**Quality improvement scientific symposium virtual session four: rapid-fire presentation – Emma Forbes**

**Accessible transcript**

**Visual**

**Two video feeds appear side by side. On the left, a woman wearing glasses and a white blazer over a blue dress sits in front of a virtual background of cherry blossom trees and rushes beside a picturesque river. On the right, a blonde woman with white ear buds in her ears and wearing a black top, sits in a room with a bookshelf behind her. A framed certificate is displayed on a side table beside the bookshelf.**

**Audio**

(Gillian): A very warm welcome, Emma, to you, and over to you. Thank you.

**Visual**

**Emma’s video feed fills the screen.**

**Audio**

(Emma): Kia ora, Gillian. Tēnā koutou katoa.

Ko Ruahine oku pai maunga.

Ko Manawatu te awa.

Ko Tangata Tiriti te iwi.

Ko Emma Forbes taku ingoa.

No reira, tēnā koutou katoa.

So, I work with the Commission. Thank you very much, Gillian. I've just got a quick poll, a really quick one, that I'm asking Jane to put up for me. So, considering ethics, I just wanna know if it's true or false. Tell me whether you think it's true or false, considering ethics only applies if the quality improvement activity is reviewed by an ethics committee. I'm gonna give you a few minutes, few seconds for that one, so quickly – time's running. Hopefully you're all doing it. Yeah, I'm hearing some clicking. All right, Jane, can you just close the poll now and just display the results for me? Ooh, look at that. Seems like I don't really have much of a job to tell you guys, because actually, I think you're correct – the answer to that is actually definitely false. So I'm gonna talk to you briefly about considering ethics in quality improvement. So, as you all probably know, ethics is a large and complex subject. So I'm really only gonna be touching very lightly on it. So my aim today is just to outline why ethics is important to consider in QI, just some key points from the standards. Have a brief look at the principles that underpin those standards and just some things to remember when considering ethics in your QI projects. So, I'm just gonna share my screen now.

**Visual**

 **Emma’s video feed shrinks and moves to the right of the screen. A title slide fills the screen. Green and blue banners run along the top and bottom of the slide. The blue and green logo for Health Quality and Safety Commission New Zealand, Kupu Taurangi Hauora o Aotearoa. Below this is a title in bold blue text: ‘Ethics and quality improvement’. Under this in a smaller grey text: ‘Emma Forbes, Quality improvement advisor.’ The slide changes to show the website for NEAC, National Ethics Advisory Committee. The selected webpage has a subheading reading: ‘National Ethical Standards for Health and Disability Research and Quality Improvement.’ Hyperlinks on the side of the website lead to Parts One, Two and Three. Under the website is its address:** [**https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement**](https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement)

**Audio**

(Emma): So, the National Ethics Advisory Committee standards were released and the standards for... Health and Disability Research and Quality Improvement were released in December 2019. One of the things that's quite unique about them is that, actually, it's the first time they incorporated quality improvement into them. It is also where they're brought together via ethics principles in Te Ara Tika framework. The other thing that they did as part of this is they incorporated a risk-management approach.

**Visual**

**A new slide is titled in a bold blue font: ‘Why consider ethics?’ Under this, bullet points in a smaller black font are listed:**

* **Consumers may experience burdens or risk through their participation.**
* **Some consumers may benefit from quality improvement activities at the expense of others.**
* **Quality improvement activities involve the use of health data.**
* **Quality improvement activities can create potential conflicts of interest, when findings indicate shortfalls in care.**
* **If quality improvement projects are not methodologically sound, resulting knowledge cannot be shared with other health care providers.**

**A hyperlink to a website is in the green banner along the bottom of the slide:** [**https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement/part-two/18**](https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement/part-two/18)**.**

**Audio**

(Emma): So, why do we consider ethics? So this is from the standards, but essentially, it's around the fact that people, consumers may experience burdens or risks. It's also that different people may benefit in different ways from the quality improvement activities. We're always using health data as part of our work in quality improvement. And sometimes some of the activities we do actually can create conflicts of interest.

