



## **Supporting Information**

### **Supplementary methods and results**

**This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.**

Appendix to: Perry MA, Jones J, Devan H, et al. Non-invasive ventilation for people with neuromuscular disorders in Australia and New Zealand: a qualitative study of clinician perspectives. *Med J Aust* 2023; doi: 10.5694/mja2.52036.

## **1. Supplementary methods: Semi-structured focus group and individual interview questions**

Focus group interviews were conducted by Hemakumar Devan, Tristram Ingham, Bernadette Jones, and Meredith Perry. Individual interviews were conducted by Bernadette Jones and Meredith Perry.

### **The experiences of clinicians in providing non-invasive ventilation services to people with neuromuscular disease in Australia and New Zealand**

AIM: To develop an understanding of current experiences of non-invasive ventilation provision for people with neuromuscular disease. In particular barriers to service, access to service, safety and patient outcomes.

Welcome and introduction to the interviews

- Explain format (breakout into small rooms, interviews will be taped and then transcribed, anonymized data will be analysed)
- Each focus group will last about one hour
- Clarify any questions.

### **Brief mihi (introductions and explanation of interest in the topic of conversation)**

#### **Main questions**

1. What is your experience of providing support to an individual with neuromuscular disease and their caregivers (family/professionals, etc.)
  - Prompts
    - Access?
    - Barriers?
    - Safety?
    - Outcomes? (person-centred)
  - Positive experiences
  - Negative experiences
2. How is the current level of service and/or service standards meeting clinical decision making?
  - Prompts
    - Problem-solve based on points from 1 above (e.g., resources, service configuration)
3. How do you or would you envision implementing/using (bi) national guidelines in your centre?
  - Prompts
    - Full document versus brief synopsis
    - Guidelines versus standards

## 2. Supplementary results: Additional supporting quotes

Theme	Participant quotes
<b>Decision making for current practice</b>	
<i>How clinical need for non-invasive ventilation is established</i>	
	I guess treat them symptomatically as they go on their journey of change, yeah. But then you know one mask leak they can't fix can unhinge that terribly, so you have to be very careful. Focus Group1 New Zealand
	Yes, there's evidence for non-invasive ventilation to be life-prolonging, but that's not the basis on which we've agreed to provide the service, we provided it to treat symptoms. Treating symptoms gives you a slightly freer rein than treating specific physiological derangement, because you've got a bit more of a free hand to say 'well, he feels better therefore we will', so I think that's the tack we've taken. Focus Group1 New Zealand
	I mean, the Duchenne's boys, they can go for years and years and years and years, but then they're symptomatic by the time they come to you. Becoming symptomatic is what would prompt review. Focus Group1 New Zealand
	If the patient starts to have more aggressive weight loss, then we have to start the non-invasive ventilation before it's too late. Focus Group2 New Zealand
	So, we use the New South Wales one and an international one. There has been another guideline which I think was proposed, I think it was a European society, but it was never published, and I think they are all similar. So, they all use a combination of symptoms and bio-chemical markers, and spirometry, really. Focus Group3 Australia
	I had read a lot of guidelines initially, but I would say that now it's more clinical experience, and going by lots of oximeters of the patients, and them giving the history suggestive of possible sleep disorder breathing, trialling them on non-invasive ventilation, and depending on how they go with that. So, I think that's how it is, I mean I don't think there's a 'set of guidelines' that I follow now, but it's more clinical experience, and how the patients feel, and then the follow up investigations, I suppose. Focus Group4 Australia
	I think it's clinical and a bit of investigation, so clinically they will have features of sleep disorder, getting tired, sleepy during the daytime and their oximeter's sort of suggestive. But you sort of go by the eyeball pattern of the oximeters, and if they have symptoms of tiredness, and you know, poor cough, and infections, if they've come into the hospital with chest infections, then that's when we do try non-invasive ventilation. If a patient can come to the lab and have a proper sleep study, then you do measure, but we don't routinely measure carbon dioxide, because we think that by the time they get to that stage that they're fairly advanced, so we try and pick them up fairly early. Focus Group4 Australia
	Before we had those [New South Wales] guidelines, people didn't come until they were almost hypercapnic. Now with the guidelines, we are doing it on symptoms alone, and people are being picked up earlier. Focus Group4 Australia
<i>Need for guidelines and service specifications</i>	
	The other thing is we're talking about people's ability to manipulate the mask, non-invasive ventilation's not an entirely benign treatment in that you can...there are case reports of people desiccating an eye because it's been missed, and they've been blinded in one eye because the mask's been missed, and they couldn't seek assistance as they couldn't remove the mask. Same thing, if you've got a pressure area, if someone's mask is uncomfortable because of pressure and they can't summon help or move the mask, then again that's a significant concern. You know, facial cellulitis commonly kills people who are malnourished and unwell for other reasons. So, it's not an entirely benign treatment. That's why people need to be suitable for it and guidelines help. Focus Group1 New Zealand

