

Unfinished Business – National Mesh Forum  
Friday 5<sup>th</sup> April  
Melbourne, Citadines on Bourke



Consumer Survey –  
What are your hopes for the day?



## Introduction

Unfinished Business - National Mesh Forum is a partnership project of the Health Consumers Councils across Australia. It builds on the work done to inform the Senate Inquiry into the [Number of women who have had transvaginal mesh and other matters](#) to support a unified national response to the recommendations from this Inquiry.

In addition, Health Issues Centre Victoria developed a report documenting the experiences of men and women impacted by hernia mesh repairs, and [this report](#) was released prior to the Forum. The National Mesh Forum will address both pelvic and hernia mesh.

This consumer survey entitled “What are your hopes for the day?” was developed to ensure that consumers could have their say whether they were attending the forum in person, attending virtually or not able to attend at all,. The survey was forwarded via social media to the mesh injured peer groups across Australia. The questions asked appear below.

1. What are your hopes for the day?

- A chance to have my say
- A chance to meet with other people and find out what's happening in other states
- Some real progress with the Senate Inquiry Recommendations
- Banning the use of mesh
- Other (please specify)

2. Do you have any concerns about the day?

3. Is there anything that you think Health Consumers Councils can do prior to the event to address these concerns?

4. When thinking about the services you need, what's most important to you?

- Diagnostic services so I know what mesh I have, where it is now
- Pain management
- Full mesh removal surgery
- Assistance with complications, e.g. SUI, hernia etc.
- Psychological counselling
- Financial assistance
- Assistance to access disability support
- Physiotherapy and Occupational Therapy
- Links to peer supports
- Access to legal information and support
- Other (please specify)

5. What type of mesh do you (or your loved one) have? Check all that apply.

- Pelvic mesh
- Rectal mesh
- Hernia mesh
- Other

6. What state or territory do you currently live in?

7. What consumer/carer groups, if any, are you connected with? Tick all that apply

- Australian Pelvic Mesh Support Group
- Mesh Awareness Australia
- Mesh Injured Australia
- Australian Mesh Injured Support Group
- WA Pelvic Mesh Support Group
- SA Pelvic Mesh Support Group
- Queensland Pelvic Mesh Support Group
- Gold Cost Pelvic Mesh Support Group and Twitter Profile
- Sunshine Coast Pelvic Mesh Support Group
- Victorian Pelvic Mesh Support Group
- NSW Pelvic Mesh Support Group
- Mesh Down Under
- Hernia Mesh AustraliaMesh Too Western Australia
- Other (please specify)