**Visual**

**A new slide is titled in a bold blue font: ‘Underpinning principles.’ Under this are two grey-coloured columns with dark blue banners at the top. The left column has a title in white text in the blue banner reading: ‘Te Ara Tika’. In the grey column are bullet points:**

* **Whakapapa**
* **Tika**
* **Manaakitanga**
* **Mana**

**The column on the right has a title in a white font inside its blue banner reading: ‘Bioethics’. Bullet points in this grey column read:**

* **Beneficence**
* **Non-maleficence**
* **Respect for people**
* **Justice**

**Audio**

(Emma): So the principles that underpin the standards are Te Ara Tika and bioethics. So, with Te Ara Tika, there is whakapapa, which is about relationships; tika, which is about research and design; manaakitanga, which is around cultural and social responsibility; and mana, which is around justice inequity. You'll see that there are quite strong links, as well, with the bioethics principles of beneficence. Non-maleficence, which I always have trouble with saying; which is around don't do no harm; respect for people, and justice. So there are some strong linkages within those things. But it's really awesome that these have been brought into the standards, cos actually, it's a great way of really underpinning Te Tiriti O Waitangi obligations and commitments.

**Visual**

**A new slide shows a webpage titled ‘Te Ara Tika Guidelines for Māori Research Ethics.’ Beside this is diagram of concentric circles titled: ‘Māori Ethical Framework.’ The concentric circles are divided into quarters, with each quarter and each ring of the circle within each quarter being labelled. The four quarters of the circle are titled: ‘Tika - Research Design’, ‘Manaakitanga - Cultural and Social Responsibility’, ‘Whakapapa – Relationships’ and ‘Mana - Justice and Equity. Under the webpage is its address:** [**https://hrc.govt.nz/resources/te-ara-tika-guidlines-maori-research-ethics-0**](https://hrc.govt.nz/resources/te-ara-tika-guidlines-maori-research-ethics-0)**.**

**Audio**

(Emma): If you do want to know more about Te Ara Tika, if you haven't read it before, then it's on the Health Research Council's website. You'll see from the diagram that's there that Te Ara Tika is quite an in-depth model, and it's actually got quite some good pointers on how to do research with Māori.

**Visual**

**A new slide is titled in a bold blue font: ‘Key Points.’ Under this, bullet points in a smaller black font are listed:**

* **The Standards apply to quality improvement activates regardless of whether they are reviewed by an ethics committee.**
* **Quality improvement activities should aim to limit ethical risk and maximise potential benefits.**
* **Ethical risks will need to be assessed regularly and managed throughout the activity.**
* **Quality improvement activities generally have low or negligible ethical risk.**

**Audio**

(Emma): So, just back to some key points about what's coming through some of the standards. So, the standards apply to quality improvement activities, regardless of whether they are reviewed by an ethics committee or not. Quality improvement activities should aim to limit ethical risk and maximise potential benefits. And that actually, those risks need to be assessed regularly and managed throughout the activity. If you reflect on some of the QI activities you have done, you know that there are ways that we come up with new ideas or new things, and so actually, when you come up with those, you've really got to make sure, actually, what's the ethical risk or the potential benefits of doing this. So, quality improvement activities generally have a low or negligible risk.

**Visual**

**The next slide shows a page from the Health Quality & Safety Commission New Zealand website. A title in white text in a green banner reads: ‘Ethics guide for health providers conducting quality improvement activities.’ The web address is listed below:** [**https://www.hqsc.govt.nz/our-programmes/building-leadership-and-capability/projects/ethics-guide/**](https://www.hqsc.govt.nz/our-programmes/building-leadership-and-capability/projects/ethics-guide/)**.**

**Audio**

(Emma): So, this is the guide that we came up with. It's on our website. It's very much a summary. We aimed it for people who are at the front line, around... to help them when they're doing the QI project and understanding what the ethics is around it.