Theme	Participant quotes
	They phone an ambulance and have an ambu-bag if there is a machine failure. That's genuinely the situation we've had, meeting after meeting about it, and that's why it is important I think we get national guidelines to standardise that this is the expected standard of care. Focus Group1 New Zealand
	Every situation is so different, I don't know if having a national or regional guideline is the most important...I think we need to get some support in tightening up the funding really, I think the focus, is getting support with funding. Service provision, and funding, rather than reinventing the wheel for New Zealand. Focus Group1 New Zealand
	We have a protocol of when patients discharge on non-invasive ventilation, it's one-week phone call follow up on the first week, and then in three months' time, they need to come back and repeat overnight oximetry. Then we adjust the setting if it's required. If it's not then we go to six monthly, and when they come back if everything's okay then we go to twelve months. Focus Group2 New Zealand
	I guess the other thing that's lacking is a standard policy on what type of equipment these people need at different stages of their disease. Each state seems to have adopted its own policies, and we've done the same, and they're not consistent across the country. Focus Group3 Australia
	Look, I've been in our institution since two thousand and five. At that stage we had no sleep lab, no non-invasive ventilation services in our hospital at all. No neuromuscular services at all. That's for the entire of southwest [large city]. So since then, things have improved in our hospital, so we now do have a sleep lab, we do chronic non-invasive ventilation on the ward, we offer a step-down service...and with a little bit of luck, we will start a trial of acute non-invasive ventilation next year. But it's been a journey. Part of the thing that hasn't really come up today is there isn't a framework for implementing non-invasive ventilation services, in new institutions, and that's a problem, because everyone sort of does it based on their local experiences and what's available. That's good to an extent, but it's not helpful for people that are trying to get it up and running. Focus Group3 Australia
	I think it would be a useful thing to do, to update. I'd say is an enormous amount of work went into those New South Wales guidelines, but I don't think it needs to be reinvented. Like I said, they were a few years ago, and evidence has changed. Focus Group3 Australia
	In [state] we haven't got a specific set of guidelines, although their care is fairly centralised, the provision of care is fairly centralised. So, there hasn't been quite the need for a set of guidelines to apply across the state because it's all pretty much happening in one institution. But it's not a bad idea. Focus Group3 Australia
	I have a bit of a problem with all of these recommendations that are based on consensus sort of thing, to an extent because then people sort of use them as gospel, but at the end of the day there is no evidence. Focus Group3 Australia
	I think the New South Wales guidelines developed by [name] group have been using those non-invasive ventilation criteria, especially for the motor neurone disease, I think they kind of work well with the neuromuscular groups, so we use them with a combination of clinical and bi-clinical, and spirometry parameters. Focus Group4 Australia
	So as far as the guidelines go too, there has been some interest between New Zealand and Australia to get a set of Australasian guidelines...guidelines in relation to non-invasive ventilation only or guidelines that extend beyond that to other aspects of care for other neuromuscular patients...I guess, even if it's just focussing on non-invasive ventilation guidelines, I think that would be very valuable, yeah. Very valuable. Would be welcomed by us. Focus Group4 Australia
	Use guidelines...It's streamlined the management, really. Focus Group4 Australia
	Having national guidelines would be ideal. Individual2 New Zealand