8. How would you like to stay in touch about consumer and carer involvement in this issue?

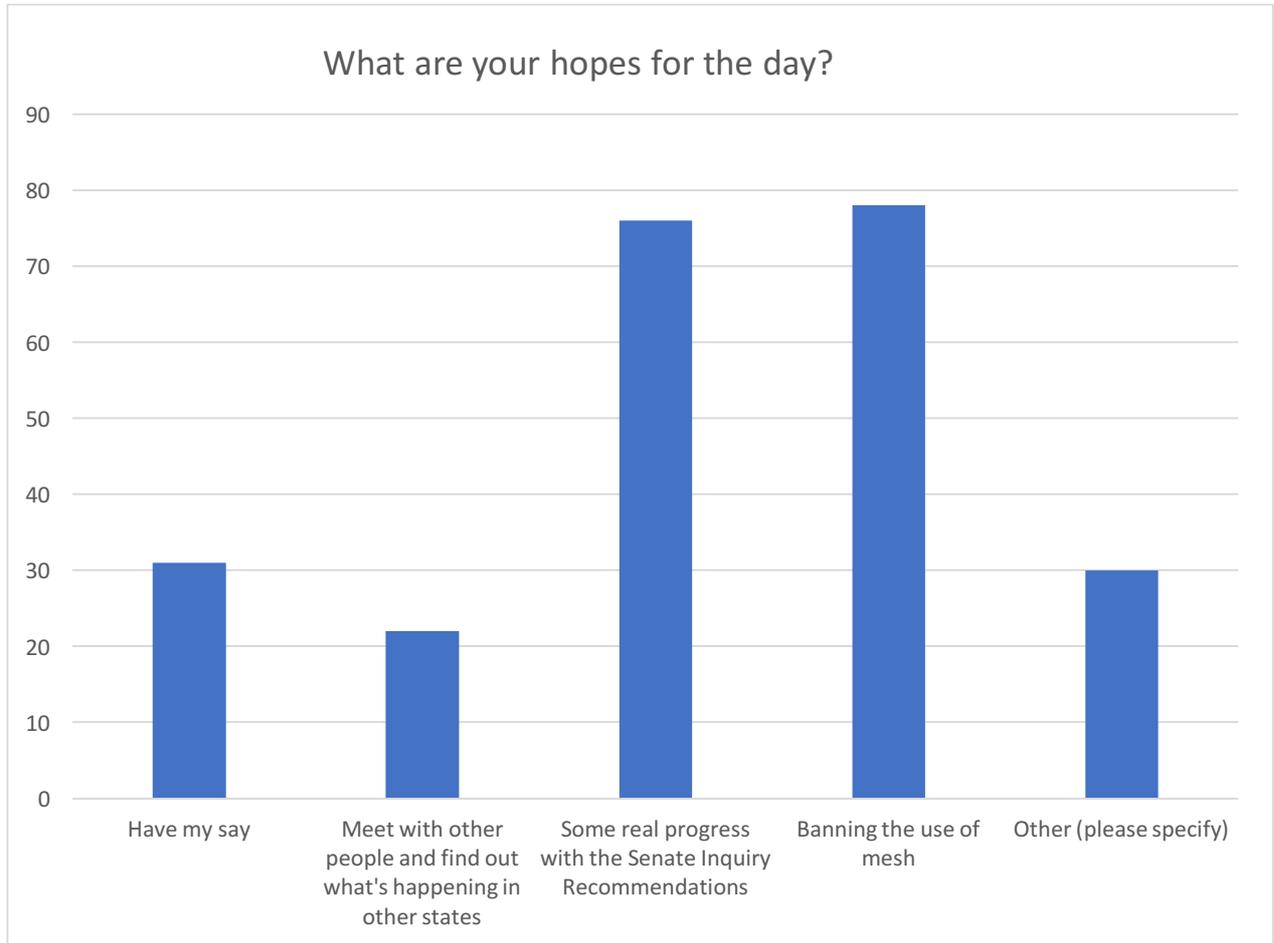
Tick all that apply

- I already stay in touch through Facebook Group(s)
- I am happy to be asked to respond to anonymous surveys up to 5 times per year
- I'm not sure
- I don't want to stay in touch
- I am happy to be on a mailing list maintained by the Health Consumers Councils

# Survey Results

## Question 1

What are your hopes for the day?



### Other (please specify)

#### Summary:

Financial assistance was mentioned many times, including the need for support in obtaining disability support pensions. Mesh removal options including bringing Dr Veronikis to Australia, and ensuring clinicians are trained in full mesh removal were also highlighted. There was a clear call for a Royal Commission as well.

## “Other” free-text responses in full

- *Scheduled fee revision and increase for mesh removals*
- *The Senate Inquiry Recommendations didn't mention anything about compensating women in any financial way. Women are unable to work, unable to support themselves and therefore unable to seek out medical treatment because they have no money. Centrelink doesn't recognise Mesh Issue and women should be able to seek help with the financial side of all their ongoing never ending medical costs (even after the mesh is removed). At the bare minimum will need a healthcare card.*
- *A support group for everyone or every state run by somebody in the know such as Health Consumers Qld or who is setting up the mesh clinic to minimise misinformation and personal opinions and fighting amongst group admins and members*
- *Help for the already damaged, in the form of Government assistance - a pension for the wounded.*
- *Be informed*
- *O/seas mesh removal and PN specialist brought here*
- *Real help for mesh sufferers not lip service*
- *Help in the way of money to have it removed.*
- *Getting Dr Veronikis here*
- *Changes to literature to include autoimmune symptoms not just pelvic and bladder symptoms*
- *For actions to be put in place. Push for full funding for those maimed. Discussion concerning Royal Commission into the TGA. For Specialists to finally admit their wrong doing and admit that mesh is not safe*
- *TGA reform, safe full removal of mesh slings in Australia*
- *That someone. Anyone. Will look into the corruption in WA that forces me to go to the Eastern States just to get proper medical care which I can't get in WA due to nothing other than a guilty surgeon who is stopping me getting help.*
- *And bringing Dr Veronikis from America here to remove mine and others suffering from this horrid mesh to Australia to also train our doctors here*
- *Australia-wide regulations and services that will have REAL AND POSITIVE impacts for mesh injured Australians and their families. Things that are MEASURABLE and able to be evaluated for effectiveness. Not just pretend, tick the boxes things that look good on paper but actually make NO DIFFERENCE to mesh injured people. A commitment from*

*the Australian government for the same services Australia wide, so that it is not just pot luck, dependent on which state you live in whether you get proper care and treatment. A commitment to financial and medical assistance for mesh injured and their families. The willingness of surgeons to learn from overseas experts. Bringing overseas experts at mesh removal to Australia.*

