department of Health and Social Care (DHSC). The fact that she's given up time to come to this event, I think, really reflects how important this topic is for the health and social care system. So, we're really grateful that she's given up time to do this. She's going to outline a vision for, and promote, the implementation of MLTC research into policy and practice, and also demonstrate how everybody's got a role to play in thinking about how research is configured to have impact on policymakers. So, Lucy, we look forward to hearing from you. Thank you.

Lucy Chappell

00:03:29 [Lucy Chappell, key note](#)

Thank you very much, Chris. Really good to be here today, and actually just seeing everyone's names and roles pop up in the chat really reinforced to me what an incredibly varied and diverse group there is today. And I think that's one of the most exciting things. So, if I think about the

challenges in health and care, and what you are doing at the moment in this field, it is absolutely one of the really important cutting edges of our science and research.

I think the poll also showed where perhaps I was before I came into this role as Chief Scientific Adviser at DHSC. I think as a researcher, there has been work to bridge this gap, but today is really about helping this community to see many more of those bridges, and it's not just what happens this morning. It's what you take away and do differently as a result.

I see at first-hand as an obstetrician, and I'm still practicing, why this matters. And I was also on a hospital visit yesterday, and in both my own field and at the hospital visit, something is shifting.

So, what I'm seeing is that I would normally talk to researchers and clinicians, and everyone would be in their single disease silo. And for the first time yesterday I saw everyone talking about the importance of MLTC. It is coming so much more into the language. So, I would say you're all at the crest of the wave, at or ahead of it, and I think we're going to need many more of you in years to come.

The other thing is that multi-disciplinarity that I saw from your roles, and again that is a real strength of this system.

First slide please. Thank you, Sophie, for sharing [the slides].

00:05:15

So, I just want to give you some thoughts on where we are as a team. Some of you may know that I chaired the artificial intelligence in multiple long-term conditions. So, this is something I was involved with, and has stayed with me.

So, just to set out what I suspect all of you are very familiar with, which is that the health and care system doesn't really work well for people with MLTC at the moment.

NIHR, a few years ago, ran a series of workshops with people living with MLTC and their carers. And actually, the themes will be something I think you are all familiar with:

- The impact of stigma
- That really poorly coordinated care, sometimes with the good exemplars, and we want to hear more, as Chris said, about what works, what an enabler is, and how that care could be better coordinated, but still too much of our health and care is sitting in the single disease silos.
- And then the way that we've been trained. Certainly, me as a doctor, and I suspect many other health care professionals on how we frame it in terms of outcomes, clinical outcomes that might matter to us.

But we're not so good at asking what matters to you as a patient. Why aren't we designing our care around those outcomes?

And I think this also talks to the very particular need to ensure that mental and physical health are not seen in completely separate places, despite the fact that much of our training and care system is designed exactly like that.

So, if we involve people with MLTC and their carers at the heart of not just our policy making, but our research offer as well, and integrate all of those, I think we're going to get a much better-looking service underpinned by evidence.

So, we know that this is also a complex challenge to policymakers, and if you look at the conversations that have been going on, say, over the summer and into the winter, into the autumn, about the challenge of winter pressures, you'll see that patients with MLTC are really crucial to understanding this.

Very few people walk into hospital with a single condition and out again, smoothly. So, we think there's more than fourteen million people in England alone living with MLTC, and that these [patients] are accounting currently for half of the NHS (National Health Service) primary and secondary care costs. This isn't to finger point; this is to say, this is a huge need. And we also know that, if we look at our demographics, these numbers are expected to rise as we see that ageing population. So, if we're not on that wave now, we're going to be playing catch up for many years to come.

And just to remember that our view is that whilst it is more prevalent in older people, as an obstetrician and as having talked to the paediatric community, this is not just a concept that is associated with diseases of older people. We really need to look at, for example, children and young people with complex care needs, where they have to navigate everything in the health and care system and education. And also, for example, the group that I look after - pregnant women with multiple long-term conditions. So, let's really include everyone and ask how we learn across all of those boundaries.

00:08:37

So, the NIHR, together with colleagues from MRC (Medical Research Council) and ESRC (Economic and Social Research Council), who are here today, are really taking steps to address those needs through research.

But really, the point of today is also to join all of you up with policymakers. Let's not leave it in the 'too difficult' box, and let's look at how looking at clustering can really be a sort of a stepping-stone to helping us understand.

Thank you, Sophie.

So, the Academy of Medical Sciences report really highlighted this concept of clustering, and I think that it's something that's going to be woven through much of what we do.

NIHR and MRC [UKRI] and other funding initiatives have already invested over 45 million into clustering research. And we're really seeing the fruits of that. So, for example, Tackling Multimorbidity at Scale to look at disease clusters, determinants, biological pathways, and just to really get us away from the one disease, one mechanism and say, where are the joins in this. And what we really want to do is say, where is the scientific foundation for these new approaches working with industry, so that they come with us on this journey to look at sort of how to do early diagnosis, drug development in a different way, and not just to say, well, let's go down the ever-increasing polypharmacy route, but to look at smarter ways of approaching it.

And then I mentioned that we invested 23 million in the Artificial Intelligence for Multiple long-term conditions [call]. And what I really saw when I chaired that committee was that we had two groups, from an AI (artificial intelligence) background and from an MLTC background, and both in the committee and in the applications, it was really striking how these groups had come together to coalesce around this one issue. So [we received] really innovative applications. And we also put in [place] a Research Support Facility (RSF).

That is when I started getting involved in sandpits like this one, where the sum of bringing people together, there was much less of the highly competitive academic environment, and I saw much more of what we've got here this morning.

So, both of these programs are in progress and awards are expected to finish between 2024 to 2026, and it's absolutely vital that we say 'so what; what next'? At this point rather than waiting until 2024.

Thanks, Sophie.

00:11:08

So, the projects within the cluster portfolio are particularly interested in working towards different parts of these pathways, and, as I say, it might feel as if we're getting ahead of ourselves. But actually, if we built in the 'what next' at this stage of the projects we know that we're going to be much more likely to have outputs that really stick with policymakers and really are relevant. They're what policymakers will recognise as being important and work that they can apply.

So, it's never too early to start that. And even if you think you're in an earlier phase, and what's Lucy talking about? Make the connections that you can see today, and this is really the point of it, to say what does that that pathway look like?

The other side of this is that we have to involve people with multiple long-term conditions and the health care professionals who are involved, so that they recognise what are the outputs of this project going to look like. So how are we going to provide those services? How might we best intervene to prevent people developing multiple long-term conditions? How can we address the polypharmacy issue? And think about how we tackle the harm from medication, particularly when you see more than one condition.

Thank you.

So, we've thought about this left or right, [pre-clinical development versus clinical development versus implementation] pipeline, and some of you will be familiar with the valleys of death, and the valleys of death are particularly where we've not necessarily thought about that pull through, that translation, and that's really one of the reasons why we're having the meeting this morning. Because if we can see the valley of death coming before we fall down it, then I think we'll be so much better prepared to say, 'where's our bridge'? Where's our bridge to the next stage? And that includes working with all these groups that we've talked about.

Next slide, please.

But as many of you know, I talk about the translational circle, and I think multiple long-term conditions are really the best exemplar. So, the circle means that you don't just go left, right, and then stop. That you go left, you go around the circle from the discovery science into the clinical trials phase through the phases into implementation into real world. And you stop and say, well, what's working and what's not? And it's that real world, that implementation to the real world, that tells us whether it's for the patients of today, that 14 million with multiple long-term conditions, and then you go, it's bi-directional, you go backwards and say, well, the earlier in this translational circle that you involve people with multiple long-term conditions, the more likely you are to understand those disease trajectories, those disease clusters, that would enable us to have treatments that really do work.

So, patients in the real world are not often like that very tightly defined phase two trial group. Now, I work with plenty of people who work in the phase two trials space, and they tell me why it's

important. But our own EME (Efficacy and Mechanism Evaluation) programme is really looking at how to encourage people to be more inclusive rather than the more exclusive, so that we really think about that pull through sticking. And the clusters work is also going to be crucial to understanding those biological mechanisms and thinking about drug targets from a different perspective. So not just going down the disease pathways, but really thinking about well, how does hypertension and diabetes interact? And where could we find drugs and interventions that worked in synergy for both of them?

So, by looking at it as a circle that also pulls in where the policymakers are really relevant to this, and saying, if we just involve policymakers in the top left stage into that real world and that implementation, what if we involve policymakers at understanding the upstream areas? And where does this addressing health inequalities get woven in around the whole circle, so that again we're not surprised when an intervention doesn't work as well when you roll it out across the country, if we've not even included those representative groups in the earlier phases. So that inclusive approach, I think, is so crucial to making our research really land.

Next slide, please.

00:15:25

So, we've talked about how the strategic framework really is aiming to address the evidence gaps that that were named in the Academy of Medical Sciences report to use the cluster approach to say how can we take a scientific approach to understanding what these clusters look like and the 'what next' comes. So many of you might have seen the SEISMIC call (Systems Engineering Innovation hubs for Multiple long-term Conditions) which is to look at systems engineering. Why are we doing that? Because if we involve researchers from different communities to tackle a complex problem, we are much more likely to see solutions from different perspectives.

And one of the themes of today should be: listen to those different perspectives. Listen to all voices. I saw students putting their names into the chat. What have they got? They're going to see something from a perspective that those of us who are working in certain areas might not see. So, listen to all the voices in the group today and ask, what are they seeing that I might not see?