<b>Theme</b>	<b>Participant quotes</b>
<i>Education and training for non-invasive ventilation with people with neuromuscular disorders</i>	
	Most places have a degree of expertise, most people who've gone through respiratory training in New Zealand have an awareness of how non-invasive ventilation works but I'm not sure they have the expertise to run it long term, but they'd be able to initiate it, to a degree. Focus Group1 New Zealand
	There's a week's worth of sleep disorders being discussed, lectures and practical sessions, [...] it's a relatively superficial coverage of the topic. Focus Group3 Australia
	In [state] we do run some training programs for non-invasive ventilation for nursing and allied health staff, but they're introductory courses. They're courses about the device, and this is what it does, and this is how you interpret a blood gas, rather than really getting into the nitty gritty of managing patients. So, the rest of it really is learnt on the job. Focus Group3 Australia
	I have read about it, so initially I was nervous, obviously trying to do things for the first time, without much experience. Focus Group4 Australia
	When I was training there was no structured training as such, so what we'd do is we attend courses, and then upskill ourselves, and then to each other. So, with the non-invasive ventilation, we've got nurses who have been doing it, and so they are skilled, and they train the carers, about the machine. Focus Group4 Australia
<b>Resource constraints</b>	
	Isn't everyone underfunded and understaffed? Focus Group1 New Zealand
	I mean the big stumbling blocks for us is resources. It's about having time to spend with the patient to set them up, it's about having the device available there and then. Focus Group1 New Zealand
	We believe we're under-resourced, our unit is too small, every year we just don't have the physical space to manage the number of patients who need ventilatory support. Focus Group3 Australia
<i>Dedicated funding</i>	
	After certain points in time in the financial year, ridiculous though it sounds, we don't have a device ready to use for someone. Focus Group1 New Zealand
	If you prescribe an expensive drug, it comes out of a different fund, whereas if a respiratory department says 'right we're going to take on all these difficult patients, and were going to work hard to get them right, and we're going to resource them well, and we're going to fund them well, and were going to devote a lot of time and effort and pay for all the machinery, and the associated machinery for someone, such as the alarms, and the back-ups machines, and all the other stuff that's nice to have,' that money has to come out of the respiratory budget, and so the respiratory department has to do less because they're doing more for this one group of patients. Focus Group1 New Zealand
	The funding is a bit funny. Like all devices, I mean cardiologists have the same with pacemakers, but nobody worries about spending thirty grand on a pacemaker, 'cause it's cardiology. Whereas people fuss about spending ten grand on a neuromuscular patient, even though the life expectancies might be quite similar for some heart failure patients with a bi-ventricular pacemaker. Focus Group1 New Zealand
	That's the thing, there's no official service provision is there? We're all trying to get a little bit from here to give to the patient, but there's nothing specifically allocated, funding that's for them. Like we secretly get the physios to give them treatment, then the consumables, mask, and things like that, and I'm sure that the managers would have a hernia if they knew that's what we're doing, and it's just not having that funding. Focus Group2 New Zealand
	But it's not in a protocol, I feel there is a lack of resource from the non-invasive ventilation perspective, there is no resource there for those people using non-invasive ventilation long term, for continuous support, in the community. Focus Group2 New Zealand