- *We need Dr Veronikis as no one can remove all my mesh and hundreds of others are the same*
- *Plans to bring Dr Veronikis to Australia several times to do mesh removals*
- *Politicians and medical professionals realising the urgency of this issue and recognition and assistance those suffering from hernia mesh*
- *My letter I sent into the Forums Dropbox to be taken seriously*
- *Help with mesh injured women and the DSP process.*
- *A commitment to funding a continuum of care mesh service to address the physical mental psychological needs of persons injured plus comprehensive medical and allied health staff training*
- *support a call for a Royal Commission into the detestation caused by mesh*
- *Surgeon training for full mesh removal*
- *Addressing the issues with Australia's regulation of all medical devices*
- *Start authentic conversations on Dr Veronikis being allowed into Australia to do removals. Talk about the removals that cannot be done in Australia. Honesty and openness from RANZCOG and the AMA, complicated meshes cannot be removed in Australia.*
- *Banning the use of mesh with an alternative instead of mesh.*
- *Recognition that mesh injured need support: mental health, removal, ongoing nursing, financial assistance, other services to assist in disability.*
- *upgrading diagnostic methods in public hospital (3D/4D ultrasound, nurses trained to use them). Medicare rebates for hospital stay in private hospital when public hospital is not an option. (\$7000 dollars for one night at private hospital for those with no insurance).*
- *Progress with SAFE removal options in Australia*
- *Financial Assistance with full mesh removal and ongoing care.*

## Question 2

Do you have any concerns about the day?

### Summary:

This was a free text response and some people spoke about their concerns both that clinicians would be there, and that clinicians wouldn't be there. People expressed concern about feeling overwhelmed during the event and also the difficulty of sitting in one place for so long. Some expressed concerns about not being able to attend and therefore influence proceedings. There were concerns articulated about conflict between consumer groups which has been apparent through interactions on Facebook peer support groups. A key theme that ran through the responses was that the day may not achieve real change.

*The emotional welfare of attendees and the triggering effect it has when there is conflict*

*Yes, that the health departments, medical staff and government will continue to ignore the plight of people who are truly suffering due to mesh, that we will not be acknowledged and that we will hear about this 'gold standard' treatment, as we sit with our health and lives ruined.*

*That John Skerritt and any government officials will be completely uninterested in learning anything new. And that they will just talk rote about the few small changes to leaflets and re-categorisation of some mesh products and ACSQHC information sheets and so called credentialing standards - and that they will make these out to be more significant than they actually are.*

## Free text responses in full:

- *It could be overwhelming*
- *I'm unable to attend as the meeting is in Melbourne and I'm in Sydney.*
- *I'm not good with technology so I can't do a video to submit. Also, the medication I'm on to alleviate the pain from my mesh implant affects my brain and I'm finding it difficult to articulate how I feel.*
- *I'd like to help. I hope my efforts are enough as this mesh debate has been going on for too long with little action.*
- *More needs to happen to make the changes for people suffering from mesh implants and the surgeons who are still implanting.*
- *My concerns are that the financial burden placed on women pre-mesh and post mesh will be totally overlooked and/or down played.*
- *Yes, confidentiality and consumer reps trying to access people's personal information or oversharing what they may already know certain people. I am also highly concerned with some women setting up a charity and fundraising activities and not being transparent as to where the funds will be used.*
- *I don't want it to be dismissive of women's needs.*
- *Media does not sensationalise individual cases*
- *That we will continue to be overlooked and ignored. That GPS will continue to disregard our concerns. That it's only a token gesture by politicians and medical professionals with no real positive outcome*
- *Agenda seems a bit abstract & bureaucratic. - A patronising talkfest. I can't make it. - Too much pain.*
- *That nothing will be done.*
- *Yes, that it's is only being held in one place, so not everyone can get there, and a large number of people will not know about this meeting.*
- *Hoping it's well organised and government officials are real about listening and acting on concerns.*
- *Yes, just want somebody, Company, to take responsibility for this terrible product and take responsibility for the damage it has done.*

- *That John Skerritt and any government officials will be completely uninterested in learning anything new. And that they will just talk rote about the few small changes to leaflets and re-categorisation of some mesh products and ACSQHC information sheets and so called credentialing standards - and that they will make these out to be more significant than they actually are.*
- *The emotional welfare of attendees and the triggering effect it has when there is conflict*
- *Unfortunately, I am unable to attend due to being overseas. Fear that those of us damaged by these toxic & inhuman devices are not listened to. That money means more than our health.*
- *That it will be all talk like everything else and my concerns will not be looked at like it is with every department and MP and health authority.*
- *There are no surgeons invited*
- *Yes, that the health departments, medical staff and government will continue to ignore the plight of people who are truly suffering due to mesh, that we will not be acknowledged and that we will hear about this 'gold standard' treatment, as we sit with our health and lives ruined.*
- *Being uncomfortable and in pain from sitting/standing too long*
- *That those with these mesh implants won't get their full recognition and won't really be listened to.*
- *not attending as in Tasmania.*
- *Will there be media to report?*
- *"Yes - if surgeons are present, this will be extremely intimidating for many implant victims, and will make it impossible for victims to speak 100% openly about issues. The same concern if lawyers are to be present.*
- *I am also concerned that the TGA get so much time to speak, and wonder what outcome could possibly come from their airtime - the TGA have lied at the Senate Enquiry (this is proven by the letter that Dr Tim Jeffery sent to the TGA on 11 November 2009 where he refers to over 100 complications as a result of mesh implants. yet the TGA said at the Senate Enquiry that they knew of ~ around 12.*
- *The TGA can talk about policy or defend their position, but this will not help current mesh victims - I don't believe that their airtime is going contribute to a positive outcome for current victims.*
- *Yes, that Mesh Injured Australia leaders will monopolise the event*