Next slide, please.

So, I mentioned the SEISMIC call. How can the groups on this call look at this and say, what could I do in this space? Where can you come together in collaborations that really start to sort of firm up the networks that you've heard about from Chris this morning? And looking at the development phase, and then those innovation hubs. You are going to be part of the move to change multiple long-term conditions research and work pulling through into policy. And this SEISMIC call is part of that work.

Next slide please

So, happy to take questions, but I'm going to throw a challenge out. What will you do differently after today's workshop? What will you take away that just shifts your thinking? And where this sandpit of people who are excited about these opportunities can do so much. Ask what your pathway to impact is. In days gone by, when I was a researcher, I thought it was something you did at the end. Now I think it's something that we should do at the beginning.

And then where do we also pull in health inequalities? At the beginning. If I look at my slides that I give in other talks, the health deprivation is such a crucial driver, and if we can make it woven into all the work that we do on multiple long-term conditions, our impact will be so much greater.

Thank you very much. Chris.

Chris Salisbury

00:18:02

Lucy. Thank you very much. That gives us a really great overview of the topic, and where NIHR see things going. I think we've got time for perhaps one or two questions. So, if anyone wants to urgently ask a question, perhaps you could put it in the chat.

Let's see what happens. While people are just doing that, can I just ask Lucy - a lot of money has been invested in the first of those four priorities. What about the clusters? Do you have a view about the other three?

Lucy Chappell

00:18:33

So, I think that we need to see funding going forward in a couple of ways. One is through dedicated funding, but the other is that we have to start socialising this across every bit of research. So, we both need the special pathways, and we need people to ensure that this becomes part of normal research, as in it is not something special that only needs special calls. I can't speak for MRC and EPSRC (Engineering and Physical Sciences Research Council) and ESRC, but I want to think that all research funders are going to recognise the needs. And that the research team headed up by Leanne and others on the call, we are constantly looking at NIHR at how can we ensure that we've got the next stages and the pull through. I might have given a different answer before last Thursday before the autumn statement, but I am more confident, after last Thursday, that there is a continued commitment both from this government and any future government that might come our way in 2024 to say, this is a health and care need, that it is relevant; it's not going to go away. So, we need to consider that parallel track of dedicated funding and this community to go and be ambassadors for this being woven into everyday work as well. And I think there's a place for both.

Chris Salisbury

00:19:50

Right. Thank you very much. One of the great things about those four aims is that the first one on clusters has engaged a whole group of researchers who probably weren't involved in MLTC research. But there's things for every other kind of social scientist who wants to look about what's important to patients. Health services researchers like me want to think how do we change the way it gets delivered? There are questions that will affect everybody, I suspect, here.

I can't see any questions – oh, I can see a question in the chat here [Kamlesh Khunti - NIH have just started calls for MLTC research. Should we initiate collaborations now? And can NIHR help foster those collaborations?]

Lucy Chappell

00:20:21

Kamlesh has a question. Kamlesh it's always nice to know that NIHR is ahead of the game compared to NIH (National Institutes of Health, United States). What another brilliant example. So that's a really interesting question, and I could take it a number of ways. We can collaborate with NIH, but we know that they will always have a bigger budget than us, that's how it works. So, we can look at who should be our partners, and I think we've got a couple of interesting options. The first one is global health research. We have our own Global Health Research Programme, and I'd

like to ask this community to think about what can your impact be in partnering up? And I know there's already work in this area. But where do you, where do we support colleagues in global South, other areas in low and middle income (LMIC) countries, because I think we can have really huge positive influence in supporting researchers from those. And if I had to say, where do I think our impact will be greatest, top of my list would be those in the global health community. The other area that we're looking at is international, non-ODA (Official Development Assistance) funded work. So other high-income countries. And whilst I think NIH is always interesting, there are others. So, we have an existing partnership with NHMRC (National Health and Medical Research Council) in Australia. And, for example, we're looking at partnering with the South African funders, where again it's about our impact.

So, it's not that I think we're just the younger sibling to the NIH, I just think that this group of researchers should be proud of what we're doing in the UK and think about where to utilize your wider networks. You know, not excluding the Americans, but also particularly in the LMIC space. Kamlesh, I don't know whether that addresses your question, but hopefully; that LMIC space, I think, is something we are so strong at.

Chris Salisbury

00:22:15

Excellent Thank you. I'm sure there could be more questions, but we have to move on to keep this on time. So, Lucy, thank you so much for giving us your thoughts. Very nice to see you here. And I'm now going to hand it over to you Kamlesh Khunti, who is going to chair the next part of the meeting. Kamlesh, Thank you.

Kamlesh Khunti

00:22:31

Chris, thank you very much for introductions and Lucy for setting the scene. So, this is a real quick question and answer session. We've got the panel members who have been working in the area, particularly in terms of the implementation aspects of multiple long-term conditions. So, we'll have two minutes from our panel members, and there'll be a quick-fire question & answer session. We've got about 30 minutes here. So, first of all, Richard McManus. Richard, who is well known in the area of hypertension. But he's been working in the area of multiple long-term conditions and has got an ARC-funded study (NIHR Applied Research Collaborations) at the moment. So, Richard, over to you.

Richard McManus

00:23:13

Thanks Kamlesh. As Kamlesh has said, I'm a GP (General Practitioner) and researcher, particularly in prevention of cardiovascular disease. I guess that in my two-minute soapbox, the thing I'd like us to think about is, that is when we're doing research, firstly, that we don't throw the baby out with the bathwater, and historically we've excluded people with multiple long-term conditions by design almost. I've been on a European Guideline Committee this morning and looking at the data in trials of people over eighty, for example, something like two thirds of the people that we see in primary care, get excluded from those trials. And I think that we should, as well as thinking about diversity in terms of protective characteristics, we should be thinking about diversity in terms of multiple-long term conditions. The second thing is that we saw during Covid that routinely collected data in the UK is second to none internationally, and I think should make more use of that. The study that I'm being funded on in the ARC call is about looking at structured medication reviews and intervention, which seems an obvious thing to do, but there isn't actually

very much evidence. We're studying it, but actually when these things were set up there could have been a whole set of indicators put in using routine data that could have done this.

So, I don't really want to get myself out of a job, but I think where we're implementing new interventions with less evidence, that should go alongside routine data to find out whether they're actually doing what we think they're doing.

Kamlesh Khunti

00:25:00

Thanks very much, Richard. A little bit more than two minutes, but I'll let you off on that one. Next one - Chris already has been introduced. Chris has been doing some great work over the last ten years, particularly in models of care, so Chris over to you.

Chris Salisbury

00:25:14

So, as you've said, I've been working in multiple long-term conditions for about twelve years, and I'm studying on the epidemiology, the measurements, developing interventions. And probably the thing people might know is the 3D [Multimorbidity] trial of a randomized, controlled trial (RCT) of an intervention a couple of years ago. And currently I'm trying to do an implementation study to try and understand what makes it so hard for practices to change the way they provide the care, and how can we overcome some of those areas.

My kind of key message would be - we were asked to come up with one key message - I think it's naive of any of us as researchers to think that any one piece of research really makes a difference. Rarely does it make a difference in the real world. It's when policymakers hear the same message repeatedly from lots of different sources, and in particular, when they hear it from patient groups. And that's why I think it's really key to work with things like the Richmond Group of charities, who've got some emphasis on this. So, it's just trying to get the message across, in multiple different ways, so that it keeps on being heard. And I think then that's what leads to change.

Kamlesh Khunti

00:26:20

Yeah, thank you. Chris. Now over to another good friend Rohini Mathur. Rohini, over to you.

Rohini Mathur

00:26:29

Thank you very much, Kamlesh. So hello, everyone. My name is Rohini, and I'm an epidemiologist based at Queen Mary University. I'm working on a multimorbidity project, looking particularly at early onset multimorbidity in minority ethnic groups, and in particular, differences by sex. And I think the work that we have done has really shown the importance of understanding that multimorbidity covers a range of conditions which are not necessarily common in the general population. So, for example, in our work, particularly among South Asians, female infertility and painful conditions come out as really key priorities. And so, I think the key messages from our work are really about how to prioritize healthcare services, and to target populations that may not fall under our traditional banner of multimorbidity.

I understand that conditions which are more common in minority groups, or particularly sex specific groups, may have a really high financial healthcare impact. And so, to keep this in mind

when we're designing services and thinking about how to provide care equitably for different populations.

Kamlesh Khunti

00:27:38

Thank you, Rohini, and our final panel member is Professor Sinead Brophy, Deputy Director, National Centre for Population Health and Wellbeing in Wales. Sinead, over to you.

Sinead Brophy

00:27:51

Thank you. I'm the Director of the National Centre, which brings together public Health Wales and three universities. I'm also the early years lead in the Administrative Data Research Wales, which is a partnership with Welsh Government, and I'm a member of the MuM-PreDiCT which looks at multimorbidity and pregnancy using routine data.

So, my key message, in my experience, is implementation is really about timing. So, I think there are cycles when a policy or a service is being reviewed or updated, and that's when evidence is very much welcomed. So, there are specific times when I feel there's an open door, and people do want to know what evidence there is, that can be used to inform change, and what's about to happen. And that's when research really is welcomed. Outside these windows quite often the latest evidence isn't seen to be that interesting or relevant to the cycle that's going on at that moment in policy or decision-making. So, I think knowing the timing is really, really important. If you want to make a difference to get your research listened to. That's my view.