**Visual**

**A new slide is titled in a bold blue font: ‘Define your activity’. A subheading in black text reads: ‘Research or quality improvement?’ Beside this is a table which is titled: ‘Table 1.2 - Differentiating research from quality improvement.’ The table is split into two columns. The column on the left is labelled ‘Human participant research.’ The column on the right is labelled ‘Quality improvement activities.’ The table has two rows. The first row is labelled ‘Description.’ In the ‘Human participant research’ column, it reads:**

* **Activities which attempt to create new generalisable knowledge in response to an acknowledged information gap.**

**In the ‘Quality improvement activities’ column, it reads:**

* **Activities which aim to improve healthcare by assessing current situation and systematically implementing evidence-based knowledge within a local organisation.**

**The second row of the table is titled: ‘Goal.’ In the ‘Human participant research’ column, it reads:
Quantitative research**

* **Acceptance or rejection of a hypothesis in relation to treatment, cause, risk or diagnosis of a health problem. Small differences may represent a significant finding.**

**Qualitative research**

* **Description and interpretation of something in its natural setting. May address how treatments and relationships are experienced.**

**In the ‘Quality improvement activities’ column, it reads:**

* **Ensure healthcare delivered by organisations are effective, safe and equitable through the application of improvement science methodology.**

**Along the bottom of this slide is an address:** [**https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement/part-two/1-scope**](https://neac.health.govt.nz/national-ethical-standards-health-and-disability-research-and-quality-improvement/part-two/1-scope)**.**

**Audio**

(Emma): So, first off is to define your activity. So is what people are doing research or is it quality improvement? Because there are some similarities across those two aspects of work, but actually, there are some differences. And in the guide, in the standards, you'll see that there is, which I'll show on the screen, is that you can see the... that the human participant research and quality improvement activities have some differences around what they're doing. It's gonna help make it easy for going forward. What we've done is we have incorporated those into... We've incorporated those and some questions, some top-level questions into that, so that we can understand, actually, have they- how do you define research, and how do you define quality improvement?

**Visual**

**A new slide is titled in a bold blue font: ‘Consider ethical risks and potential benefits.’ A subheading in a black font reads: ‘Questions related to principles.’ Under this is a series of bullet points:**

* **How will/have Māori been engaged with the quality improvement activity?**
* **How will this quality improvement activity avoid causing harm to individuals and communities?**
* **Who will benefit from the quality improvement activity?**

**Audio**

(Emma): The next thing you do is once you've agreed, once you know that you've definitely got a quality improvement activity, you then consider the risks and potential benefits of... for that activity. So, we've developed some questions related to the principles, for instance, like how will/have Māori been engaged with the quality improvement activity? How will this quality improvement activity avoid causing harm to individuals and communities? And who will benefit from the quality improvement activity? So the point of these questions is to help teams decide, actually, and explore actually, what it is, what are the ethical risks and the potential benefits for the piece of work that they are doing?

**Visual**

**A new slide appears with the same title in bold blue text: ‘Consider ethical risks and potential benefits.’ Under the title, a block of black text reads: ‘If potential consequences for participants are identified, put in place actions to manage them.’ Beside this is a diagram made up of small hexagons surrounding a larger hexagon, making a honeycomb pattern. Each hexagon contains white text. Grey shading between the smaller hexagons indicates movement from the hexagon at the top and travelling clockwise around, ending at the large central hexagon. Starting at the hexagon at the top, they are labelled: ‘Privacy and confidentiality’, ‘physical’, ‘psychological’, ‘emotional’, ‘social and cultural wellbeing’, ‘financial’, and the central hexagon is labelled ‘participants’.**

**Audio**

(Emma): So once you have identified any adverse consequences or ethical risks for participants, you are kind of looking at, you know, is there a risk to their privacy and confidentiality, their physical, their psychological, their emotional, their social and cultural being and their financial. And if you do identify risks, then the key thing here, in any good risk management process, is to put actions in place to manage these.

**Visual**

**A new slide is titled in a bold blue font: ‘Data Collection.’ Under this is black text reading: If collecting new data from participants, think about whether data collection:**

* **will put an additional burden on participants**
* **will need culturally safe and appropriate methodologies**
* **involves information that is sensitive in nature or application**
* **involves vulnerable individuals or groups**
* **potentially may cause distress.**

**Audio**

(Emma): With data collection, there are additional risks that could become- that could come through. So if you're collecting new data from participants, you need to think about whether data collection will put additional burden on patients, on participants. Will there be a need for culturally safe and appropriate methodologies? Does the data collection involve information that is sensitive in nature or application? And also have you vulnerable individuals or groups that you're talking with? And also, will there be a potential for causing distress to participants as part of doing the data collection?