- *Yes, that I won't be taken seriously and be denied the help from an expert surgeon to do mine and others complex full removals*
- *I just hope that everyone is nice to each other we are all injured, women don't need extra stress by having to have alliances*
- *Regulators pretending to do something.*
- *I believe commitment should be given to the above through federal state and local funding allocations. The establishment needs to be consumer driven. The concern is the day will achieve great discussions with little sustainable outcomes.*
- *I hope this meeting opens up what's been covered up for many years.*
- *Afraid I will be in pain and not mobile enough to get about*
- *Unfortunately, I will not be able to attend*
- *Yes, go forwards towards helping women with mesh implants and not get forgotten. Also, that doctors recognise that there are problems with mesh and it is not in our heads.*
- *"No or little progress from Inquiry*
- *Urogyns heading clinics as they support mesh and have already seen evidence of this*
- *Conflict between mesh groups*
- *Yes, so many.*
- *That because I can't attend my input will be missed.*
- *That it will be very overwhelming and uncomfortable (particularly to be in one place for a period of more than 30 minutes either sitting/standing) for most injured who attend.*
- *I just want all mesh injured and government officials to work towards a resolution for all of us suffering*
- *That there is a real positive to ban the Mesh and doctors saying there are insufficient numbers injured to ban the mesh.*
- *Yes, I hope no surgeons who implant mesh, will be there.*

### Question 3

Is there anything that you think Health Consumers Councils can do prior to the event to address these concerns?

patients surgeons know Make will changed Yes come mesh affected  
people many implant consumers information much injured

### Summary of responses

Several responses requested comfortable seating and quiet spaces for people to retreat to. There was again both calls for surgeons to attend and for them not to be there. An invitation was extended to key surgeons in all jurisdictions, but they elected not to attend. There was a call for investment in advertising, but unfortunately the budget for the event did not cover this. There is an anticipation of further media coverage which aims to raise community awareness of the issue.

Yes, get Government ministers to take this problem seriously, let all sufferers know that there is someone of some substance that will make sure sufferers are heard and listened to, give us all some hope that this terrible product and its consequences are subject to greater scrutiny and that here is indeed a light at the end of this long tunnel. I did not ever expect that this would affect my marriage or health so much. Who was it that said that "life wasn't meant to be easy" well these manufacturers have been in control of my life for long enough, and I want it back

Set good behaviour policies of all attendees at the start.  
Show strong leadership