Kamlesh Khunti

00:28:59

Thanks very much, Sinead. Great. We've got 96 people on the panel here; I haven't seen one question as yet. So please, these are really great experts here who you can get lots of information from. They've been working in multiple long-term conditions for many, many years, so please do ask them questions.

So, I've got a question here from Jackie. What is the best way to achieve wider representation and capture patient voice and patient involvement in groups that are physically difficult to reach? Who would like to take that from the panel?

Rohini, you're talking about the minority of the population. Maybe if you want to start first, and then others could have a think through.

Rohini Mathur

00:29:42

Yes, so I think talking about, identifying groups which are hard to reach, really is about kind of redesigning our services to ensure that they are included when we are targeting and designing our services. And so, East London, we're very lucky. We've got a really strong network of community engagement, partially through the Genes and Health study. And so, we really involve people in understanding about the research that they're contributing to feeding back regularly to our participants, who contribute not only to the cohort studies, but also to the electronic health record data which we are using to do all of our multimorbidity research. And so it's really, I think, about keeping people on side engaging them throughout, and making sure that their contributions are valued, and they don't just go into the ether.

Kamlesh Khunti

00:30:36

Any other panel members to discuss representation for the rest of the population? Yes Richard, please do go ahead.

Richard McManus

00:30:42

Yes, happy to talk about this. We're doing some work in pregnancy at the moment, and really trying to target people who are harder to reach in that context. And I think a lot of it is just opening your eyes at the beginning and not just going for the low-hanging fruit which in any kind of research, often tends to be white middle class and middle-aged people, who perhaps aren't working. And there are plenty of patient participation groups that one can engage with to start with, but also actually just making it clear that you are going out and asking for people's views can make a huge difference. I think sometimes you have to particularly, I think, the question referred to people who are with carers and so on. Many practices have carers registers. It is possible to find people by their carers. I think taking it out of the "too hard to do" box is probably the thing, and putting resource in.

In the study that I was referring to in pregnancy, we put a significant, we put a whole workstream about diversity and difficult to reach groups. So, you have to actually put your money where your mouth is. And I think funders are, seem to be, happy to play that on board.

Kamlesh Khunti

00:32:06

I think you're absolutely right, Richard. We've been working in diverse populations for many years, and the only way we get representation is using different methods to recruit these. You know it's no use to use our usual methods of going through primary care practices and sending them letters, you need to work through all the community organizations. We have a number of community champions that we employ ourselves to recruit the population of Leicester, which is, as you know, 50% from minority ethnic background and deprived populations.

Okay, we've got some more questions here. So, there's one here regarding, this is a really important question. Should we be talking about the number of multiple long-term conditions, or should we really be talking about specific clusters of conditions? This is from Ali.

Chris Salisbury

00:32:59

Can I respond to that, Kamlesh? Yes, please do, Chris.

I think it depends on what kind of research you're trying to do. Those of us who are into this world, talk about the distinction between co-morbidity research, which is diabetes plus other things or hypertension plus other things, versus multimorbidity research, which is a more generic term.

I think there certainly are questions that co-morbidity research about specific diseases needs to be answered, but in a way they are, there's been lots of that. And I think what's more difficult and what really challenges me is more generic research about changing the way in which we provide health care for people with multiple unspecified diseases.

So, if you're in primary care, I just don't think the future is designing services for a specific clinic for people who've got lupus, and arthritis and diabetes, and a different clinic for people who've got

hypertension plus asthma plus heart failure. You know, we need a model that applies to the fact that most people using health care have got multiple conditions irrespective of what those conditions are. And I suppose that's the challenge that excites me. But it isn't to say that there aren't good questions about specific diseases, of course.

Kamlesh Khunti

00:34:09

Okay. Any other panel members want to come in? Richard, I think maybe frozen. Well, he's frozen to me, anyway.

Richard – I'm still here.

Okay, Any points for panel members? Otherwise, we'll move on.

Okay, I think, Sinead, next question was directly to you. You can read the question - advice you'd give us on how we can keep ahead of the health and social care policy across the four nations.

Sinead Brophy

00:34:38

Well, in my view, working as researchers, so working across the four nations, really with local people, so not trying to run things from one place, but actually working across with other researchers, so that everybody is aware. So, there is somebody in each place who can be aware of what's happening in their area or in their nation, really.

And so, I think not working in silos, basically but actually working with others very much multidisciplinary and working with people in different nations helps you stay ahead or helps you. And I think it is local contacts that make the difference to knowing what the good questions are to even start looking at. That and being able to work with local people, and so that you can have impact, because obviously people only want to bring in things that they feel are important and relevant from the beginning.

That'll be my quick answer.

Kamlesh Khunti

00:35:42

Thanks very much Sinead. This is another really great question from Shukrat, and many of you, I know, are using patient-reported outcome measures. And so, how widely used and how useful are patient-reported outcomes for multiple long-term conditions in clinical practice?

Chris, you've used them in your 3D study and others as well.

Chris Salisbury

00:36:05

So, I think they are really important, because I think some of the outcomes that really matter, can only be detected by patient-reported outcomes. So, things like people's well-being, and their quality of life which are generic measures of what we're trying to achieve. I can't see how you can get those things except through patient-reported outcomes.

On the other hand, I don't think they are widely used at all, in my current research - implementation research - and I'm trying to introduce them as a kind of routine part of care, to shape care. And it's difficult; it's administratively difficult.

There's no point doing them in a kind of lip service way, as many people do with things like the friends and family tests where they get highly selected group of a small number of people replying. You've got to get it from most people. It's got to be really embedded in your routines, and I don't think that's really working, at least not in primary care at the moment. I don't know how well it works in hospitals.

Kamlesh Khunti

00:37:01

Okay, Thank you. Anyone else want to come in.

Richard McManus

00:37:04

Well, I was just gonna say along the lines of what Chris has just said. I think these aren't widely used. I think, particularly in multiple long-term conditions, but they may have, some really interesting places. There's, for example, a developing literature about restricted activity as a sort of a holistic measure. Just something simple like, have you gone to bed for more than half a day in the last week? And that appears to be quite a useful measure in both predicting future mortality and potentially hospitalisation.

And so, these sorts of measures, I think definitely bear further study and may allow us to detect, for example, deterioration in a global sense, in someone who's got multiple long-term conditions. All the people who are really at the extremes of that, with lots and lots of different things, but getting them to try and monitor things individually, is just impossible.

Kamlesh Khunti

00:38:04

I completely agree with you, Richard. I mean in terms of frameworks for what patients with multiple long-term conditions prioritize, there's 2 or 3 of those. And the two things that they care about is, one is mortality, and the other one is quality of life.

And similarly, using simple measures like that in clinical practice, as you mentioned, Richard would be useful. The other one we have used, haphazardly, I'd say, is, how fast can you walk? Slow? Medium? Medium-pace, slow-pace or fast-pace? And that's been shown to impact on outcome and a really simple question. And a lot of the data from that is from the [UK] Biobank.

Anyone else want to come in at all on patient-reported outcomes?

No? So, Tim's got a question here: do panel have opinions on safe data environments being set up, and how mature they are, will be, over the next few years in order to undertake research with routine EHRs (electronic health records)?

Please, Sinead.

Sinead Brophy

00:39:10

I can say a bit about that because I know HDR UK (Health Data Research UK), where Tim is also part of, is working very much on trying to make it easier and making data fair so, people being able to find it and use it and access it.

I think it's really good that that's a work in progress, if you know what I mean, but I think at the minute it's still extremely hard to work across different trusted research environments (TREs). They all have different requirements. Most of them cost. And so, it is quite a long and difficult process to access data from different places.

Covid changes, changes brought in due to Covid, made that quicker and easier, during Covid. But I think some of the gains on that maybe being slightly lost now. And it's again becoming quite hard to work across different trusted research environments; quite long, time consuming, and expensive. But I think there is a lot of work being done to try to change that. And I think, HDR UK are doing that. That would be my opinion.

Kamlesh Khunti

00:40:28

Anyone else?

Rohini Mathur

00:40:30

Yeah, I can. [Kamlesh] Please go ahead Rohini.

I just want to say, Yeah, I completely agree with Sinead. And I think we're not maybe at the stage where they are completely mature. But we've got some really good examples of good practice through HDR UK. And platforms like Open Safely, which are not yet being used for non-Covid research, but have shown the proof of principle that actually, if you set up an environment where people have access to all the tools, you don't need to have the raw, potentially identifiable data locally to actually produce high quality policy-relevant research. So, I think inevitably it's the way of the future. And I think it'll be coming soon. Working across the TREs will be the next big challenge.

Kamlesh Khunti

00:41:11

Okay, in view of time we'll move on. Got a few questions. In terms of the data environments, I think we are in a great position, as Richard initially mentioned.

I know Jonathan will be talking about some excellent work they've been doing on the NHSE [NHS England] environment. We're already doing pragmatic trials at practice level in multiple long-term conditions, either intensification or mitigations or de-intensification. I think we're in a really good position. But we could, I'm sure, improve.

A question from Amrit. What is the scope for estimating the health and economic burden of multiple long-term conditions and estimating cost savings for interventions? Very broad question. Any modellers here?

No, I personally don't think we [are] there yet, because we haven't got that many interventions that have been shown to improve outcomes. Once you've got that that's when you can do the long-term economic modelling. I don't know if you agree on that.

Richard McManus

00:42:13

You can certainly collect costs at the moment. In terms of resource use, and you know, prescriptions and the resources from a wider societal point of view, in terms of the resources that families may be having to expend in terms of caring. So, I agree with you that the effectiveness side of it is a work in progress.