Theme	Participant quotes
	Out of the sleep funding. So, basically, we have the sleep budget, and we just go ‘Okay, we need this many [ non-invasive ventilation]’, and we don’t have a dedicated non-invasive ventilation clinic or anything like that we just see them out of our sleep time. You know, these people obviously need much more input compared to our average obesity sleep apnoea patient. You don’t do them justice without that extra resource and funding. Focus Group2 New Zealand
	We have the Neuromuscular Disease Association provide equipment for people who’ve got neuromuscular disease, and I suppose they’re some of the issues. Focus Group3 Australia
	But something must have changed because we had no budget, and we do have one now. Focus Group3 Australia
<i>Access to non-invasive ventilation service and waiting lists</i>	
	We do have a non-invasive ventilation clinic, ever second week, but it’s often fully booked, and extremely difficult to change that, unless you do other ways to get around it. Focus Group1 New Zealand
	They need to know the non-invasive ventilation service, it’s not twenty-four hours, it’s only eight hours, from eight to four thirty. Focus Group2 New Zealand
	If they can get access to our clinic, and that’s one of the other barriers. We’ve now got a big waiting list for our MBD clinic and so there can be delays in getting people into the clinic in the first place. Focus Group3 Australia
<i>Adequacy of non-invasive ventilation machines</i>	
	I think it’ll take someone to die, in our [hospital], because their machine has failed before it is taken seriously. Focus Group1 New Zealand
	No one cares about people quietly dying at home on a ventilator. Focus Group1 New Zealand
	Very few people were sort of getting non-invasive ventilation in a timely fashion, just because the referral process to get into the clinics to see people was hopeless. Focus Group3 Australia
	There’s a pressure on the system and it can’t cope... it is unsustainable. Focus Group1 New Zealand
	A: We provide servicing- we provide replacement parts, we provide replacement mass parts, but we do not- and it’s a bone of contention, we do not provide a back-up machine. It’s a huge bone of contention because it flies in the face of a lot of guidelines et cetera. But we do not provide a back-up machine, which is a real... it’s bonkers, it’s a real problem for us, so... B: So even someone who’s completely dependent during the day? So if their machine breaks they die? Focus Group1 New Zealand
	We have so many areas out there communities out there, that suffer regular power failures. It’s a real concern. Real worry. They’re far, far away from the ambulance, and other health services. Focus Group1 New Zealand
	We do have a guideline, about who has the battery back-up, and for people that are having usage over fifteen hours, then we are giving a battery back-up for those people. Focus Group2 New Zealand
	We are not able to routinely provide back-up machines at the moment. Focus Group2 New Zealand
	Because of limitations on funding, you’re making choices on machines that are not fit for purpose. Focus Group3 Australia

Theme	Participant quotes
	We had a death of a patient, so this is someone who had I think Duchenne's if I remember correctly, and there was a power failure, and he died. He was in a nursing home...it does not [the power failure and lack of back up] determine the cause of death, because he could actually ventilate himself if he is propped up...now we're looking at funding models, and you know, in conjunction with our [name of state] colleagues, we have looked at the federal funding, and now we are getting funding for what we call the (Trilogy) machines, which is a bit more robust, back-up battery, and that kind of stuff. Focus Group3 Australia
<i>Staffing</i>	
	I mean the big stumbling blocks for us is resources. It's about having time to spend with the patient to set them up, it's about having the device available there and the Focus Group1 New Zealand
	We don't have the time or the staff really do any acclimatisation. But that would be lovely if we could. Focus Group2 New Zealand
	Right, so we're fortunate in that our hospital does have a respiratory home community liaison nurse, but we have one nurse, for all of respiratory, for our region, and there's no other region in the state that has a nurse, so our nurse basically is for the whole state. Not just for neuromuscular patients or non-invasive ventilation, but for every respiratory issue. So, there is no way that this person's going to be able to perform that job, right. So, we're very under-resourced in that respect. Focus Group3 Australia
	We've got a number of staff who've stayed with the unit for quite a long period, but it's hard to retain and keep the best of those. You need good experienced clinical nurses and other allied health for a unit like that to run as effectively as it can. Focus Group3 Australia
<i>Care pathways</i>	
	It's the facilities and not having the pathway there is a problem. Focus Group1 New Zealand
	I think for the Duchenne's guys, you'll often re-titrate them as they transition from paediatrics to adolescents, you'll often re-titrate relatively regularly there. You'll sometime have this pattern of every four, five, six years. Or as symptoms develop. That's sort of quite common. So, the ones passed from the paediatric service you're more likely to need to be re-titrated. Focus Group1 New Zealand
	There is a big gap in our system for the non-motor neurone disease, the people with neuro muscular disease, because we don't have another clinic for that. They just have to slip into our sleep clinics. But it's not a great service, because there is this creep of people who come in through paediatrics, and it is actually a creep, because there is no sort of place for them, because like Duchenne's and stuff like that, they live a lot longer, so once that population grows, and it will, there is no sort of framework or pathway. Focus Group3 Australia
	Transition from paediatric to adult is a really big challenge as well, to look for adult sleep physician who has an interest in paediatrics, that's where the problem is. Focus Group3 Australia
	I mean we've certainly had people who've had a very rocky path as well, or who've just basically got lost. Who end up coming into hospital at some stage when they're eighteen or nineteen or whatever, and who've been lost for two years. Focus Group3 Australia
	Where I was working at [London hospital], they were probably about five years ahead in terms of transitional care, and they were building a juvenile, like an adolescent ward for respiratory for Duchenne muscular dystrophy. They coordinated adult cardiologists for adults to do their echoes regularly, because they get cardiomyopathy. They were thinking about coordinating care. So, I think there are places in the world that do it very well, that we should all look at. But that was certainly an example where they had a multidisciplinary clinic with a rehab specialist, and transition clinics and a ward that they were looking at sort of adolescent health. Focus Group3 Australia
	I think you're right, there's got to be some transition process. Focus Group4 Australia