## Free-text responses in full

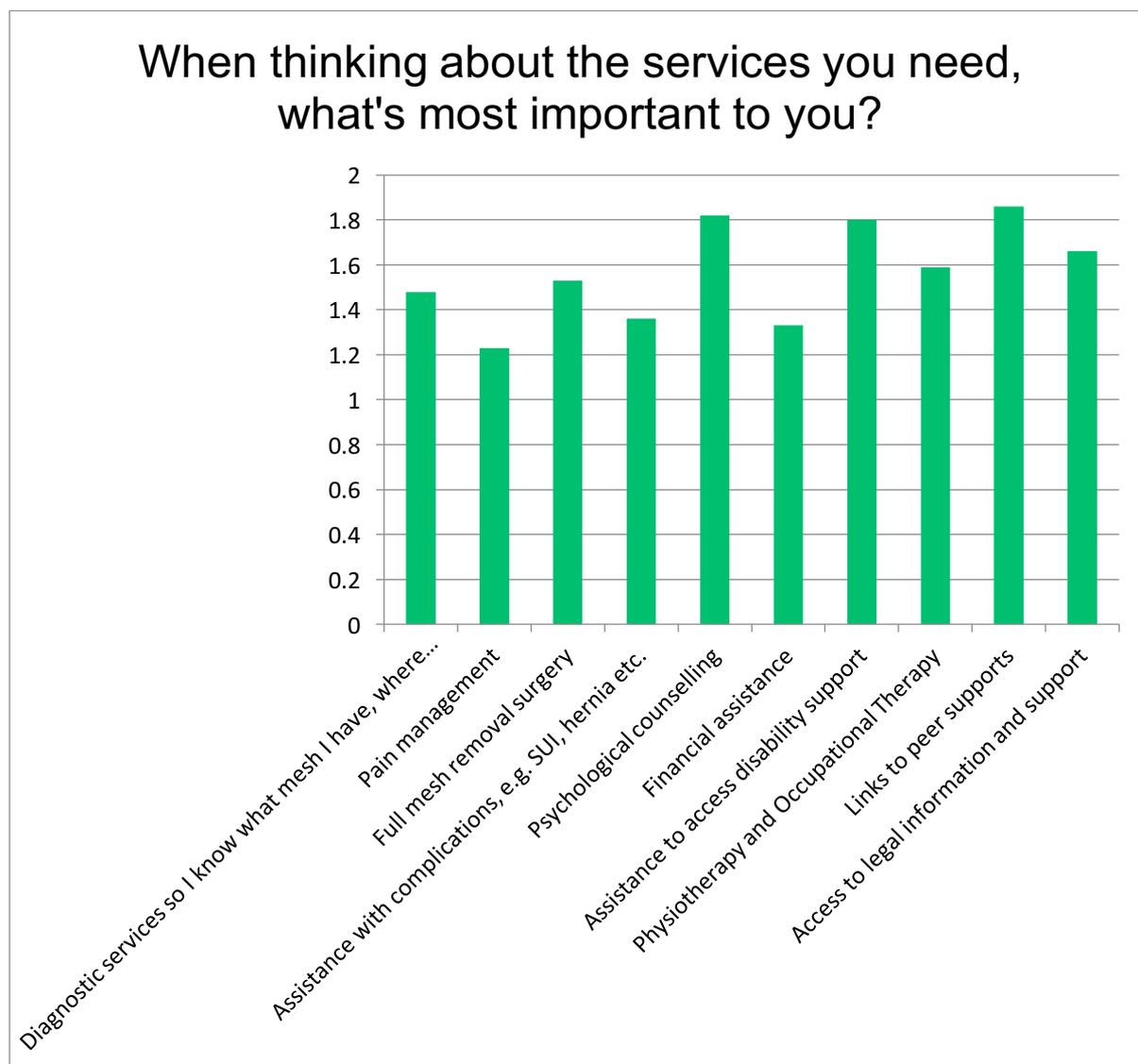
- *An area where people can retreat and have a cup of tea if they need to regroup*
- *Unsure*
- *Yes, please find out why the Northern Territory Health consumer group isn't getting involved in this forum. I understand there may not be a Health Consumers Councils by the same name but isn't there a similar organisation in the NT. The women of the Northern Territory are being forgotten about.*
- *Yes, stop so called consumer reps from spreading information online that is not correct or causes anxiety as they say something that raises questions but then won't answer those questions.*
- *Take out full page ads in all major newspapers and primetime news reports calling for all injured by mesh.*
- *Not sure*
- *Support mesh victims, educate, ensure recommendations from senate enquire are fully acted upon*
- *Have real objectives in the agenda, then there can be action points, strategies, timelines of achievement and people responsible for them.*
- *What monetary assistance will the government provide mesh affected patients?*
- *Research women who have this horrible thing in our bodies.*
- *Advertise widely across all of Australia that this meeting is on*
- *No program looks well put together.*
- *Yes, get Government ministers to take this problem seriously, let all sufferers know that there is someone of some substance that will make sure sufferers are heard and listened to, give us all some hope that this terrible product and its consequences are subject to greater scrutiny and that here is indeed a light at the end of this long tunnel. I did not ever expect that this would affect my marriage or health so much. Who was it that said that "life wasn't meant to be easy" well these manufacturers have been in control of my life for long enough, and I want it back*
- *Please ensure that seating for those affected by mesh have seating with plenty of padding & ample leg room.*

- *Toilets are not too far from conference room & that there is disability access*
- *Prep John Skerritt and any doctors and government officials to come with a genuinely open mind. Let them know that consumers are already aware of what has, and hasn't changed since the Senate inquiry. Let them know that they can be a force for meaningful change, if they are willing enough. That they should come with the attitude that isn't 'computer says no'. The reform that is necessary is huge, tinkering around the edges within the boundaries of current mandates and institutions won't work. Ask state authorities to come with real answers about who is experienced at removal of mesh.*
- *Set good behaviour policies of all attendees at the start. Show strong leadership*
- *Listen & take action to ban mesh & to help those of us injured & permanently damaged to get the correct medical care.*
- *Yes, get an advocate to come to my Dr appointments and see what's happening.*
- *Invite surgeons*
- *Not sure*
- *I hope that the forum will bring about this change. However, in many states, it is still business as usual and people with mesh injuries impacting their lives forever are still ignored and left to suffer immensely.*
- *It's unavoidable. Comfortable seating isn't always an option but would help.*
- *I feel contacting as many of the people that have these mesh implants would help to gain a better outcome for this forum and for those who have had their lives changed for the worse because of this mesh*
- *no. You are gathering information from those affected.*
- *No. They are.*
- *Yes - have attendees register by name and representative type - i.e. are you a 1) mesh implant patient, 2) health professional, 3) legal representative 4) media, etc....*
- *AND*
- *seek permission for any photographs or media content that includes attendees at the event*
- *Make the day about individuals as much as possible*
- *Look into the legalities on how the fast track Dr Veronikis from St Louis to enter Australia to perform our full removals whilst training our Australian surgeons his skills*