Chris Salisbury

00:42:39

But I agree with the implication in the question that there probably is scope for more work on estimating the health and economic burden. So that if we do have effective interventions, we can see that it's worth investing in developing these, because the burden, I'm sure, is very high. And even slightly effective interventions could still save a lot of money.

Kamlesh Khunti

00:43:00

Okay? Next question, I think, Chris, directly to you, and then we'll move on in terms of providing more holistic care in clinical practice.

Chris Salisbury

00:43:11

I think this is asking about hospitals. I think the problem is the same in hospitals and in primary care, which is that we increase the design of our systems around single diseases, and what people need is somebody who takes over responsibility for them and treats them as a whole person. And I think that's a bigger issue in hospitals where I would suspect that what treatment you get when you've got multiple conditions is largely predicated on which specialty you happen to get admitted under. And I think that, and I don't know if I should give opinions about how hospitals should organize themselves, but I think that there needs to be somebody who could take a whole person perspective, and then could coordinate the role of all the other specialists involved, and it seems to me, as an observer from the outside, that that's lacking in hospitals as it is in primary care sometimes.

Richard McManus

00:44:01

Thank you. That's a good rationale for more clinical academics in geriatrics or gerontology because those are the people who have got a broad view of the medical side.

Kamlesh Khunti

00:44:15

Question from Jessica. Can the panellists share thoughts on pros and cons of focusing their efforts on local service improvement versus research in this field? And I know some of you are involved, particularly through the ARC, through local service improvements. Anything you can add to that?

Rohini Mathur

00:44:36

Yes, I can start. So, I think particularly in the work that I do, and I'm sure it's true for everyone here, is that quality improvement and research are two sides of the same coin, and you need one to inform the other. So, there's always a continuous cycle of back and forth, and continuous quality improvement which relies on the evidence that we get through our research. And with the MLTC research that we've been doing, we've been using data from across the country. So, the findings that we have are relevant both to the whole population, but can also be tailored to our East London population, because we've looked at differences by ethnic groups, as I've mentioned. So, I think there isn't necessarily a tension between these two aspects, and they both are really important and rely on each other.

Sinead Brophy

00:45:26

I would suggest that it shouldn't be a divided this or that. But actually, the two do need to work closer together on what are the right questions, and what are the right ways of getting the answers to those questions. And so that it isn't research comes up with things that it doesn't help local service improvement and then they can't get their research implemented. But actually, these are one thing of the two working together.

Kamlesh Khunti

00:46:00

I think we will stop there in view of time. We need to go on to the next session. Becky, your question is about policymakers. I think we should be able to take that in the next session, which is about influencing policymakers.

So, I'd like to thank all our panel members, first of all, for your quick presentations, and taking lots and lots of questions. I hope you all find them useful. There are still some questions coming in. Maybe, if people are aware, do answer these questions in the chat, please. Thank you.

Over to you, Chris.

Chris Salisbury

00:46:32

Thank you. Back to me. I'm changing role, back to chair again. And it's my pleasure to introduce - we've had one panel from researchers, and now we want to hear from some policymakers, and I want to hear your questions for those policymakers.

In the interest of time, I'll let them introduce themselves rather than me saying all about them. But we've got four excellent people from different fields and different parts of the UK. So, I wonder if I could ask them each to spend up to two minutes introducing themselves and sharing one key message, or piece of advice that they want to give to attendees. Jonathan. Jonathan Valabhji.

Jonathan Valabhji

00:47:10

Yes, hi everybody and I'm Jonathan Valabhji, National Clinical Director for diabetes. Diabetes and obesity for NHS England for almost a decade now. I'm a diabetologist by trade, my clinical and academic base is Imperial in West London. Over the ten years, I suppose, I've been privileged to have the opportunity to implement a number of work streams in the diabetes and obesity space. I think we've got 14 in total. And I suppose the principal of approach has been firstly, and I think

that's most relevant to today's discussion, to identify high-quality evidence that can be translated effectively at health system population level number one.

Number two is then to make the case, and this is my role then, to make the case for funding within the health system, and very much to back up Sinead's earlier point, that those funding opportunities are not continuous. They're episodic and that's a really important point to understand. And the cardinal opportunities come with a government comprehensive spending review that usually follows a general election, so the next one is likely to be in around two-years' time.

So, having then successfully made the case for funding, we've looked at implementation within the live environments of the NHS at scale.

And then the fourth point is to always evaluate. And we're very fortunate, as has already been mentioned, so evaluation using real world data is the real opportunity we have here in England.

So, that is the cycle. An example would be, I suppose, the first and largest undertaking was the NHS diabetes prevention program launched in 2016 achieved universal coverage of the population of England by summer of 2018.

We've had over 1.1 million people referred in, and the latest evaluation using real world data shows that it does what's written on the tin. It reduces incidence in participants, but also using difference in different approaches is exploiting the phased roll-out of the program seems to have a modest impact to reduce incidence at population level as well.

So, those are the principles I think, of policy implementation. I think that's why I'm here today. Kamlesh did allude to some work we're doing. We exploited the power of national data set linkage during Covid, which is huge, and led to us being able to answer some of the sort of important early questions in the pandemic. But we're using the same linked data sets now for a piece of work around multiple long-term conditions, which is what Kamlesh was alluding to earlier.

I think you're on mute, Chris.

Chris Salisbury

00:50:09

That's when I did it first. Lorna, Lorna Kelly, please introduce yourself.

Lorna Kelly

00:50:14

Thanks, Chris. I'm Lorna Kelly. I'm the National Strategic Lead for Primary Care at Health and Social Care Scotland. So that's the network of all the integration partnerships in Scotland. And I work closely with Scottish government and currently chair their primary care health inequalities development group. So clearly a different policy landscape Scotland, but really important to be able to operate across this policy context, both within the UK and further afield.

So, I've got a bit of a background on both sides of this debate. So, both in policy and strategy, but also previously heading up a research program and leading an impact model. But really, I've spent most of my time in the grey area in the middle, where, having clear access to evidence of research really helps me to influence policy effectively.

When I worked at Glasgow Centre for Population Health, we were challenged once by a community organisation, who said, 'Why are you researchers all so obsessed with bloody

policymakers? What about real people?' So, I want to pass that challenge on to you this morning and prompt you to be thinking about who's really your audience.

So, it's not just a single policymaker in a darkened room somewhere. What's that widest group of those who are helping to shape policy and practice. And how can you make it easy for that broad audience to find, use, and implement your findings. And to start with, are your questions and your lines of inquiry grounded in an understanding of real-world problems and priorities. Thank you.

Chris Salisbury

00:51:41

Thank you, Lorna. And Jacoline Bouvy, Thank you.

Jacoline Bouvy

00:51:46

Thanks very much. So, I am Jacoline Bouvy. I am the Technical Director for NICE (National Institute for Health and Care Excellence) Scientific Advice and what I want to highlight is a couple of ways in which NICE and researchers and other organizations who are developing research or developing evidence that might be looked at by NICE at some point, can actually engage with us to ensure that the evidence that is being generated, and that research that's being conducted, can actually be considered by NICE hopefully downstream. And there are two main ways in which we do that.

So, the first thing that I would like to highlight, especially for researchers who might be developing a clinical study or methodological research or new methods in taking better account of multimorbidity and multiple long-term conditions. NICE has a science policy research program, and that program offers different ways in which researchers can engage and get input from NICE in different stages of their research. So, we either take consideration of research that has been conducted but in the early stages of developing your research, NICE can offer different ways in which that research can be supported.

So, one thing that we do is that we can offer letters of support for grant proposals that are addressing important research recommendations that have been made by NICE in the past, or research that might align with some of NICE's research priorities. And I think we can put the link in the chat to the landing page, where you can find more information about that. But I did want to highlight that NICE actually has a clinical guideline on multimorbidity, and that one was published in 2016, so it might not be terribly up to date anymore. But there are a number of recommendations for research that were made by that Guideline Committee which usually identifies important evidence gaps for that particular clinical guideline. So, if anyone is developing research, or is planning to do research that might address or might close some of those evidence gaps, that as an area where NICE would be particularly interested. And getting in touch with our science policy research team, I would definitely encourage you to do that, to make sure that we can give consideration to that research.

And then, finally, the team that I lead within NICE - the Scientific Advice Team. We offer advice services to any organization or company that might be developing evidence that might be evaluated by NICE at some point. Although that primarily focuses on advising pharmaceutical companies that are developing clinical studies, that is not limited just to that group of stakeholders. So, if you are developing more large-scale clinical studies, that is something that you can also get in touch with us in that way and see how we might be able to support your clinical studies. I'll leave it there.

Chris Salisbury

Thank you, thank you very much. Calum – Calum Higgins

Calum Higgins Policy and Public Affairs CSP

00:55:13

Hi, I'm the Public Affairs and Policy Manager at the Chartered Society of Physiotherapy (CSP) in Wales. I'm not a clinician by background. I've worked for politicians and third sector organizations in the past. I had a legal background before that. I moved into public affairs by accident, when really seeing people come through the pipeline, at Citizens Advice where I was, and finding that health issues were what were triggering their problems at the end of the day, looking at the source of their problems it was health issues in the main, physical or mental. And I wanted to have an impact on that, and really try and help them at the other end of the pipeline and influence decision makers in the health sphere.