**Visual**

**A new slide appears with the same title in blue text: ‘Data collection.’ Under this is black text: if using existing data:**

* **Use non-identifiable data where possible**
* **Use in-line with the consent given.**

**Audio**

(Emma): The other thing that we tend to rely on is around data, and often we use routine existing data, through audits or through our patient management systems or other systems. So the key thing here is that where possible, use non-identifiable data, and use it in line with the consent that it's been given for. One of the examples they provide in the standards is that you shouldn't really be using the contact information for patients to try to find out that- to try to approach them to be part of a survey or an activity.

**Visual**

**A new slide appears with a title in bold blue text: ‘Data collection and management.’ Under the title, a block of black text reads:**

* **Make a plan for ensuring the sovereignty, privacy and confidentiality of data.**
* **Ensure data has been collected and will be analysed in a culturally appropriate and equitable way.**

**Beside this is a diagram made up of small hexagons surrounding a larger hexagon, making a honeycomb pattern. Each hexagon contains text. Grey shading between the smaller hexagons indicates movement from the hexagon at the top and traveling clockwise around, ending at the large central hexagon. Starting at the hexagon at the top, they are labelled: ‘collection and access’, ‘storage’, ‘management’, ‘sharing’, ‘analysis’, ‘publishing of findings’, and the large central hexagon is labelled ‘plan’.**

**Audio**

(Emma): So, probably the big thing, and I think we all like- as QIs, we all like to have a plan. So this is great, because we need to have a plan for ensuring the sovereignty, privacy and confidentiality of the data - the data that we collect, that we access, that we store, that we manage, we share, we analyse and we publish. So therefore, we gotta make sure that actually, all of that plan is covered off as part of it. We need to ensure that data has been collected and will be analysed in a culturally appropriate and equitable way. So that's about strength based language as well, and ensuring that actually, our implicit biases are not coming through when we're doing our collection and our analysis as well.

**Visual**

**A new slide appears with a title in bold blue text: ‘Suggested Reading’.**

 **Under this is black text:**

* **Standards sections on:**
* **Research and Māori**
* **Research and Pacific peoples**
* **Disability research**
* **Ethical management of vulnerability**
* **Informed consent**
* **Health data**
* **Te Ara Tika**

**Audio**

(Emma): So, I've just got some suggested reading for you. There are a whole lot of areas around informed consent. There's areas around research and Māori, research and Pacific peoples, disability research, ethical management of vulnerability and the whole area of health data as well, which encompasses Māori data sovereignty. So I think if you really wanna delve a bit more, like I have, it'd be really good too, if you are gonna do particular research with particular populations, then make sure you're aware of those particular parts of standard, because remember the key points,…

**Visual**

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* **Quality improvement activities generally have low or negligible ethical risk.**

**Audio**

(Emma): …which is that the standards apply to quality improvement activities, regardless of whether they are reviewed by an ethics committee; quality improvement activities should aim to limit ethical risk and maximise potential benefits; and that the ethical risks will need to be assessed regularly and managed throughout the activity. And also, just to note, so that people don't get afraid, is that quality improvement activities generally have a low or negligible ethical risk.

**Visual**

**The next slide shows a webpage from the Health Quality & Safety Commission New Zealand. A title in white text in a green banner reads: ‘Ethics guide for health providers conducting quality improvement activities.’ The address is listed below:** [**https://www.hqsc.govt.nz/our-programmes/building-leadership-and-capability/projects/ethics-guide/**](https://www.hqsc.govt.nz/our-programmes/building-leadership-and-capability/projects/ethics-guide/)

**Audio**

(Emma): So, I've just gone through a whole range, a whistle-stop tour around ethics and quality improvement. It's a really light brush. I've talked through why it's important. I've also talked through the principles of Te Ara Tika and bioethics, which underpin those standards, and just given you a bit of a framework around what the key points are and also what the guide is that we've done. We're really interested to see how your feedback of using it is, so please let us know. So this is where the guide is. So thank you very much.