- No
- *Ensure the surgeon specialist are not invited to the meeting to enable open, frank, discussion among key stakeholders - the consumers, government stakeholders and service providers.*
- *To have as much information and support for the cause.*
- *Have doctors, surgeons, gynaes been notified or invited to attend or as usual do they shun mesh injured women, refuse to participate or hear the truth*
- *Speak to known groups if possible to set aside for the day*
- *Make sure that the Health consumers maintain their independence.*
- *Contact personally.*
- *Break out room with comfy places to lie down (yoga mats and a few pillows might be useful), also for those overwhelmed with anxiety or panic for a "quiet" space with soft music to regroup, and then go back out into another area. Possibly to talk to someone (qualified) if particular issues come up for individuals. Trauma is one of the worst things we suffer.*
- *Address the limited information us as patients receive and choices made concerning our incontinence*
- *Find a way to produce a National Register as a matter of priority to ensure everyone implanted with mesh, sling, tape is aware this could be the reason why they are so ill. Too many are not aware their implant is making them ill. And these implants are still being used today, with Doctors telling patients it is a safe mesh and different to the others with problems. I too was told this in 2012, and now know I was lied to by the urogynecologist and the TGA. My mesh had already been banned in many other countries prior to 2012. Not good enough.*
- *I believe they could have collated from all mesh injured people, the reported injuries.*
- *Tangible evidence.*
- *Yes, ensure that no surgeons who implant mesh will be there.*

## Question 4

When thinking about the services you need, what's most important to you?



## Summary

The highest weighted preference was links to peer supports. Access to disability support and psychological counselling tied closely behind this. Interestingly, pain management was the lowest scoring priority, perhaps because chronic pain is something that can be managed well in primary care and is not unique to mesh injured consumers.

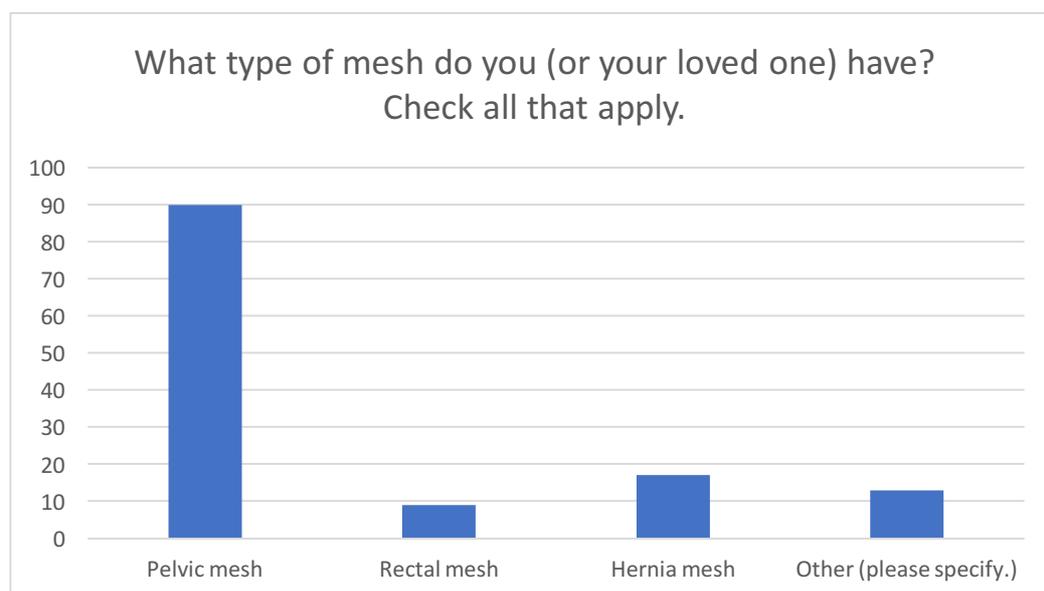
## Other (please specify)