So, my message today is to look at influencing a bit differently. I like to say it's the art of storytelling about your work. Take a step back and think as Lorna said about your audience. And really, most people we forget are human, and they listen to a good story. They listen to a story with a hero. I like to say there is a bit of a story arc to it, and you ask them to take action to help you in that story. That's the key thing, you want to make them buy into what you're trying to solve.

So, if you just take a second to think about your work. I imagine most of you are very academic in the way you work. You have lots of evidence to back things up. But what gets somebody to read it? That's the key question. What gets somebody to sit down and think 'that evidence - I want to read that. I want to see the methodology behind their point'. And that's what the story gets you. That story gets you to somebody to sit down. Somebody who has not got that much time and is trying to make lots of decisions, is looking at budgets, looking at rational things. You get the emotional buy-in if you can present the story behind your work, and why you're doing what you're doing, and that's really my advice is. Right at the beginning of your work, of your research, think about why you're doing it and package it in that way. Slightly differently depending on the audience you're talking to but particularly at a political level, if you want that buy-in, you really need to think about why you're doing it, what the problem is, what's the villain in your story, what's bad and what needs fixing, and how can they help you achieve what you want to do as a researcher and get your point across. So, it's taking that step back is my point, and really think about why you're presenting to the person you want to influence right from the beginning.

Chris Salisbury

00:57:35

Thank you very much. So, we've got four people with a lot of experience, but very different kinds of backgrounds. So, they're really well-placed to answer your questions, so can I encourage you to put lots of questions in the chat, and we'll select from them.

Just to get started, I want to pick up one from Jessica Catchpole, who got in there really quickly with a really excellent question. She says this question is for Jonathan, but I think it relates to what Lorna said as well. How can we better use the voices of people living with MLTCs as advocates in a way that policymakers actually take notice? Worked for many years at Diabetes UK mobilizing people with diabetes, and one of their frustrations is they put in a lot of emotional work and don't feel listened to.

So, Lorna said policymakers say we want to hear - what about the real people? You know they are people, and yet the people say nobody pays any attention when we express our view. I'll start with Jonathan because it was addressed to him. Any thoughts?

Jonathan Valabhji

00:58:30

Yeah, thanks, Jessica. And I know that you're affiliated with Diabetes UK. I mean, I think it is the role of policymakers to take account of what people want as well as what research is being produced out there. Of course, nowadays for research, there's a very clear requirement that the views of people affected by the sort of area research have inputted right from the start, which is an advantage. But I think it's really important, I alluded to in my little sort of two minutes intro, that the first stage in the cycle was to identify high quality research, and what makes something identifiable and useful, a major pull, is that people want it. And to take an example that you'll be familiar with, Jessica, because Diabetes UK funded the DiRECT Trial, which is about achieving remission of type 2 diabetes, you know, the very clear enthusiasm with which that was received by the diabetes community more broadly, including, you know, obviously people living with diabetes. What I'm referring to was so obvious and loud that that made it a very much easier choice to run with that piece of policy.

So, I think that's a really important component and answers, I hope, Jessica's questions at some point. We've been working on this multimorbidity theme within NHS England for about around 15 months now. Personally, I think it's fair to say that we found it much more challenging to engage with people of relevance, with lived experience, because, and this goes right back to the beginning to the intro that you gave Chris, everything is geared towards single conditions. We often, in my line of policy, we engage with Diabetes UK to support us, to glean the views of people with lived experience. But when you look to do that for multimorbidity/multiple long-term conditions, it's a very immature field, and it's not quite so easy to knock on the door of a third sector organization, let's say, to support us to do that. We have the NIHR actually to support us with that. But it's quite challenging, I would say at the moment, and I think many of the people on the call may have more insight into that in terms of launching their research than many of us on the panel actually.

Chris Salisbury

Thank you. Lorna, do you want to add in? Can I just say to all of the panel, can we try and keep our answers short, so that I get a chance to ask some more questions, as far as you can. But, Lorna.

Lorna Kelly

01:01:02

Yeah, I think it's a real challenge back to policymakers, because I think we can be very greedy about how we use lived experience and patient input and suck a lot of information out of people and not give an awful lot back. So, I think there is a challenge around how you show that things are being listened to, and what the outcome of that is because it may be a long time before something gets to policy and practice and changes what happens. They go to their GP or go to other services. So, I think, pushing for that kind of response and being able to show how that works, if I can give an example. We've been working on a national inequality screen with a community organization. They've done a very specific piece of work looking at digital inclusion, and we've been able then to show back to them where that's gone, who it's been sent to, where the report is. And when they appear at other sessions and see that their work has had an impact.

Day to day it doesn't make a huge amount of difference to them, but it does at least make them feel as if they've been heard. So, I think that's a really fair challenge.

And there's something around trying to shape lived experience input to be answering a specific question or part of a particular project that's got an outcome, because otherwise I think you're right. It can all be absorbed and listened to, but perhaps not get very far.

Chris Salisbury

01:02:28

Thank you. Let's move on to a different question. One for Calum. Very helpful advice about storytelling and villains. What would be your advice for grabbing policymakers' attention in the first place?

Calum Higgins Policy and Public Affairs CSP

01:02:43

Yeah, thanks for that. I'd say that the biggest thing is having collective voice. So, speaking from experience in the rehab space in Wales, during Covid, we grabbed policymakers' attention by collectively, as professions, the AHPs (allied health professionals) in particular together, and third sector charities representing patients. That collective voice had a huge impact. We were able to go to the Government with a package of recommendations and things that we wanted to put in place collectively. We were telling what the problem was, and how we wanted to fix it at the same time.

And that was an easy grab for policymakers to go, brilliant, thanks, we were wondering who to ask but you've come to us. So, it's making that easy approach. Having done the hard work for them if you can, if you can get that work done, the stakeholder engagement beforehand, you're a step ahead, and you make life a lot easier for the policymaker in that sense, and I think that gets you the initial buy-in and trust if you go in the approach to influence something straightaway.

Chris Salisbury

01:03:50

Excellent. Does anyone want to add anything to that question? Please keep your questions coming in the chat. Jonathan.

Jonathan Valabhji

01:04:01

Yeah, maybe if I could just state a truism from a policy perspective. I can see the sort of framing of the questions is, if only those policymakers with deaf ears would listen to us, and if only we could get their attention we'd be able to translate our research. I think a really important consideration is, is the research translatable?

And dare I say, much isn't, and I think it's really important from the outset to consider the translatability of what you're doing, and you know, really important factors are number one affordability. I've talked about funding opportunities, but it has to be a reasonable cost envelope to make the bid for funding, number one.

Number two is the delivery in live environments in the real world, and of course, the biggest challenge for our health system and many health systems globally is workforce. So, you need to be mindful of what the additional ask of the workforce would be to be able to translate your research findings into routine practice. And if the ask is huge, and huge additional man hours of

workforce, in time investment, it's probably just not doable. And so, I think considerations of that upfront are really important.

Chris Salisbury

01:05:18

Thank you.

We should follow through on the stories a bit more as well. I kind of feel we sometimes talk as if decisions are all based on scientific evidence, and researchers often think that means randomized controlled trials. And yet policymakers often say, but there isn't one that's exactly in my scenario, in my setting, or that's translatable, because it's a different context. And I think that decisions partly get made in a rational way, but often may get made a lot through conversations, through networks, through people who know people, through people who trust other people who've said things before, and often there isn't a perfect answer that's in the evidence. They have to make sensible decisions with the uncertain information. And that's true of probably of all big policy decisions. There isn't one randomized controlled trial that tells you what to do. You're doing things that seem sensible that've got some sort of basis in that they're consistent with the evidence, even if there isn't absolute evidence to say it's the right thing to do. The policymakers sometimes just have to make decisions. Things that are sensible and affordable, and often they'll listen to people they trust, because they've known them for a while, and they've these networks and contacts, so it's having those stories alongside, but making sure that as scientists our stories are true. I mean, they're based in the evidence. They're not just stories.

Keep some questions coming in the chat. I can't see anyone any more at the moment. Sophie is there anything I've missed?

Sophie Lewis (DHSC/NIHR)

01:06:49

No, nothing coming through at the moment.

Chris Salisbury

01:06:52

Okay, in which case can I ask you, those of you who are happy to make decisions based on evidence, where do you look? How do you find your evidence? Where do you look? What kinds of evidence do you find helpful or unhelpful?

Jacoline Bouvy

01:07:13

I think, I'm sure many people will be familiar that NICE has well-established methods for how we identify and then assess and appraise evidence, and it depends a bit on what part of NICE we'd be looking at. So, often we rely on a systematic literature research as published evidence. But depending on different types of programs within NICE, it might be unpublished evidence that is submitted to us by pharmaceutical companies, or real-world evidence. It really depends on what the actual decision problem is that NICE would be looking at, and that differs in different functions that NICE has.

But I would echo, I think, what Jonathan was saying earlier and what you were saying Chris as well, that NICE as well, even when there are RCTs available, those have their inherent limitations as well as that they often have. And I think that's very relevant in this particular setting, that they have great internal validity, but their transferability to an actual population in the NHS is not

always great. And NICE also relies on Independent Committee, because the evidence is one input into that, but if there is very scarce evidence or the quality of the evidence is not very good, NICE still has to make recommendations, and I think that is an important area to highlight, that the evidence does not always tell them, usually does not tell us everything, and a recommendation still needs to be made. Which is also why NICE has a keen interest in helping the field and helping researchers to make sure that the quality of the evidence that we see and that it addresses the questions that NICE committees need answering.