Theme	Participant quotes
	This is at a GP level, but I actually have different programs so they can- you know, they go into their clinical health pathway. Individual1 Australia
	That's another problem we've got, is poor transition from paediatrics over to us, and it's been very bumpy. Individual2 New Zealand
<i>Multidisciplinary clinics</i>	
	A: A joint clinic, like a clinic where you'd have respiratory, neurology, genetics, speech, or something, like a physio, like so that the patient could just come in from wherever they are, get their lung function, get their neurology assessment, their respiratory... B: In a way that's easy for the patient to come in. Focus Group1 New Zealand
	A joint clinic, you could get everything done for them in one day...and then the people could talk as well, between each other. Focus Group1 New Zealand
	Locally we've set up multidisciplinary teams, which have been sort of led by us, and the speech and language therapists and the physios, so we've got a multidisciplinary team where there isn't a neurologist involved. Focus Group2 New Zealand
	We've tried to develop a multi-disciplinary clinic, so we do that with neurologists, we have community chronic disease service who also attend and help us in the community. We're trying to link with the palliative care services. We haven't had a great collaboration with our palliative care services, but we're developing that, that's a really important thing, that's one of the issues that's been a problem for us over the years. Focus Group3 Australia
	We've been just so lucky in terms of the amount of good will that's been involved in this clinic, 'cause there's been no funding. It's been set up with zero funding. We were actually advised not to do it without a coordinator, and it has been challenging, because we haven't had anyone to chase things up in between clinics, but we made sure that people understood that up front, that that wasn't the purpose. Focus Group3 Australia
	I think the concept of a coordinator is something that would really be helpful for our service, 'cause at the moment, there's a whole lot of different parties and layers involved, and interests. We don't really have a coordinated approach to it. That's one of our problems. Focus Group3 Australia
	It's not a neuro muscular clinic, or an anything clinic, it has to be motor neurone disease diagnosis. But that does mean that there is a big gap in our system for the non-motor neurone disease, the people with neuro muscular disease, because we don't have another clinic for that. They just have to slip into our sleep clinics. But it's not a great service, because there is this creep of people who come in through paediatrics, and it is actually a creep, because there is no sort of place for them, because like Duchenne's and stuff like that, they live a lot longer, so once that population grows, and it will, there is no sort of framework or pathway. Focus Group3 Australia
	We work really closely with the neurology team, cause the motor neurone disease clinic is multi-disciplinary, so we've got a neurologist, a palliative care physician, a gastroenterologist, a physio, occupational therapist, we got everyone in one group. Focus Group4 Australia
	Having a multi-disciplinary clinic is actually better quality of care. Individual5 Australia
<i>Interprofessional collaboration</i>	
	As a clinical physiologist, I'd really like to know more about what the whole care plan actually looks like. I'd really like to know what else is actually going on in terms of their care but we're a bit shut off. The doctors look after them, feeding all the information through, making decisions with the patients, and that's terrific, you know, it's brilliant, but I would like to know a little bit more about these people that we're caring for. Focus Group1 New Zealand