- *One great hospital set up just for mesh cases to be seen as soon as possible.*
- *For the Mesh Message to go Australian wide, viral, so Medical Professionals can start to understand its real, it's happening and start to help those in need*
- *A Royal Commission into medical ethics*
- *Counselling for family members also.*
- *Free catheters for daily self cath, action on being exempt from paying back Medicare, health fund etc!! When taking legal action having access after payouts for being damaged from the surgery*
- *Government to lift BAN on Interstate travel for mesh removals for all. Government to Pay for Doctors and Removal Operations in Both Public and Private Sectors.*
- *At the moment, all I want or need is to be able to go to a Dr in my hometown without being told total lies about my health. I've lost 25kg in 5 mths. I'm terrified but it's not even worth going to a specialist because they deliberately keep right results from me.*
- *Meet our needs as they apply to us*
- *Financial assistance to see Dr Veronikis - he is the BEST qualified and experienced surgeon to deal with mesh removal... and of course we all want the BEST for our affected citizens, don't we? (Many women in Australia are suffering to the point of being suicidal as a result of messed up mesh removal attempts by inexperienced local surgeons... we MUST find a way to open up ease of entry and support for Dr Veronikis to operate in Australia... he has over 2000 successful removals and is the leading bona fide expert in his field, world-wide*
- *Mandatory reporting of mesh complications by GP's, Media, i.e. tv/newspapers ads outlining mesh complications & directing those people to services*
- *Urgent training for medical, nursing and allied health. Training for chronic pain management and mental health issues. Training about drugs of dependence, addiction management, natural healing non-drug pain management strategies.*
- *Access to honest gynaecologists - if they exist? - If I can be referred to an honest Gynae I will travel interstate*
- *Access to anti-mesh Surgeons and access to Dr Veronikis either by way of Him being allowed into Australia, or the Australian Government giving Us Mercy flights to America. Not being left to die in limbo would be great. It's also important that women like myself, with mesh for 21yrs, loads of it, doing massive damage, should be prioritised. Life is very limited.*

- *To have Dr Veronikas remove my mesh*
- *More awareness among doctors (we are treated as difficult cases but I can keep hearing from doctors and surgeons "they know little about mesh and its complications). There is also no information about mesh and mesh complications at any medical centre I have been to.*

## Question 5

What type of mesh do you (or your loved one) have? Check all that apply.

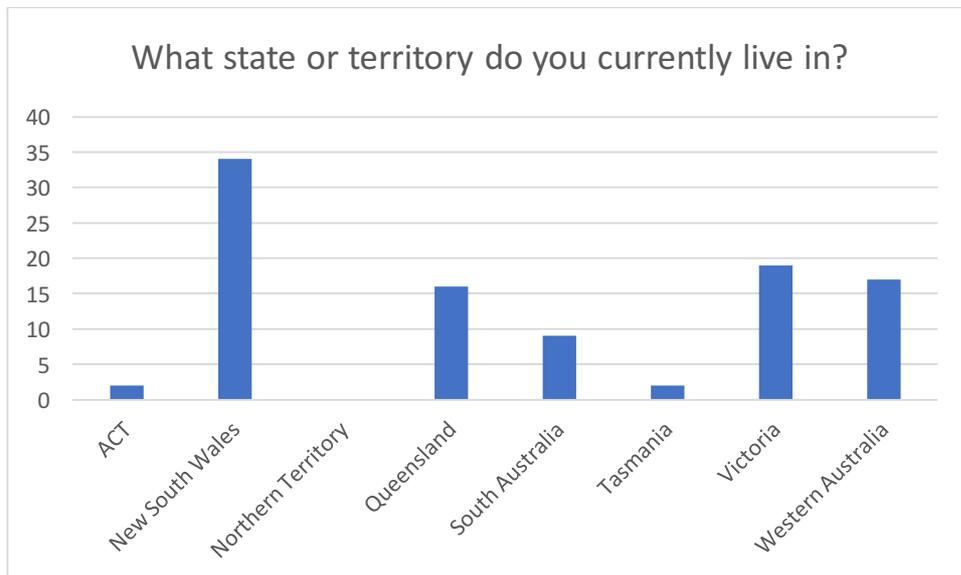


## Other (please specify)

- *Bladder sling.*
- *Tram flap mesh*
- *TVTO & banned Proxima POP mesh*
- *Tfs & biologicals x4*
- *Had removal in America*
- *For prolapse (March 2007) AND SUI (August 2007) Both causing problems*
- *X4*
- *Removed 5/1/19 sacrocolpopexy removed by Veronikas.*
- *2 lots of pelvic mesh ...*
- *TVT, removed in full in Australia 2018*
- *Had pelvic mesh - fully removed - on-going complications & pain*
- *Teflon sling*
- *with a hernia that needs fixing, but am too afraid to have it done/fixd*

## Question 6

What state or territory do you live in?