Chris Salisbury

01:09:09

Thank you. Other members of the panel? Lorna.

Lorna Kelly

01:09:14

Yes, I was thinking about not so much how I make decisions, but if I'm trying to influence the wider piece of policy, or have an opportunity to be talking about multimorbidity? Where do I gather evidence? And how do I do that really quickly? Because I just don't have time to stay on top of absolutely everything. And some of that's relationships. So, I know there's a couple of people in universities in Glasgow and Edinburgh that I can pick up the phone to, drop an email to [ask], 'what's going on around this at the moment? What do I need to know?'

I will spend half an hour on Google. So, you need to make sure that whatever you do is visible, and comes up clearly, either as research or because it influences other things. And I'll often look to organizations like the Nuffield Trust, like the Kings Fund, like the Health Foundation who are just really good at being able to present things in the way that's relevant to context. And some really basic things - infographics, use of presentations. I saw a presentation last week of some research that had been done in the University of Glasgow, that I'd read before - I read it about a year ago - but the way it was presented very, very clearly made a couple of things stick in my mind that I can think of where I can play those into a national piece of work around access. Think about that presentation, and how easy you're making it for people to find.

Chris Salisbury

01:10:30

But again, it fits with the stories idea that you know you've got to have an elevator pitch of a key point, like you got from the infographic. Jonathan.

Jonathan Valabhji

01:10:39

Yeah. I mean the most important source of high-quality evidence to consider for implementation is the peer-reviewed literature, and within one's field, one has to do one's best to be up with that from a policy perspective.

Also, in terms of your point, Chris, really good point that sometimes there won't be an ideal randomized controlled trial that fits what you're after. It doesn't stop at the end of the randomized, controlled trial. And I've mentioned implementation science with wrapped around evaluation using real world data. We are incredibly fortunate in the UK to have such richness of real-world data. You know, every data point in health is captured electronically, certainly in general practice – we're a bit slower in hospitals but catching up.

The second dimension is that it's nice to think that policymakers can sit there and choose the best evidence and implement evidence-based policy. It's not always like that. Sometimes there will be someone very powerful in government who wants something done in some area where there is a lack of evidence, and that can be a much less comfortable position for someone, for a policymaker. Certainly, from our perspective, and I could quote some examples of that where there has been an absolute imperative to run with something with lack of evidence. But again, one does one's best to go with as good as evidence there is. Implement and evaluate, but be very clear, and that's what we call a pilot, and some people say that the NHS has, what's the term, more pilots than NATO (North Atlantic Treaty Organisation). But you know you pilot something and evaluate with the very clear deal that if the evaluation is panning out, well okay, scale up. But if it's not that you, park it.

Chris Salisbury

01:12:32

But that those very important people get their ideas from somewhere, something they want done, and I think, where do they get that idea from? And I'm guessing that it's partly again what I say about networks. It's partly about pressure groups. It's noise in the newspapers. So, in a way, I think it is up to us to generate the right kind of noise. Working with patient groups, for example. When enough people are saying something needs to be done about, I don't know, waiting lists. Then very important people will say something's got to be done.

Somebody asked the question as well as the people on the call. How do we best search for policy contacts? That's a very good question. And as a researcher, sometimes I want to engage with policy, but I don't quite know how to find the right people to engage with.

Any thoughts?

Calum Higgins Policy and Public Affairs CSP

01:13:23

I'll just jump in. Yeah, you know that's what I do for my members. So professional bodies will have people who have these connections for you. So, if you are a member of professional body, I would bite a hand off my member who approached me saying 'I want to speak to policymakers' because I'm always trying to encourage them, and it's actually quite difficult sometimes to get people to do it. Maybe that maybe they're just a bit shy, or they haven't got the confidence, they're thinking they're going into a very strange world in terms of policy making, and then politics and that sort of thing. But there'll be people out there, professional bodies or network chairs, and people like that out there who really would like engagement with people who are interested in influencing policymakers. So, it's a matter of putting yourself forward to these people if you can find them. And make those personal contacts and relationships, and then you'll find that once you do it a couple of times the door is open and more and more people will know your name and will approach you. There's no easy way of doing it. It's about networking, really, and using every opportunity you can to highlight your work in any stakeholder events or anything like that that comes up. Just get out there and sell what you do with some confidence.

Chris Salisbury

01:14:40

Great. Absolutely. Any other thoughts?

Can you give an example of something that researchers have done to engage with them, that they found, Lorna's given one example already - the infographic. But has anyone got any other

examples of things that they found really helpful that researchers did to help get the message across.

No?

Jonathan Valabhji

01:15:06

Well, it's obviously useful for researchers to engage as early as possible in the process with policymakers. I'm very happy to be approached in my neck of the woods early on. The NIHR in particular, and most grant awarding bodies, are actively encouraging that from very early stages, and I've very much noticed an increase flux into my inbox of approaches from people very early on. And I suppose there needs to be a balance of how much time one can invest getting one's brain around multiple projects at the pre-submission phase of the first call, balancing that with projects that are more likely to get funded. And so, there's an issue of how you best deploy your time. But I think, trying to get your objectives, and your projects on the radar of policymakers, or at least you know bounce the ideas off them as early as possible, I think is a, you know, really sensible ploy, if people can do that.

Chris Salisbury

01:16:12

So, anyway, you're creating the appetite for people to want to know what the answer is going to be, because they've known about this.

Lorna.

Lorna Kelly

01:16:20

I think the best things from my point of view are things that put the research into context, and that's partly the implementation context, but also partly just the I suppose, the wider service and social context of what we do. Because very often research will be very specific, it might be quite narrow, but it adds to the field of knowledge, and so I think, as researchers, it's really important and incredibly valuable if you understand your field, not just your research. So, you're able to really clearly say what this adds, what everybody else is saying, and then what it might mean for practice, because it starts to put it in a kind of language I can do something with.

Chris Salisbury

01:17:03

Hmm. That's helpful. Thank you.

I see There's another question from Simon Fraser, but I'm afraid Simon we've run out of time really to answer it. But if anyone would like to answer that in the chat please feel free. But I'm keen that we stay on time, because you now have a ten-minute break.

Please go and quickly make yourself a cup of coffee, or whatever. I suggest you leave your zooms on and then we'll start up again at half plus eleven.

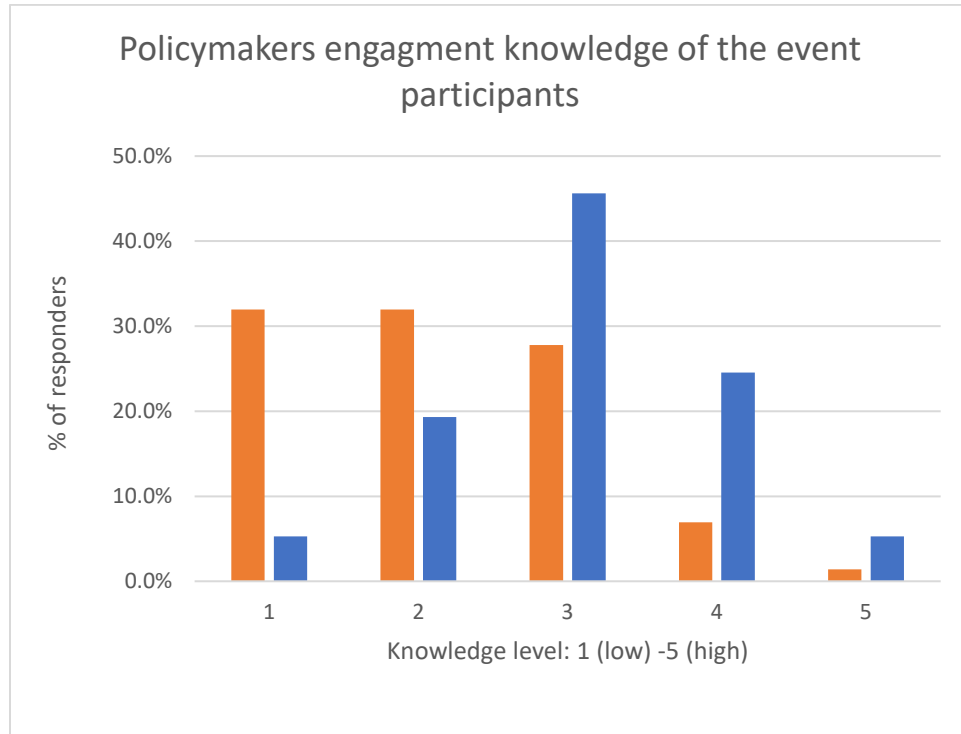
Sophie, I think you wanted to quickly do a quick poll again.

Sophie Lewis (DHSC/NIHR)

01:17:38

Yeah, just before people leave it's going to pop up. It should be on your screen now. This is just to again help us understand how useful the event has been.

What is your current level of knowledge of engaging with policymakers? scale 1-5: 1 (low level) – 5 (high level)



Jane Strom - MRC UKRI

01:17:46

Yeah, also, while you are doing, poll and taking break, I would just like to request everyone to please consider if there is anything more that funders can do to support your knowledge and understanding on engagement with policymakers on MLTC-M research. Please pop up any suggestions or feedback in the chat, or after the event we very welcome you to write any notes or thoughts to the multimorbidity email address (multimorbidity@mrc.ukri.org). Thank you.

Chris Salisbury

01:18:16

Thank you.

So, everyone feel free to go. But be ready to start again at half past eleven. I want to make sure you finish on time, so we'll try and start again on time. Eleven thirty. See you soon.