<b>Theme</b>	<b>Participant quotes</b>
	There are issues around community respiratory physiotherapy. 'Cause our hospital physios can't look after people with coughing that persists. Focus Group2 New Zealand
	In Australia, neurologists diagnose, and they don't manage once they've done the diagnosis. Focus Group4 Australia
	We have respiratory physicians giving the non-invasive ventilation, but it's not supported by the other allied health staff, which is the physiotherapy, the dietetics, the nutritionists. Focus Group4 New Zealand
<i>Upskilling of patients and caregivers</i>	
	A lot of patients don't have any resources, especially if they're not in a major centre. So, to have something that's available to patients would be really helpful. Patient resources and information, in addition to clinical guidelines for healthcare purpose. Focus Group2 New Zealand
	There's a few environments where actually they need to be taught how to put things on, you know, there's quite a lot of ways in which you can stuff it up. So, training is a really important issue as well. You know, who trains the carers? Focus Group2 New Zealand
	We've basically stolen what we could off the [Country] 'cause we found those resources looked the most user-friendly. Focus Group3 Australia
	I mean I'm deeply aware that it is like patchy, it's not a well localised, well-developed document, it's what we've sourced off the internet that we've printed out to give to the patients. Focus Group3 Australia
<i>Burden of treatment costs</i>	
	You get some people saying, 'I actually can't afford the petrol to get there'. So that's another problem. Focus Group1 New Zealand
	I work at two different hospitals; one hospital will loan you non-invasive ventilation for three months. But at the other you just have to hire on your own for the outside community. Focus Group3 Australia
	You'll be spending a hundred to hundred and fifty dollars per month, is the hire rate depending on the type of machine. Focus Group3 Australia
	'Cause he had superannuation, he had to pay [...] a proportion of the cost of the machine. But servicing [...] next year it will be about two thousand dollars for servicing both his ventilators. Focus Group4 Australia
	In [State], if the funding goes federally, so if they go into a nursing home, suddenly they can't get a ventilator. The ventilator won't be funded by the state anymore, it goes over to the federal. The nursing homes will not pay for a ventilator, so they actually lose support and pay themselves. Focus Group4 Australia
<i>Rural health service delivery</i>	
	[Health area] have a lot of roadblocks...they've got a very widely distributed population, they've got these large communities, quite distant from the hospital, with a lot of deprivation, a lot of poverty, it's not uncommon for somewhere from [town] to have one vehicle for three family groups. While [the health area] does outreach, it's very difficult to do an outreach sleep lab because of all the equipment needed, and so it is very challenging and [health area] is one of the most difficult ones because they cover such a vast area. Focus Group1 New Zealand

Theme	Participant quotes
	The other problem with these non-invasive ventilation patients is that as they get sicker, travelling becomes much more of a burden, and if they're doing fine it seems- you sometimes feel a little ridiculous, they've just basically struggled all the way down from [remote area], and they've travelled further than they have for six months, because that was last time they came to see you. They turn up and you spend fifteen minutes with them, look at their machine and go 'Okay, that looks good', and then send them packing...But if you don't check on these people, you run the risk of having people all the way up in [area] on their own deteriorating, when you can make them a lot better. So it's a difficult balance and the problem is not easy to... you can't just nip up to [area] and set up shop in a GP surgery, cause you need to do testing and use equipment. Focus Group1 New Zealand
	Or even the nurse, the community nurse, having them come out to see the non-invasive ventilation patients. Rather than necessarily always having to come in. Those sorts of things help. Focus Group1 New Zealand
	It'll be a lot easier once we can remotely log into the devices, we can't quite do that yet. Technology's there but the funding isn't. Which is a lot of the problem in New Zealand. Focus Group1 New Zealand
	But the actual provision of non-invasive ventilation at a hospital level is very much based on the local health district. Focus Group3 Australia
	In [state], that's a very big state with a lot of people who don't live anywhere near anywhere. That seems a shame with the current technology to have limited use of tele-health. I understand the issues about privacy and stuff, but it's a [state] health issue. Focus Group3 Australia
	One of our problems is because of our large geography in [State], is for both access for rural patients, and also very disabled patients coming to the clinic. I've been interested in tele health, and remote monitoring. But the issues in Australia are that you can get a subsidy if you live in a rural area for a tele health consultation, you can get a payment for that. But if you live within the metropolitan area, and you do a sort of tele health, you can't bill that. So, there's no perfect way of enabling very disabled people to get access to services, maybe not complete services. Focus Group4 Australia
	One of the areas that you've got to be very careful when you put them [people with neuromuscular disorders] on non-invasive ventilation is when the progression occurs, and we need to upgrade them. If they're within the city, it's not too bad, because we can physically get in the car and drive out. But when they go back to a country area and we... need to make sure that they have the right equipment, making sure it's set up correctly, how to use the mouthpiece or changing the interfaces, lung volume recruitment, swallowing, speech, and it becomes harder the further away from [major city] they are and once they go home, it's too hard to come back to the city area. Focus Group4 Australia
	Trying to explain to them what to do, and yet you're not seeing the patient, and they just don't have the skills in the more isolated areas. Focus Group4 Australia
	We've got a number of motor neurone disease patients on non-invasive ventilation, and they do travel, but obviously it's very variable, and with the newer ventilators, they obviously have (modems), you can change pressures, you can mainly remote monitor their modems. Yeah, so they click it on, and they send the data back. Focus Group4 Australia
	'Cause [state] is not a very big state, population wise, but distance wise it is huge, I must admit that with the non-progressing- slowly progressing neuromuscular disorders, most of these patients do tend to drift towards cities, that's my experience. Probably because as a child, you know, they needed more service than the family could manage out there. Focus Group4 Australia
	If the patients are lucky enough to have a carer who is able bodied and can manage, they are probably going to be the main ones in the rural area who do well. Individual3 Australia
<i>Postcode lottery</i>	
	So, there is definitely- we can see the differences between regions Focus Group1Australia