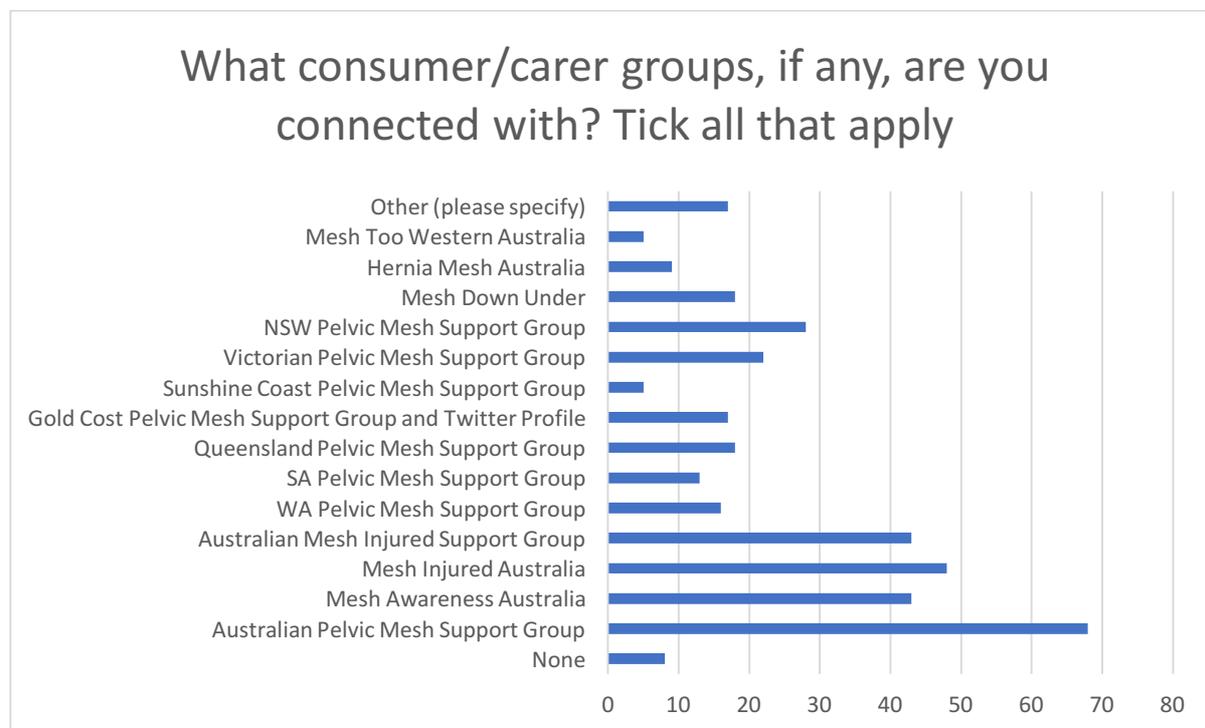


## Comments

*Implants were done in Western Australia, I currently live in Asia but would like to return to Victoria (my home state) for mesh removal surgery if Dr Veronikis was to be given an opportunity to do surgery there... having said that, I would go anywhere in Australia for this surgery with him.*

## Question 7

What consumer/carer groups, if any, are you connected with? Tick all that apply.



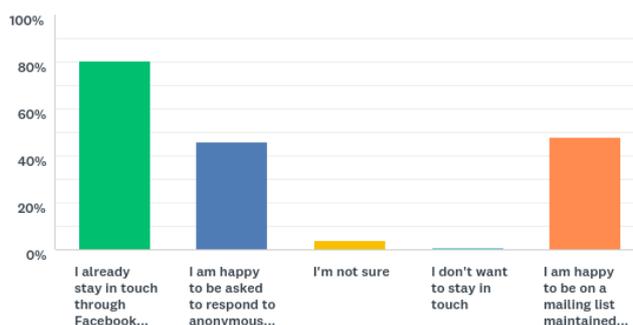
## Other

- Northern Territory Pelvic Mesh Support Group (I am the Admin)
- Consumer Member of the Steering Committee Pelvic Mesh Safer Care Vic
- Sling the mesh (7 mentions)
- Pudendal Nerve Support Group
- Facebook only
- I run My Meshed Up Life Social Network. I was an original member of Australian Pelvic Mesh Group but left due to PTSD & what I call Veronikis guilt
- Mesh UK Charity Trust
- Mesh Down Under Support Group
- NSW on Twitter, I'm not involved with the other groups, there's too much drama & the leaking of personal information last year was concerning
- Scottish mesh group.
- have my own site
- Hernia Mesh AU
- There are various social media profiles for Mesh Injured Australia also, such as twitter, Instagram, Pinterest, as well as Facebook and their own website
- Sunshine coast mesh sisters online support group

## Question 8

How would you like to stay in touch about consumer and carer involvement in this issue? Tick all that apply

Q8 How would you like to stay in touch about consumer and carer involvement in this issue?  
Tick all that apply



I already stay in touch through Facebook Group(s)	79
I am happy to be asked to respond to anonymous surveys up to 5 times per year	45
I'm not sure	4
I don't want to stay in touch	1
I am happy to be on a mailing list maintained by the Health Consumers Councils	47
Other (please specify)	5

## Summary

Most people noted that they are already linked in with Facebook Groups, but 47 elected to be on a mailing list, and 45 indicated they would be happy to respond to anonymous surveys up to five times per year.

## Other

- *I would like to be part of the Health Consumer Council for the Northern Territory (I don't believe they have one). No-one is helping the women of the NT.*
- *Staying in touch and completing surveys for years is not solving my problem*
- *None, I just hope and pray that all sufferers get to see some resolution, and justice for this abomination of a product is obtained before many of us die, but maybe that is just what these big Companies are waiting for, less "guinea pigs" to pay compensation too.*
- *As long as they are anonymous would want to know how that would work*
- *I am already involved as an SA consumer mesh injured advocate*