01:18:29 (11:30:19)

Welcome back everyone! We're ready to start again, and in a moment, we're going to put you into breakout rooms where you're going to have 25 minutes to discuss and agree on. Your task is to

identify three facilitators to achieve the implementation in MLTC research and one barrier. Make sure we're focussed on the positives. So, 3 facilitators but just 1 barrier.

Could you nominate one person from your breakout room to briefly feedback. I'm not quite sure yet how many groups they're going to be but be prepared to give a very short feedback on what your 3 facilitators and 1 barrier were. We'll be coming back, ending the breakout rooms at 11:55, so you'll probably find it just suddenly stops, and you get put back into the main venue. So be prepared for that and be ready to go. I hope that's all clear.

Chris Salisbury

01:19:20 (11:56:40)

Excellent. So, I'm hoping everybody is back from their breakout rooms. We've now got 20 minutes to just hear what you all said. We've got 8 breakout rooms, so that gives you about two minutes per group, so try and keep your comments brief. And maybe, if what you are going to say somebody else has already said you, can either say something else, or you just have 2 facilitators and one barrier. Let's try and think of the positives, the positive facilitators. So, I don't know if they've got numbers or something. How am I going to introduce the breakout rooms?

While you're working that out, I will start with the group I was in where Alice Harper is going to tell us what people said. So, Alice, do you want to start?

Alice Harper

01:20:11

Yeah, perfect. So, I think the first thing we talked about which was relevant to today is thinking about the kind of events that you have within the multimorbidity sphere. And you know, good networks, and working with different people across lots of different disciplines to, I guess from a sort of junior researcher perspective, know sort of who you can approach to help facilitate implementation of research.

The other thing we talked about was working with other organizations. So particularly within a kind of IT sphere if we're doing, sort of trying to implement things within clinical practice it's about working with other organizations to provide the appropriate tools and resources which can then be used hopefully, nationally for other people to implement elsewhere as well.

And we talked about the availability of data as well, so increasing recognition of trying to link up data that's available from different areas. So, particularly between primary care and secondary care. And so that was three quite quick facilitators there.

Barriers we talked about were health care professionals in different pockets maybe not having academic backgrounds. So, we had a dentist within our group, and she in particular was talking about barriers to pathways for academic training within dentistry, and then it's about getting sort of different voices across the MDT involved in research for those with multiple conditions, because obviously everyone needs to be involved.

Chris Salisbury

01:21:54

Brilliant. Thank you. Thanks for keeping it brief. Well done.

So, we were room two. And now we want room one, which is the room that has Alex Dregan and Anna Freeman in. And I don't know who's going to speak on behalf of that group.

Emily Henderson

01:22:09

I am Chris. Hello, it's Emily Henderson.

It's a bit like, say bigger, because you've crossed off a couple with group two. So, just in terms of facilitators, we talked about having adequate resources broadly in terms of expertise and skills and finances and time to try and facilitate things.

And the major barrier really came under the umbrella of complexity at the individual level in terms of aspects like cognitive impairment and dementia, the sort of settings people are often in, like care homes, and then more structural aspects, such as the way in which health care systems are structured, and people have mentioned kind of silo approaches to health care already, in a nutshell.

Chris Salisbury

01:22:55

Thank you.

Then Room 3, which is the room that had Carrie Coope, Amrit and Jonathan in. Would someone like to speak on behalf of that group?

Jonathan Valabhji

01:23:15

I think I got voted to feedback. So, facilitators for implementation of MLTC research were:

Number 1 - harnessing the voices and views of those with lived experience makes it more compelling, number 1.

Number 2 - We were fortunate to have Laia, who is a health economist who suggested that effectively communicating the output of health economic analyses, so that the outside world and policy makers can understand is an important facilitator. So that's our number two.

And number 3 was developing interventions for MLTC with those/ alongside those who will be responsible for delivering those interventions meaningfully.

Those are the three interventions, and we agreed on a major challenge is actually designing endpoints that are sufficiently sensitive to be able to show differences between intervention and control groups where perhaps the Cochrane Review in the past has highlighted that just using patient experience maybe too blunt a tool to actually pick up those differences. How's that?

Chris Salisbury

01:24:22

Excellent. Thank you. You're all doing very well, keeping brief. So that was room 3. Room 4 is the room that had Kamlesh Khunti, Andrew Hutchings, Rosa Parisi in.

Andrew Hutchings

01:24:33

So, I'm Andrew Hutchings. I'll be feeding back on room four. So, we've covered quite a bit already. I suspect we're getting to the stage of duplicating quite a bit, so we agreed on the databases. We agreed on some of the practical elements of making research doable. Things like having the tools. And the third big one we came up with was about engaging communities. So,

mobilising local communities, involving patients and the public in that, bringing in the lived experience. So that was our other key facilitator.

On challenge, we went for complexity, but within that, then some have been mentioned already. But other questions are the range of different conditions that contribute to MLTC. Prioritisation of research, and how we prioritise what is most important. The range of research designs from qualitative to quantitative, genetics to very applied, and different health and care settings. And also, the questions ranged from everything, from prevention through to treatments and a whole range of other types of question that we'll be dealing with. That's it. Thanks.

Chris Salisbury

01:26:02 (12:03:22)

That's both a challenge and an opportunity, all those different questions. Yeah, thank you, Andrew. Room 5. That was the room with Anni Bailey, Gillian Yeowell, your Mon Fletcher and Nigel Harris.

Nigel Harris

01:26:14

It's Nigel. So, I've been nominated.

So, in terms of facilitators, we felt that the environment is right. So, in terms of, really recognition of the of the scale, and that we need to do something.

The second is around the funding. So, the funders understand that this is a challenging area and are making funding available, which obviously is a really big enabler.

We talked a bit about working together. And one of the areas or one of the big opportunities is that some of the charities, the Richmond Group of Charities, are now working together. So, for example, the Stroke Association, Diabetes UK, are all working together to bring the voice of the patient. So, we're not getting this siloed thinking, which we think is also, which can be a barrier. And of course, the formation of the ICSs (integrated care systems), although it's too early to tell, that clearly, around commissioning and provision of care, it's a big opportunity.

In terms of challenge, really it is around systems change. And I gave the example of the Swiss cheese model where you get an incident and getting all the holes lined up, and the same is true of implementing positive change. It's around how can you get the holes all lined up in the different elements to implement that.

Chris Salisbury

01:27:43

Excellent Thank you.

Room 6 is, so it could be Emma Broom, Jackie McRae.

Jackie McRae

01:27:53

Hi, I'm Jackie McRae. I've been nominated to feedback for my group. Say for us, yeah, a lot of things have already come up. But we had a discussion around getting involved with ARC, your local ARC and getting closer to decision makers early on, and embedding implementation science as well, early on as part of your research. Again, we also talked about charities as facilitators, collaborating widely.

And some of the barriers really are around funding for engaging patients for even research priority setting. So much earlier along the line and co-design. But also, we identified that as sometimes those links with patients break down when particularly early career researchers are involved in short term projects. So those links aren't maintained, and sometimes it breaks down the trust that you are trying to build up with minority groups.

So yeah, I think that was the extra bit on top of what everyone else said.

Chris Salisbury

01:28:55

Lovely. Thank you.

Room seven. Sinead Brophy, Katila George, Mariam Asaad

Sinead Brophy

01:29:03

We, one of the facilitators is events like this which actually greatly improves networking and ideas and strategies.

Another facilitator is that pathways to impact is now built into funding grants. So, it is something that people are assumed to think about and have ideas and strategies on.

And also, like with the charities, that there is now recognition that multimorbidity is part of even in the individual charity. So, there's really good funding opportunities, if framed correctly.

The barrier, though, is it's very hard for early career researchers to break into this because it needs such a multidisciplinary and really very large approach to the research. And quite often the funding you can ask for at the end isn't enough for early career researchers. So, you have to work with charities to lobby and make a difference, to continue this, because for early career researchers it's really quite short term.

Chris Salisbury

01:30:10

Okay, thank you.

And then last, but not least, from eight, which is Emma Healy, Marlous Hall, Ratna Sohanpal.

Marlous Hall

01:30:16

So, I'm Marlous Hall. I don't think we got as far as nominating anyone, nor did we really write down three points. But, just picking up on this similar discussions, we really came up with the thought that it was quite difficult for individual researchers to have good and meaningful and PPI engagement with, you know, enough representation from the multimorbid community. And we kind of thought that actually the funders could help with establishing groups such as this, which kind of could have lots of PPI involvement, and maybe feed into several projects, so that the PPI representatives themselves feel engaged on a number of different projects, and they might kind of align themselves to a particular area. But also, so that they don't kind of lose interest when inevitably research takes a long time to kind of develop. If there's several projects going on, there might be more things to update them on a regular basis. That was kind of our main enabler for future research growth in this area that's meaningful.

Chris Salisbury

01:31:20

Excellent. Thank you. Any barriers that you wanted to highlight? No. Okay.

Good. Thank you. What you've got. I've just been writing down this to about 15 different things that people have said which is great.

And I could see that Mon Fletcher has just put something in the chat to say that the commercial sector, both pharma and med tech, are also beginning to change strategies and look across diseases and could be a powerful driver in the future. That's something we haven't talked a lot about the commercial sector, but certainly NIHR will be very keen on us working with them.