Theme	Participant quotes
	But it's actually the postcode lottery. A lot of patients don't have any resources, especially if they're not in a major centre. Focus Group2 New Zealand
	A: I'm so jealous you have that service. B: It's the postcode lottery, isn't it. Focus Group2 New Zealand
	There's quite a variation...it depends on which hospital you end up in as to what you get. Focus Group3 Australia
	But the actual provision of non-invasive ventilation at a hospital level is very much based on the local health district. Focus Group3 Australia
	It just seemed a little inequitable, depending on where your post code was. Focus Group3 Australia
	A: If you've got ventilatory failure and whatever, and you need bi-level, you get bi-level. You haven't got a rent, or any of that kind of stuff, it gets provided where I am. You've got to demonstrate you'll use it to keep it, but that's all. B: You don't need a concession card, so you'll need to have a health care card, or pension card, you know, to validly obtain a publicly funded continuous positive airway pressure. But that's not the case for people who need ventilative support with non-invasive ventilating device. Focus Group3 Australia?
	But it is difficult to reconcile the fact that even within states, like we're all talking about quite different rules for the provision, and it does seem to me that they are the same condition, there is a big difference, in terms of what you get. It's a big difference. Focus Group3 Australia
	'Cause we deal with across the border. Across the border they're a different health district, so if you're across on this side of [state] it was different than if you were out west way. They were different in the guide too, not in regard to whether you got the machine, but what happened. So, some would say you can have the mask and the machine, but you wait longer, and others would say no, the patient has to pay for the mask but they'll get the machine earlier. Focus Group3 Australia
	It keeps changing in [City], but I think now in [state] is again thirteen smaller local health districts. So, the funding is very much local health district. The supply of non-invasive ventilation equipment is through the [service provider], so once people are assessed, and are compliant, there's a single set of rules for whether you're eligible to get a machine. Focus Group4 Australia
	It's much better funded, than a lot of the other states, I think we're quite lucky in that way. So, if you meet the criteria, you get your machine, there's no delay in getting the machine, you haven't got to rent. Focus Group4 Australia
	A: I think [service provider] program is a good one, but I think it's very prescriptive, and you won't be able to get a patient a machine if they don't really fit in the criteria, and that's the only thing with them... they will never downgrade, they might say look, you're not going to meet the criteria, but often they try and upgrade patients. B: I mean my experience has certainly not been these problems. 'Cause we've had a lot of committee meetings about the criteria, and recently I think they are better than they used to be. Focus Group4 Australia
	In [state] we are with [service provider], we've got very clear guidelines when a patient can get a machine, which for neuromuscular patients is a lot laxer than if you had obesity hypoventilation, if you had even probably kyphos scoliosis, or with chronic obstructive conditions it's much harder to get a machine. It's very easy. Focus Group4 Australia

Note: A = one individual in the group speaking; B = another individual in the group speaking.