Thank you everybody. I think we've come up with a fantastic list of things that you've done really well to keep you positive and not just focus on the barriers. Many barriers are also facilitators in the sense that these are the problems, but we can see ways of trying to overcome them. And if we overcome them, then they could become real facilitators. So, the example of the data sharing we were talking about. It's difficult to link up data sets, but there are lots of people who are trying to do that. And when it's achieved that becomes a facilitator to do really good research across primary and secondary care, and health care and social care.

Now, throughout this whole exercise we've had Alex Cagan, who is an illustrator, taking notes and trying to kind of capture all of this conversation within an illustration based on this discussion.

I realized I'm about five minutes ahead of time Alex, so I don't know whether you happen to do this very fast, or whether I'm asking you to share too soon, but in which case tell me and I'll try and think of a joke or something for five minutes. But tell me how you're doing.

Alex Cagan

01:33:01

Yeah, I think Sophie might have some of the images I've sent through to her, if she's around to share.

Chris Salisbury

01:33:08

Thank you, Alex. I should have introduced you earlier.

Alex Cagan

01:33:13

No problem. Yeah, that's a fascinating discussion. I also work at the Wellcome Trust. So, it's been fascinating hearing about this topic.

Sophie Lewis (DHSC/NIHR)

01:33:20

Just sharing the first illustration, which was based on Lucy Chappell's talk, which Alex has produced.

Landing **MLTC** Research in the Health & Care System

Lucy Chappell

Poorly Coordinated care designed around single conditions

Need to integrate mental & physical wellbeing

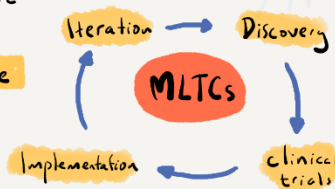
Evidence based care

14 million in UK with MLTCs

○ account for > 1/2 primary + secondary care

Not just the elderly → include everyone

Global Health Initiatives



Pathways to Impact

Research + Investment to get MLTC out of the "Too Difficult" box

Clustering



UKRI £45m investment into how diseases cluster

Improve clinical decision making

Identify ways to prevent MLTC

How to remove harms from medication

👂 Listen to ALL Voices

Health Inequalities

@ATJGagan

Kamlesh Khunti

01:33:26

Lucy's going to love this.

Sophie Lewis (DHSC/NIHR)

01:33:27

It's very accurate, isn't it.

Chris Salisbury

01:33:31

Alex, do you want to say anything about your illustrations?

Alex Cagan

01:33:35

Oh, no, just that I'm trying to, you know, as was touched on in the discussions. I think infographics can be a very useful way of kind of summarizing and communicating scientific research and policy. So hopefully, those will help contribute and kind of give examples of how those can be used in this kind of field.

Chris Salisbury

01:33:49

Yeah, absolutely. We think visually don't we.

Sophie Lewis (DHSC/NIHR)

01:33:55

I will just stop sharing and then share the second illustration that Alex has shared with us.

We will be distributing these after the event as well.

Kamlesh Khunti

01:34:05

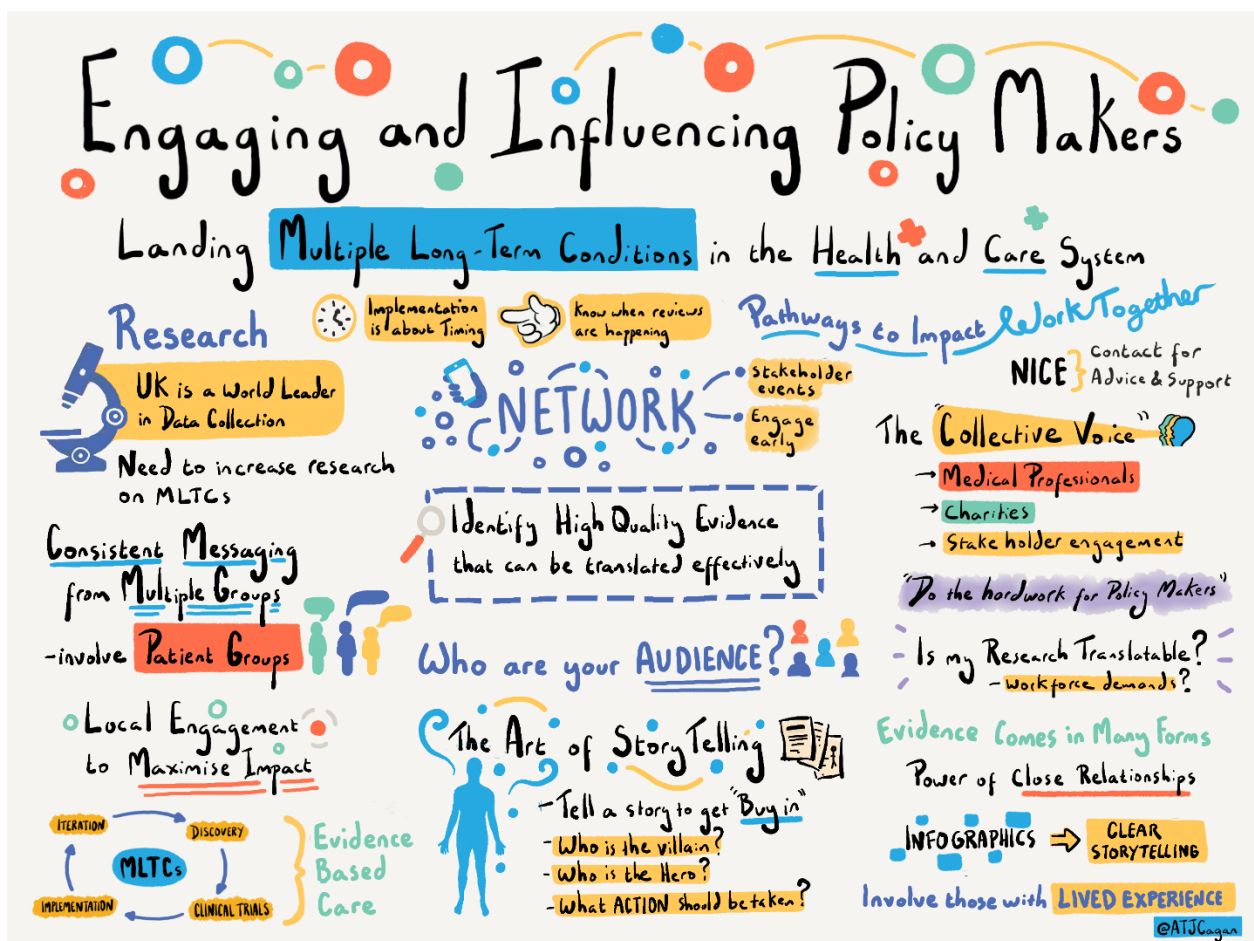
I'd get the permission from Lucy first before you share them.

Sophie Lewis (DHSC/NIHR)

01:34:11

Hopefully, that's popped up on screen. This is the second illustration.

I'll give you a little bit of time to have a look at it.



Chris Salisbury

01:34:21

I was going to say these are gonna take time to think about and take in, aren't they.

They do capture many of the things people have been saying. And I hope people will take these away and think about it. It'll remind you of some of the things we've talked about a rather more quickly than watching the whole YouTube video and, you know, I hope this will challenge some of us to think differently. All of us to think differently about how we do research and how we translate it, and how we make it available.

Kamlesh Khunti

01:34:58

Can someone Tweet these? These are fantastic, really good.

Chris Salisbury

01:35:07

So yeah, somebody saying, Marlous is saying, wow we've been dreaming of something like this; found it's difficult to find the connections.

Alex, can we use these things?

Alex Cagan

01:35:18

Yeah, yeah please, or at least from my side people are welcome to use them however they want. That's the idea of making them is to for them to be spread around and used constructively. So please anyone feel free to use them in talks or presentations or share on social media. Whatever you think would be best.

Chris Salisbury

01:35:32

Excellent. Thank you so, Sophie will you make these available so that people can tweet about them and show them?

Sophie Lewis (DHSC/NIHR)

01:35:40

Yeah, yeah, we will be sharing them, and we will be using them as well during presentations going forward. So, we're really grateful to Alex for producing those. They're brilliant.

Chris Salisbury

01:35:50

Okay, we're slightly ahead of schedule, which is actually always rather nice, I think, when I'm attending something to not be late. Sophie is there anything else, apart from thanking everybody which I'll do in a minute. Is there anything else I need to say or do?

Sophie Lewis (DHSC/NIHR)

01:36:08

No, you're only two minutes ahead, because the agenda took us till 12:15, even though we have the event scheduled until half past. So, you've done an excellent job at chairing, and Kamlesh too. Thank you very much.

Chris Salisbury



Medical
Research
Council



Economic
and Social
Research Council

NIHR

National Institute for
Health and Care Research

01:36:20

So, thank you to all of our panel members, both the panel of researchers, but also the panel of policy makers that I didn't really thank properly at the time. So, thank you for giving up your time to doing this. Thanks to Lucy, I know she's gone, but still grateful that she came along. I hope this has been useful.

I think for me it's really good that we've managed to focus on the positive. So, I think what's going to be most useful is those lists of facilitators that you highlighted in the groups, and also those illustrations which we can use to really remind me of some key messages, and how we get stories across in the ways that are going to be useful.

So, thanks everybody. I hope you enjoy seeing the YouTube video, that you have the transcript as well, if you want to look at that, rather than watch something again. And I'm sure I'll see some of you at various MLTC-related events in the future. So, thank you everyone for your time. Bye.